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To Whom It May Concern:

My name is Christopher A. Riddle, PhD, and I am a Professor and Chair of Philosophy at Utica University in New York, USA. I have dedicated my life to promoting the rights of people with disabilities and have written books on disability and justice, as well as the promoting of human rights for people with disabilities. I very strongly support Assisted Dying and have published in some of the most prestigious academic venues detailing my defense of it. The following is an excerpt from a forthcoming publication detailing what can be learned from those jurisdictions that permit aid in dying. I argue that despite criticism from some disability rights organizations, their concerns are neither justified, nor representative of all people with disabilities. This book chapter will appear as:

Riddle, C. A. "Medical Aid in Dying: The Case of Disability." In *New Directions in the Ethics of Assisted Suicide and Euthanasia – 2nd Edition*, edited by Michael Cholbi and Jukka Varelius. New York: Springer, (forthcoming) 2023.

[Contact details redacted]

Concerns about person affecting harm permeate almost all disability rights organizations' objections to aid in dying. The question at hand is the following: Is there any evidence in jurisdictions where aid in dying is legal that suggests harm befalls people with disabilities or other vulnerable populations to a greater extent than other states without legalized aid in dying?

The short answer is that no harm appears to have befallen people with disabilities or others as a result of permitting aid in dying.

Consider first, jurisdictions outside of America prior to moving to American ones. There exist more complexities with systems in most European jurisdictions than American ones, but nonetheless, these complexities do not give way to abuse.

In the Netherlands, for example, there is no evidence that people with disabilities or other vulnerable groups are experiencing harm as a result of medical aid in dying. There is some well-documented concern over under-reporting within the Netherlands, but Govert den Hartogh (2012) attributes this under-reporting to what he calls “a relic of prelegalization practice” (366), and not as a result of the legalizing of euthanasia.

Opponents suggest that doctors and other medical professionals might be inclined to hasten the death experience against the wishes of a patient. Disability Rights Organizations suggest that this practice is more likely employed against people with disabilities who might be perceived to have a life not worth living. Disability Rights objectors cite concerns that the most likely manner in which lives might be ended without request would be for those outside of the terminal window to be killed (Hartogh 2012, 365). The concern emerges from the claim that with normalizing the taking of lives, compassion might be thought to extend outside of the legal restrictions placed on aid in dying practices. Medical professionals might view suffering to be so bad that they hasten the death experience, even without death being immanent, as defined by the law. Perhaps obviously, given the ablest attitudes of many in society, disability rights organizations suggest this notion of suffering and a life not worth living might be more likely to be applied to people with disabilities. The concern here then, is that an under-reporting of the use of some drugs, such as morphine, might result in the use of it in large doses to kill those who have not expressed desire to die, and who have not navigated the legal process and the safeguards within. Opponents do not attribute malicious intent to medical professionals in all instances, but instead, can suggest such actions could emerge from a misbegotten effort to spare the disabled from lives perceived to be so dominated by suffering that they are not worth living.

That said, there appears to be no evidence of this in the Netherlands that cannot be explained by a more general underreporting of morphine use (Hartogh 2012, 366). In short, “no evidence for this causal nexus has ever been offered” (Hartogh 2012, 365). In other words, while under-reporting of terminal sedative drugs exists, although degreasing in frequency (Onwuteaka-

Philipsen 2012, 127), there is no evidence to suggest that this under-reporting constitutes an instance of abuse against disabled people or other vulnerable populations (Battin et al. 2007, 597).

Similar conclusions can be drawn in Belgium. Indeed, little or no opposition exists to Belgian laws from Belgian disability rights organizations or people with disabilities. Concern about abuse is not present in Belgium and there appears to have been little or no opposition to the legalizing of euthanasia from disabled people (Fitzpatrick and Jones 2017, 147). There is no evidence to suggest abuse of any kind, and indeed, there remains to be no organized disability-rights-based opposition to even a mere hypothetical risk of harm, let alone any attempt to suggest actual harm exists (Fitzpatrick and Jones 2017, 149).

In Canada, where aid in dying has been legal since 2016, and where 2 percent of all accounted deaths were attributed to the practice in 2019, there is no evidence of person affecting harm emerging from either abuse of the system, or the system itself (Martin 2021, 137). Indeed, recent data from Canada, the Netherlands, and Belgium are consistent with the claim that there is "no indication that individuals who *may* be vulnerable to undue influence are accessing assistance in dying" (Martin 2021, 142).

Within the United States, and Oregon in particular, the jurisdiction with the oldest assisted dying laws in America, there is no evidence of vulnerable populations of any kind experiencing person affecting harm. No Oregonians with disabilities have, since 1997, experienced person affecting harm from aid in dying. No people without a terminal diagnosis confirmed by two physicians have died in Oregon (Battin et al. 2007, 594). More pointedly, "no one received such assistance for disability alone" (Battin et al. 2007, 594). Robert Lindsay has concluded that a "decade after implementation of the ODWDA [Oregon Death with Dignity Act], the weight of evidence suggests that these predictions of dire consequences were incorrect" (Lindsay 2009, 19).

Indeed, a good deal of data points to rejecting many people who requested aid in dying, who were not deemed capable of consenting to such action. Almost 20 percent of requests for aid in dying came from patients deemed to be experiencing depression, and exactly none of them progressed to medical aid in dying (Battin et al. 2007, 596). More generally, no people availing themselves of aid in dying were concluded to have a mental illness influencing their decision (Battin et al. 2007, 596).[1] Indeed, not only has no disparate impact on those perceived to be vulnerable been detected, but there has been no slippery slope, and there has been, more generally, the effective prevention of abuse (Lindsay 2009, 22–23). Indeed, some strong opponents to medical aid in dying have publicly expressed that the concerns they previously stated have not materialized (Coombs Lee 2014, 97–98). In short, there is no evidence of abuse or coercion, and there is no evidence to suggest the misuse of the carefully crafted policies supporting aid in dying (Coombs Lee 2014, 99).

To support this point further, consider that 87.8 percent of individuals availing themselves of medical aid in dying were in a hospice setting (Al Rabadi et al. 2019, 5). If patients were typically placed in a hospice care setting prior to initiating medical aid in dying requests, there is an additional layer of protection to confirm terminal diagnosis, and to thus, avoid or mitigate the potential for the sort of abuse opponents suggest is present.[2] That said, data "supports the overall safety and reliability of the lethal medications used in MAID [medical aid in dying]" (Al Rabadi et al. 2019, 5).

But, in the absence of evidence of person affecting harm, is there still cause to be concerned about this possibility as a matter of principle? I suggest there is not.

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[1] It is relevant to note that this study has received critical appraisal (Finlay and George 2011). That said, the critical remarks focused on the study's perceived failure to identify all possible forms of vulnerability, and thus, do not undermine the claims pertaining to any potential person affecting harm to people with disabilities.

[2] Indeed, palliative care, has appeared to have improved in jurisdictions permitting aid in dying (Lindsay 2009, 19).

Arguments concerned about person affecting harm ought not to be regarded as justifying a prohibition on aid in dying for at least the following two reasons. First, disability rights organizations that suggest person affecting harm constitutes a sufficient threat to prohibit medical aid in dying are guilty of moral inconsistency. Second, these arguments also fail because of moral disproportionality.

Some forms of the argument suggest that there is an illusion of free choice when seeking medical aid in dying, and thus, people with disabilities will be harmed because they will be forced or coerced to avail themselves of it. The claim is that for some vulnerable populations, it is not a free choice, but instead, a forced one (Scoccia 2010, 481). It is suggested that when choices are made in the context of pervasive inequality, or under a structure of oppression, free choices cannot exist (Scoccia 2010, 481). Indeed, actions taken by people with disabilities to seek aid in dying might be thought to be suitably likened to those taken by others when under duress (Feinberg 1989, 98–219).

Additionally, not only is the concern that people with disabilities might avail themselves of aid in dying due to social pressures, but that they themselves might be viewed as preferential subjects or objects of euthanasia and be killed against their will (Somerville 2001, 263). In short people with disabilities might not only be pressured to invoke the legal process for aid in dying, but they might be killed, against their will, in spite of safeguards or laws designed to protect them.

Some suggest the only method to ensure the prevention of person affecting harm as a result of aid in dying is its prohibition:

> ‘[S]afeguards cannot be established to prevent abuses resulting in the wrongful death of death of numerous disabled persons, old and young.’ Indeed, the only true safeguards against abuse ‘is that assisted suicide remain illegal and socially condemned for all citizens equally’ (Bickenbach 1998, 125).

Sumner (2018, 105) calls arguments of this variety, 'arguments from abuse', and suggests the common thread is a concern over safeguards being inadequately established, or monitored and enforced. Similarly, but more generally, I have previously called these arguments, 'avoidance of harm' arguments (Riddle 2019, 188–90).

I believe arguments of this kind suffer from a moral inconsistency that renders them ineffective. First, consider how many people die as a result of aid in dying. This numbers differs significantly depending upon jurisdiction, but ranges from .05 percent of deaths, to as high as 1.7 percent of total deaths (Emanuel et al. 2016, 85). By any measure, this number represents a very low percentage of total deaths. In other words, not many people are dying from aid in dying.

In contrast, consider those who have opted to refuse or remove life sustaining treatment. Approximately 85 percent of critical care physician respondents acknowledged that they had withdrawn or withheld life support in the preceding year (Way, Back, and Curtis 2002, 1342). An American study indicated that between 1992 and 1993, over 90 percent of deaths in intensive care units resulted from a decision to withdraw or withhold life support (Way, Back, and Curtis 2002, 1342). This is true in most countries, where most deaths in intensive care units occur as a result of a decision to stop or refuse life sustaining treatment (Way, Back, and Curtis 2002, 1342).

Importantly, all the reasons that can be invoked to support the refusal or removal of life sustaining treatment, can be applied, with equal force, to medical aid in dying. Because we value patient autonomy, and relief of suffering, we permit patients to make choices about the kind of care they receive, or do not receive, at the end of their life. These reasons are so powerful, that we permit people the autonomy to make them even when it will surely result in their death. Why then, are disability rights organizations not in favor of denying patients the right to remove or refuse treatment? I suggest that for their argument against aid in dying to be morally consistent, they must.

Surely the potential for abuse that can emerge with aid in dying is also present in current practices. People with disabilities or other vulnerable groups, such as the elderly, or even those living in poverty, might be thought to be pressured into hastening their death experience. They could just as likely be subjected to an unjust death from a medical professional exercising a wrongful notion of compassion to rid them of a life perceived to be so dominated by suffering or misery, that it is not worth living. In short, our current practices that permit people to make choices about care at the end of their life are not subject to the same scrutiny that medical aid in dying is, and many more people are forced to make choices pertaining to the refusal or removal of care, than those who will be eligible, or who will seek, aid in dying. If disability rights organizations were genuinely concerned about abuse of healthcare systems and person affecting harm against people with disabilities, they should be equally as concerned about granting *any* autonomous decision-making ability at the end of life, due to both its equal potential for abuse, and its more frequent use. They are silent on this matter however. To fail to apply their moral logic in this case constitutes a moral inconsistency that is both unjustifiable as a matter of principle, as well as inexplicable.

I argue that opposition of this kind is also morally disproportionate. By morally disproportionate, I mean to suggest something like the following: as a result of a moral wrong or harm, actions to be taken must be proportionate to that harm, and similar to analogous cases where moral wrong or harm has been done. In other words, despite the fact that no demonstrable harm emerges from permitting aid in dying, *if* it could, it would be insufficient to point to an instance or instances or harm, and suggest that on the basis of that harm, a proportionate response is its prohibition. Instead, one must demonstrate, again, counterfactually, that not only will harm emerge, but that it is of a sufficient quality and quantity that it justifies an outright refusal to permit the action leading to that harm.

To be clear, such an argument has not been made with reference to aid in dying, nor can it be. To demonstrate this, consider other actions that have risks. All medicine carries risk. For example, it is thought to be the case that as high as 10 percent of patients admitted into a hospital setting will suffer an adverse reaction, or acquire a new ailment, often as a result of medical error, by virtue of being in the hospital (Riddle 2019, 190). This number is startling, and demonstrates the risk that we endure to receive medical treatment. No one suggests we ought to prohibit hospital visits as a result of medical error and the person affecting harm that emerges as a result of it. The reason this is not suggested is because it is not morally proportionate to do so. It is neither proportionate to risk aversion strategies employed in morally similar situations, nor would it be proportionate to the actual quality and quantity of harm or risk, more generally.

We can now circle back to a discussion of the refusal or removal of life sustaining care. I argue that this represents a much greater threat to people with disabilities and other vulnerable populations than aid in dying. That said, no one has argued for a denial of autonomy at the end of a patients' life in this regard. As a result of moral proportionality, disability rights organizations cannot argue for a moral prohibition on aid in dying. At most, opponents to aid in dying can argue for safeguards to be enacted, as we do with reference to hospital visits more generally, and to end of life decisions to refuse or remove life sustaining care. To suggest a prohibition on aid in dying is justifiable, is to make a morally disproportionate argument. In other words, opponents to aid in dying overstate the implication of their argument, and suggest a prohibition on the practice, when at best, their principled case can justify the enacting of safeguards, which have already been established, and proven to be reliable.

That said, not all harm that can emerge from legalized aid in dying is of this kind. There is also a concern that the mere permitting of assisted dying causing emotional, attitudinal, or existential harm, to vulnerable groups by suggesting their lives are not worth living. The prejudices that exist against people with disabilities are in fact, harmful and abundant (Morin et al. 2013). Disability rights organizations suggest that by legalizing aid in dying, people with disabilities will be further devalued and harmful stereotypes will be ignited, rather than extinguished. If people with disabilities are at present, devalued, which we have sound reason to believe is true, the concern is that legalizing medical aid in dying would be even more “detrimental to the way that [the disabled] are viewed by society as a whole” (Box and Chambaere 2021, 4).

Measuring social attitudes is difficult, especially when subjects are asked about attitudes or dispositions that they know they ought not to have, or that are not socially favorable, such as discriminatory or ablest ones (LaPiere 1934, 230). Indeed, it is often thought that actions are more representative of attitudes or dispositions (LaPiere 1934, 237). The adage, ‘actions speak louder than words’ is perhaps helpful to bear in mind here. If what we aim to discover is if people with disabilities are devalued to a greater extent in states that have legally permissible aid in dying, than examining how those states *treat* people with disabilities, and not just reported attitudes, is perhaps a good starting point. In other words, if disability rights organizations suggest that disabled people are devalued by legalized aid in dying, it should be the case that support services and spending on people with disabilities is less in states with medical aid in dying than in those without. In fact, the opposite appears to be true.[3]

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[3] It is important to note that I am not suggesting a causal effect between aid and dying and support for people with disabilities. I am not suggesting that legalizing aid in dying increases support services for disabled people. That said,

Just as with person affecting harm, let us start by examining non-American jurisdictions first. Public expenditure on disability (PED) is a measure commonly used in Europe to assess welfare programs for people with disabilities across different, and seemingly incommensurable, social welfare models. European models of disability welfare are startlingly different in their approaches and application, but have a common solidarity and commitment to both social justice more generally, as well as the provision of resources to mitigate and eliminate social exclusion, more specifically (Boeri, Borsch-Supan, and Tabellini 2001; Hemerijck 2002). People with disabilities are thought to represent approximately 17 percent of the population of Europe for people between the ages of 16 and 64 (Navarro, Rodríguez, and Santamaría 2021, 1481). Given the significance of this number, PED is an especially important measure.

The typical manner in which PED is assessed is as a percentage of total social expenditures. Thus, the higher the percentage of total social expenditure absorbed by PED, the more resources allocated to people with disabilities, and in my estimation, the greater the social value placed upon disabled people. After all, if people with disabilities were devalued, presumably the policies within those States would reflect those values, and public expenditure would at least trend in a direction that reflected those social values. Conversely, if disabled people were thought to deserve provisions necessary through the law, public expenditure would also reflect this positive disposition (or at least not a negative one) towards the disabled.

The European Union (EU) average is 7.38 percent of total social expenditure on PED. Countries that are thought to correspond to the Nordic typology, perhaps unsurprisingly, do remarkably well in this regard. Denmark, Sweden, Holland, and Finland, are all significantly higher than the other EU countries (Navarro, Rodríguez, and Santamaría 2021, 1481). That said,

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it is at least possible that in light of a concern over abuse of aid in dying, states increase support services for people with disabilities. This has not been established however.

Belgium and the Netherlands have a PED as a total percentage of social expenditure much higher than average. Belgium's PED as a percentage of total social expenditure is just below 9 percent, and the Netherlands is just above 9 percent – significantly above the European Union average (Navarro, Rodríguez, and Santamaría 2021, 1481).

In short, if it were true that legalized aid in dying causes the further devaluing of disabled people, and if it were also true that this devaluing would manifest itself in harmful social policy and less expenditure on support for people with disabilities, then those countries that permit aid in dying should be spending less on the disabled. This is not the case.

Let us shift our focus now to American jurisdictions. In the United States, the most common measure utilized for our present purposes is disability-associated health expenditures (DAHE). In 2015, for example, DAHE were $868 billion nationally (Khavjou et al. 2021, 441). This number accounted for 36 percent of total health care expenditure nationally, and it ranged from 29 percent to 41 percent across states (Khavjou et al. 2021, 441).

Oregon spent 40 percent of total health expenditures on DAHE (Khavjou et al. 2021, 444). This number is bested only by two other states. Washington, which has the second oldest aid in dying laws in the country, also has a DAHE that is above the national average (Khavjou et al. 2021, 444). Vermont, the next state to legalize medical aid in dying, is on par with the national average (Khavjou et al. 2021, 444). California, although aid in dying was legalized the same year as the data was gathered, has a DAHE two points above the national average. Indeed, no state that had legalized aid in dying had a DAHE as a percentage of total health expenditures less than the national average at the time the data was collected. More pointedly, the data in the United States suggests that states with legalized aid in dying have a DAHE as a percentage of their total expenditure of health services, that is equal, or greater than, the national average. States that permit aid in dying are not devaluing people with disabilities or under-funding support services to any greater extent than states that do not permit medical aid in dying. Just as in Belgium and the Netherlands, there appears to be a correlation between those states with aid in dying, and a higher DAHE as a percentage of total health expenditure.

Indeed, between 2003 and 2015, DAHE per capita spending increased well above the national average in Oregon. While nationally, the increase represented a 28 percent change, in Oregon it was 64 percent (Khavjou et al. 2021, 448). In other words, Oregon appears to be increasing its DAHE as a percentage of total health expenditure at a rate much fast than other states. Presumably, if aid in dying caused the devaluing of disabled people, this would result in DAHE per capita spending decreasing, or at least increasing slower than national trends, and not much faster. Again, every state with legalized aid in dying at the time these data were collected is above the national average with respect to increased spending on DAHE between 2003 and 2015 (Khavjou et al. 2021, 448).

In short, there appears to be no factual evidence to support the claim that legalizing aid in dying causes the greater devaluing of people with disabilities. More pointedly, harm of this second kind does not emerge as a result of aid in dying. It is simply inaccurate to suggest it does.

However, do arguments pertaining to this kind of harm have any principled merit? I argue that they do not. I argue that respect for people with disabilities and their autonomy demands access to aid in dying, and not its denial or prevention.

Arguments of this kind share a common sentiment: permitting aid in dying devalues the lives of people with disabilities. A primary concern is that harmful stereotypes become further ingrained into society when we suggest some lives are not worth living (Gill 2010, 35). More strongly, opponents can suggest that even if medical aid in dying provided a benefit to everyone, including people with disabilities, and did not introduce person affecting harm into their lives, that it would still be impermissible because the very practice harms people with disabilities as a group, or class (Scoccia 2010, 480). An analogy can be drawn between arguments of this sort, and arguments against something like sex work, for example, that suggest even if it were not harmful to sex workers themselves, the very practice harms women, more generally (Scoccia 2010, 480).

Arguments of this kind are such that even without harm actually befalling people with disabilities, there is a greater social harm being done in the perpetuating of harmful attitudes or demeaning stereotypes against the disabled. These arguments suggest that an already marginalized or oppressed group is only bound to have those harmful attitudes magnified if aid in dying is encouraged or allowed. Given that many of us tend to think we have even stronger obligations to avoid *further* harming already disadvantaged populations, it only stands to reason, they might suggest, that the argumentative force behind a denial of access to aid in dying is even stronger when couched as being a matter of importance for disabled people.

Opponents to aid in dying suggest that it results in an affront to the dignity of disabled people that manifests itself through social policy and laws. As a result of this vulnerability, disability rights organizations argue that aid in dying ought not to be permissible.

To the contrary, I suggest that respect for people with disabilities demands the guaranteeing of autonomy and the recognition that people with disabilities, like people without disabilities, are best suited to make decisions about their own life and their own medical care. To suggest that people with disabilities ought to be denied the ability to control what happens with their own bodies at the end of their lives is an overly paternalistic attitude that cannot be justified, and that itself, does harm.

Indeed, respect for patient autonomy and compassion for patient suffering are claimed to provide powerful *pro tanto* reasons for permitting aid in dying (Sumner 2018, 103). The very manner in which these arguments are constructed demonstrates a lack of respect for the autonomy of people with disabilities. People with disabilities are individuals, and not an amorphous group of insignificant parts. Instead, rightly regarded, disabled people are capable of making important decisions on their own (Nelson 2003, 3).

I have previously argued that denying "people with disabilities the right to exercise autonomy over their own life and death says powerfully damaging things about the disabled, their abilities, and their need to be protected" (Riddle 2017, 487). The late Anita Silvers (1998) has forcefully stated that "characterizing people with disabilities as incompetent, easily coerced, and inclined to end their lives places them in the roles to which they have been confined by disability discrimination" (133). The attitude that people with disabilities need protecting from themselves is in itself, demeaning and patronizing.

Thus, if disability rights organizations want to promote the dignity and rights of people with disabilities, denying medical aid in dying is not the proper means of doing so. The patronizing and paternalistic attitudes displayed by opponents to aid in dying *cause* personhood affecting harm, rather than prevent it. By acknowledging that people with disabilities do not need protecting from themselves and that they are capable of making choices about their own care, even if pressured from ablest social attitudes, we can begin to undo the negative stereotypes that have followed disabled people even after the enacting of human rights provisions such as the Americans with Disabilities Act, or the UN Convention on the Rights of Persons with Disabilities. If true regard or care is to be given to endorsing actions that promote accurate, positive dispositions towards people with disabilities, disabled people need to stop being painted as helpless, pitiable individuals, requiring the care and protection of others. Such a disposition plays in to ableist preconceptions of disability and further entrenches attitudes of disability as a state of suboptimal or inferior functioning.

Importantly, the general practice of aid in dying, or the particular laws surrounding its implementation, make no judgments about what kinds of life are worth living. The only inherent values in the practice of medical aid in dying are ones concerning compassion for suffering, and perhaps most importantly, respect for autonomy. Neither the practice nor the laws force anyone to seek aid in dying and to suggest that people with disabilities are especially vulnerable to social nudging is to perpetuate the myth that people with disabilities cannot make decisions of their own and need to be protected from themselves. Similarly, these laws offer no guidance as to who ought to consider such a practice, aside from those with terminal conditions. Negative valuations about people with disabilities are not perpetuated or brought to the forefront through legalized medical aid in dying. Denying its practice as a result of the perceived vulnerability of disabled people, however, does.

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December 22, 2022

Dear Members of the Tynwald,

I write to you today to urge you and your colleagues to **pass legislation authorizing assisted death on the Isle of Man**. As a practicing physician in California where assisted death is legal, I have seen up close the universally positive impact having assisted death as an option has had on my patients and my physician colleagues. Personally and professionally, my journey from open-minded ambivalence to avid support was gradual but always steadily unidirectional.

As I compose this letter, some specific formative experiences come to mind. The law authorizing assisted death (what has come to be called “medical aid in dying” in the United States) went into effect in June of 2016 in California. The following week, I received my first consult. For the first time in my career as a physician, I was about to help a man die. I remember sitting at my desk not knowing what to feel. But like many experiences before this, I decided the only way for me to sort out my feelings on the topic was to try it and reflect afterwards.

In the room, Percival* sat across from me, waiting for me to speak. There was no formal training on how to do this yet and awkward moments passed. I somehow fumbled my way through our first visit, but he didn’t seem to mind. I was most struck by how clear he was in his reasoning and how firm he was in his resolve. Unlike most of my patients, Percival had no illusions about what lay ahead. His disease was consuming him—sapping his strength and robbing him of any pleasure in life. Moreover, there was no way for him to ever get that back. “I want to end it before I get so weak that I become a vegetable,” I remember him saying.

In the weeks that followed, Percival fulfilled the rest of the legal requirements. Throughout the process, I held it together better than I expected until the time came for him to leave my office for the last time. I shook his hand and opened my mouth, but the words failed me. “Good to see you,” didn’t feel right. “See you later” was an outright lie. I had never been faced with this before. I was knowingly sending a patient to his death. I settled on, “It’s been a pleasure.” He nodded his acknowledgement and left.

I prescribed him the aid-in-dying drug that day, and he took it the next. A few days later, I called his daughter to check in on how everything went. I’ll never forget what she said. “We got to have a memorial for Dad while he was still alive. Then he took the medication surrounded by friends and family. He went to sleep and passed away peacefully. It was beautiful.” My eyes welled up, not expecting how far the gift had expanded beyond the patient.

I thought long and hard about Percival and death in the weeks that followed. It was once said that nothing in life is certain except for death and taxes, yet most people seem surprised when death comes knocking at the door. This unexpected quality that our culture has ascribed to death along with our erroneous assumption that we can somehow prevent it if we just try harder is what Dame Cicely Saunders—the mother of modern hospice—once referred to as our "death-denying society."

But then here was Percival—a man who accepted the inevitability of his death and met it head on. He took control of his suffering and exercised his autonomy in a way that was heretofore unthinkable in California. As a result, his death was not at all traumatic for himself or his family—it was a celebration.

The power in his action was transformative. It was a statement that death does not need to be something that happens to you on its terms. It gave him the agency to write for himself that last sentence in his book of life. Through this, **I came to recognize assisted death for what it is—an invaluable form of restorative justice.**

In the years that have followed my experience with Percival, I have overseen many deaths from medical aid in dying—either directly or through the medical residents in the program where I am faculty. I am now the senior medical director for aid in dying services for my large healthcare institution that includes 5,000 physicians and 60,000 employees and covers the care of 3 million patients. I can say unequivocally that **having this option available has had an enormously positive effect on patients and physicians alike.**

The way our law has been written and implemented, safeguards exist on all sides. Only patients who can demonstrate their capacity to make sound medical decisions can access aid in dying. This helps prevent coercion, and in the 25 years that aid in dying has been legal in jurisdictions in the United States, **there has never been a single substantiated claim of coercion.** In our law, two physicians must independently assess a patient and determine that the patient is eligible (terminal prognosis plus mental capacity). This serves not only as a potential check-and-balance for such a consequential determination but also offers the primary physician a valuable second perspective on cases and the complexities therein.

And most importantly, participation is optional—for patients, physicians, and staff. **Physicians and staff who have objections to the practice of assisted death for any reason are allowed to opt out** of providing this service—without fear of censure, discipline, or retribution. For the physicians who do not want to participate, they simply don't have to. However, I hear time and time again from the physicians who *do* participate how rewarding this work is. Far from being distressed, **participating physicians often describe offering this service to their patients as one of the most meaningful and fulfilling acts they can facilitate as a doctor.**

As the medical director, I personally train all physicians in our system on the process of assisted death when they are considering offering this service (usually in the context of a specific patient of theirs asking for it). Without exception, the physicians are anxious at the start—just like I was. After their respective patients' deaths, I always check back in with the doctors and I hear things like "paradigm shift" or "this was an inspiration" or "it is a privilege that we can offer this to our patients." Those are direct quotations.

What about patients who object? Patients who have objections to the practice simply do not have to pursue the option—same as all options in life. However, for patients approaching the end who want to exercise their autonomy and gain some control over their own dying process, assisted death offers them empowerment at a time that many feel powerless and disenfranchised. As I noted in an editorial for our local medical society (Spielvogel, 2022), the option of assisted death allows patients like Percival to bypass much of the suffering they know is ahead and skip to a more humane ending consistent with their values. Patients choosing assisted death are *not* choosing between life and death. Their time is up either way; it's just a question of how much suffering they want to endure. In six years and the many cases in which I have participated, **I have yet to meet a patient who wants to die. They would gladly relinquish the opportunity for more suffering-free time with their loved ones, but that's a choice they don't have.**

There will always be physicians who oppose this practice. At issue is that bedrock of medicine: do no harm. But what constitutes harm? For the imminently dying patient who has no quality of life left and is ready to move on, continuing to live may constitute harm to them. Forcing our patients to endure suffering because it is the natural order of things is not new to our profession. James Young Simpson famously experienced a backlash when he first used chloroform for effective labor analgesia in the 1800s because suffering was felt to be a necessary part of a woman's delivery. Quite clearly, it has since become common practice to ease labor pain with various medications. The insistence that all must suffer their lot when their end is near is similarly antiquated.

Ana* was a patient of mine a few years ago who was dying from metastatic colon cancer. Spinal metastases made every movement agony and took away her last pleasurable activity: going out and tending her garden. She sought my assistance to help her end her suffering, but her family stonewalled us at every turn. Due to their deeply held religious beliefs, they felt strongly that going through with this act would damn her immortal soul. So under false pretenses, the family sent her to a religiously-affiliated skilled nursing facility that would not allow her to ingest the aid in dying drug on the premises. Then they quickly sold her house so that she would have nowhere to go. Once she and I figured out what was going on, it was too late. Ana was beyond distraught at the duplicity, but she was at their mercy.

I spent a whole month exploring options for her while she wasted away in bed suffering exactly the kind of agonizing existence she wanted to avoid. I did eventually find a skilled nursing facility that was willing to take her on a charitable basis and allow her to ingest once she got there, but Ana died before the transfer could happen. Ana had made her choice and her family had denied her that.

Every time I see a patient for assisted death I think of Percival, Ana and others like them. Some make it out on their terms; some do not. I try to think about my own mortality, too. If I were facing a slow, steady decline and had intractable suffering resistant to other efforts to palliate, would I choose this option for myself? I honestly don't know, but the fact that I would have the choice makes all the difference.

Over and over again I see how having responsible and effective assisted death as an option in our society enriches it and improves the quality of life for those still here. It provides reassurance to those facing terminal illness—always giving them the final say. And it relieves the existential angst faced by many physicians as they watch their patients dwindle and suffer through the dying process. For the most part, when I now see my patients endure suffering at the end of life, I know it's their choice. Respecting our patients' choices is at the heart of being a good physician and is the highest achievement in fulfilling our oaths.

I hope that you and your colleagues find it in your hearts to author and pass legislation that will bring this humane option to the citizens of the Isle of Man. Thank you for your time and consideration. It was a privilege to discuss the matter in April of this year with members of the House of Keys, and I am again happy to answer any questions you might have and am available to provide oral evidence again if needed.

Sincerely,
[Signature redacted]

Ryan Spielvogel, MD, MS
Medical Director, Sutter Health End of Life Option Act Services
California, USA

*Names of patients have been altered for confidentiality

Reference:

Spielvogel, R. Apr 2022. Letting go: A physician's tale of medical aid in dying. *Sierra Sacramento Valley Medicine*.

"The problem was dying badly, and the answer was dying well"

Assisted Dying: A policy briefing

This briefing summarises research about assisted dying, conducted by Dr Jaimee Mallion and Lauren Murphy, between January and May 2022. Interviews were conducted with eighteen people who had experience of terminal illness, were family members of those who had experienced a 'bad death' or had travelled abroad for an assisted death[1].

According to new data by the Office for National Statistics[2], people in the UK with severe and potentially terminal illnesses are more than twice as likely to take their own lives than the general population. Currently, one person every eight days travels to Switzerland from the UK to end their life.[3] This is, unfortunately, unsurprising given that each year over 50,000 end-of-life patients will die experiencing some level of pain, whilst an estimated 6,000 patients will experience no relief from pain *at all* during their last three months of life[4]. Despite this, assisted dying is currently prohibited in the UK, and those who assist a loved one to die are at risk of prosecution.

This policy briefing identifies and summarises relevant literature, expanding on this with the addition of findings from a qualitative research project (conducted by the authors), concluding that a law change in favour of assisted dying should be supported, on the basis that it **enables terminally ill individuals to attain their basic human needs of autonomy, competence, and relatedness, and experience a good quality death.**

These conclusions are supported by three key research findings:

1) Assisted dying gives quality to the end-of-life
2) Assisted dying allows people to secure their basic human needs
3) Assisted dying does *not* result from the sense of being a burden

This briefing is based on research currently in preparation for publication, which was conducted at London South Bank University, in collaboration with Dignity in Dying.

1. Assisted dying gives quality to the end of life

Regardless of whether there was universal access to the highest quality palliative care, approximately 6,400 people annually would still suffer intractable pain during the last three months of life[5]. As Jackson and colleagues[6] explain, not only does the experience of pain result in direct suffering, but it also prevents individuals completing tasks important to them at the end-of-life (e.g., grieving for the loss of their own life, organising legal affairs, and saying goodbye to loved ones).

The ability to access assisted dying would add to the individual's quality of life by alleviating total pain (i.e., physical, psychological, social, and spiritual pain) and suffering, preventing a sense of

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[1] Some participants have requested to remain anonymous, to adhere to their wishes their names have been changed.

[2] Office for National Statistics. (2022). *Suicides among people diagnosed with severe health conditions, England: 2017 to 2020.* https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplediagnosedwithseverehealthconditionsengland/2017to2020

[3] Dignity in Dying. (2017). *The true cost: How the UK outsources death to Dignitas.* https://cdn.dignityindying.org.uk/wp-content/uploads/DiD_True_Cost_report_FINAL_WEB.pdf

[4] Zamora, B., Cookson, G., & Garau, M. (2019). Unrelieved pain in palliative care in England. Office of Health Economics. https://www.ohe.org/publications/unrelieved-pain-palliative-care-england

[5] Dignity in Dying. (2017). *Last Resort: The hidden truth about how dying people take their own lives in the UK.* https://www.dignityindying.org.uk/wp-content/uploads/Last-Resort-Dignity-in-Dying-Oct-2021.pdf

[6] Jackson, V. A., & Leiter, R. E. (2021). Ethical considerations in effective pain management at the end of life. *UpToDate.* https://www.uptodate.com/contents/ethical-considerations-in-effective-pain-management-at-the-end-of-life

hopelessness, and enabling people to retain a sense of self[7]. Consistent with this, participants we interviewed saw assisted dying as a "basic humanity" that "could actually improve current palliative care services" (Emma, experienced bad deaths of family members). The desire to end intractable pain and suffering was cited as the most important reason for seeking an assisted death, as Hilary explains:

> "If palliative care can't help me, then I want to know that I can say, 'I've had enough of this intolerable pain or this enormous discomfort.' (Hilary, mum experienced a bad death).

It was highlighted that having the option of an assisted death added quality at the end of life, with assisted dying seen as "reassuring" and a "safety-net" (Norma, who has terminal cancer). Assisted dying enables individuals to enjoy the remainder of their lives to the full, knowing that if the pain was unbearable there were still options available.

> "I can sit back and say, 'I can really enjoy my life, what's left of it now', and I don't have to worry about it anymore, because assisted dying is just ... it's a nice, gentle, dignified, hopeful way to go." (Alex, who has terminal cancer).

The option of an assisted death reduces concerns about the future, helping individuals to live in the present. Participants explain that this can help them to come to terms with dying:

> "I think not everyone that wants an assisted death will actually act it out in the end, but it may help them on the journey of dealing with their terminal illness." (Louise, whose father-in-law experienced a bad death from MND).

By enabling assisted dying, this could improve the end-of-life experience, particularly for those experiencing intractable suffering.

Under no circumstances did participants believe that assisted dying would replace palliative care, but assisted dying was perceived as an additional tool that could *improve* current practices.

2. Assisted dying allows people to secure their basic human needs

As demonstrated above, assisted dying is primarily motivated by the desire to alleviate pain and suffering[7]. To develop a deeper understanding, the current research explored additional factors which can lead some individuals to seek an assisted death.

According to Self-Determination Theory[8], there are three basic human needs: *competence* (mastery over activities), *autonomy* (sense of control and independence), and *relatedness* (feeling securely connected to others). Fulfilling all needs is fundamental for psychological well-being.

When an individual is terminally ill, it becomes challenging to achieve these. Take *competence*, as illnesses progress and pain and/or physical functioning worsens, individuals become less able to maintain activities they previously mastered (e.g., work/hobbies[9]). Factors such as accessibility, pain, and embarrassment (e.g., fungating cancers) can reduce one's ability to spend time with others,

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[7] Hendry, M., Pasterfield, D., Lewis, R., Carter, B., Hodgson, D., & Wilkinson, C. (2013). Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying. *Palliative medicine, 27*(1), 13-26. https://doi.org/10.1177/0269216312463623

[8] Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist, 55*(1), 68–78. https://doi.org/10.1037/0003-066X.55.1.68

[9] Marie Curie. (2022a). *Work and terminal illness.* https://www.mariecurie.org.uk/help/support/diagnosed/practical-emotional-support/about-work

negatively impacting on the basic human need of *relatedness*[10]. Finally, a loss of independence, choice, and dignity, prevents a sense of *autonomy*[11].

When we consider assisted dying, we often assume that it is the product of loss: a loss of function, loss of ability, loss of independence. However, our research has demonstrated that assisted dying can also **give**; give a sense of competence, relatedness, and autonomy. Critically, *these basic human needs are valued as much during the dying process as they are in life*.

Consistent with past research[9], our participants want to have control over their life and the right to choose how they experience death: giving a sense of *autonomy*.

> "I'm not scared of death. What I'm scared of is not being able to control it and not being able to do it in the way that I want to do it" (Sarah, who has experienced life-limiting conditions).

Participants highlighted that being able to make end-of-life decisions allows them to gain a sense of mastery over the dying process: fulfilling the basic human need of *competence*. Regarding *relatedness,* participants discussed how having an assisted death allows them to have their family with them during death, in a way which is peaceful and minimally distressing to all involved.

> "What a nice thing to do, to choose your time, have your family round… had a big meal, they've all said their goodbyes, you have a wee drink, and you go to sleep, how fabulous is that?" (Norma, who has terminal cancer).

By enabling assisted dying, this could allow the attainment of basic human needs, leading to improved psychological well-being at the end-of-life.

3. Assisted dying does not result from the sense of being a burden

Opponents often argue that vulnerable individuals are at risk of feeling pressurised into seeking an assisted death, because of being an emotional, physical, or financial burden on family/friends/wider society[12]. Past research has indicated that experiencing feelings of being a burden are common among individuals with terminal illness[13]. However, a recent systematic mixed studies review, found this to be among the least important and least frequently cited reasons for seeking an assisted death. Instead, unbearable suffering, pain, loss of dignity and autonomy, and hopelessness were the most important reasons[14]. This suggests that whilst feelings of burdensomeness are common in the terminally ill, it is not a strong motivating factor for seeking an assisted death.

This was supported by our current research, with findings indicating that whilst some (not all) participants 'felt like a burden', they highlighted that burdensomeness was driven by societal expectations, rather than because of personal or familial reactions to caregiving. Indeed, family members of those who had an assisted death abroad indicated that they did not perceive them to be a burden:

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[10] Marie Curie. (2022b). *"You're the first person who's sat on that sofa in 12 months: Experience of loneliness among people at the end of life and their carers in Northern Ireland.* https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/experiences-of-loneliness-among-people-at-the-end-of-life-and-their-carers-in-northern-ireland.pdf

[11] Colburn, B. (2020). Autonomy, voluntariness and assisted dying. *Journal of Medical Ethics, 46*(5), 316-319. https://doi.org/10.1136/medethics-2019-105720

[12] Not Dead Yet UK. (2022). *Why are you concerned about assisted suicide becoming legal?* http://notdeadyetuk.org/faqs/

[13] McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007). Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative medicine, 21*(2), 115-128.

[14] Roest, B., Trappenburg, M., & Leget, C. (2019). The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review. *BMC Medical Ethics, 20*(1), 1-21. https://doi.org/10.1186/s12910-019-0361-2

> "Society says they're going to be a burden so then the person thinks they're a burden… I didn't think she was a burden" (Tom, whose mum travelled to Dignitas for an assisted death).

Importantly, feeling like a burden on others was not cited as a reason for wanting or pursuing an assisted death. Instead, participants perceived *continued living* to be a burden for themselves:

> "'I'm not tired of life; I'm tired of living with MND.' And that was the burden: it was his burden. He wasn't a burden on anybody else: it was a burden to him – life was a burden to him" (Lesley, whose brother travelled to Dignitas for an assisted death).

As Lesley went onto highlight, the NHS'[15] commitment to patient-centred care should be considered when discussing the ethical considerations regarding burdensomeness:

> "'Patient-centred' and 'burdensome', in my opinion, don't go together because it's you that wants it and you're driving the process, it doesn't matter what anybody else says... it's what you want that drives everything" (Lesley).

Participants did indicate support for safeguards surrounding assisted dying, emphasising that having transparent procedures in place surrounding assisted dying could *protect* vulnerable people from the current informal, unregulated, and unreported processes that take place at the end of life (e.g., withholding/withdrawing life-sustaining treatment and palliative sedation) or from terminally ill individuals having to resort to attempting suicide using dangerous, painful, and often unsuccessful means.

Conclusion

This briefing has summarised the relevant literature, incorporating findings from a new qualitative study exploring attitudes toward assisted dying in the UK. As highlighted above, assisted dying can: give quality to the end-of-life, relieve intractable pain and suffering, add to palliative care practices, and enable people to achieve the basic human needs of competence, relatedness, and autonomy throughout the dying process. The findings of this research support the need for a change in the assisted dying law in the UK.

> In the words of Lesley: **"The problem was dying badly, and the answer was dying well".**

Dr Jaimee Mallion, London South Bank University
[Contact details redacted]

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[15] NHS England. (2022). *Involving people in their own care*. https://www.england.nhs.uk/ourwork/patient-participation/

compassion
& choices
Care and Choice at the End of Life

11 January 2023

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Assisted Dying Bill Consultation
c/o Clerk of Tynwald's Office
Legislative Buildings
Finch Road, Douglas
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Submitted to privatemembersbill@tynwald.org.im

Dear Committee:

Compassion & Choices is the oldest, largest and most active nonprofit working in the United States to improve care options and empower everyone to chart their own end-of-life journey. For more than 40 years, Compassion & Choices has worked across the United States to raise the voices of those people nearing the end of life, to change attitudes, practices and policies so that everyone can access the information about the full range of care options to ensure they have greater autonomy and comfort at the end of life. We submit this evidence to demonstrate what can be learned from medical aid in dying as authorized in the United States. We are submitting this evidence to the UK Parliament and the Isle of Man, as well.

Nearly 30 years ago, in November 1994, Oregon passed the nation's first law allowing mentally capable, terminally ill adults to have the end-of-life care option of medical aid in dying to peacefully end unbearable suffering.[1] Medical aid in dying is the preferred term for this end-of-life care option. Since that time, 6,378 terminally ill people have used this compassionate option to peacefully end their suffering.[2] There has not been a single

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[1] Frequently Asked Questions: Oregon's Death With Dignity Act (DWDA). Available from: https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/faqs.aspx

[2] *Medical Aid-in-Dying Data Across Authorized States, 2023*. Compassion & Choices. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical_aid_in_dying_utilization_report_12-13-2022.pdf?sfvrsn=697faeca_2

documented incident of coercion or abuse.[3][4] Ten states and Washington, D.C., have authorized the compassionate option of medical aid in dying.[5]

With nearly 25 years of data since the first implementation of Oregon's medical aid-in-dying law in 1997, we no longer have to hypothesize about what will happen if this medical practice is authorized. The evidence is clear: medical aid in dying protects patients, affords dying people autonomy and compassion during the most difficult time, improves end-of-life care, and costs jurisdictions almost nothing to implement.

Eligibility Criteria, Core Safeguards and Established Process

Each law authorizing medical aid in dying in the U.S. establishes strict eligibility criteria, practice requirements, and core safeguards to ensure the highest standard of care, as described in the clinical criteria and guidelines published in the prestigious, peer reviewed Journal of Palliative Medicine,[6] To be eligible for aid-in-dying medication,[7] an individual must be:

- An adult (aged 18 or older);
- Terminally ill with a prognosis of six months or less to live;
- Mentally capable of making their own healthcare decisions; and
- Able to self-administer the medication through an affirmative, conscious, voluntary act to ingest the prescribed medication to enable the terminally ill person to die peacefully.
    - Self-administration does not include administration by injection or infusion via a vein or any other parenteral route (i.e., situated or occurring outside the intestine) by any person, including the doctor, family member or patient themselves.

Advanced age, disability, and chronic health conditions are not qualifying factors for medical aid in dying.

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[3] Letter from Disability Rights Oregon (DRO), Available from: https://www.compassionandchoices.org/letter-from-disability-rights-oregon-dro

[4] Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups, Journal of Medical Ethics. Available from: https://jme.bmj.com/content/33/10/591

[5] Medical Aid in Dying, Compassion & Choices. Available from: https://www.compassionandchoices.org/our-issues/medical-aid-in-dying

[6] *Clinical Criteria for Physician Aid in Dying.* Journal of Palliative Medicine; D. Orentlicher, T.M. Pope, B.A. Rich, (2015). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4779271/

[7] Medical Aid in Dying…Who is eligible for medical aid in dying? Compassion & Choices. Available from: https://www.compassionandchoices.org/our-issues/medical-aid-in-dying

In addition to the strict eligibility criteria these laws establish the following core safeguards[8]:

- The attending healthcare provider must inform the terminally ill adult requesting medical aid in dying about all other end-of-life care options. These other options include comfort care, hospice care, pain control and palliative care;
- The attending healthcare provider must inform the terminally ill adult requesting medical aid in dying that they can change their mind at any time. This patient right to change their mind includes deciding not to take the medication once they have obtained it.

Additional Legislated Requirements

U.S. jurisdictions that have authorized medical aid in dying through legislation modeled their bills after Oregon's Death With Dignity Act. Jurisdictions' regulatory and procedural requirements are slightly different, but each requires that:

- The terminally ill adult must make at least one request to their attending healthcare provider.
- The written request must be witnessed by at least one person, who cannot be a relative or someone who stands to benefit from the person's estate upon their death.

Further, at least one healthcare provider must confirm the terminal diagnosis, prognosis of six months or less to live, and the person's ability to make an informed healthcare decision prior to the attending healthcare provider writing a prescription. If an attending healthcare provider suspects the individual has any condition that may be impairing their ability to make a rational informed healthcare decision, then the individual is required to undergo an additional mental capacity evaluation with a mental health professional (such as a psychiatrist, psychologist, licensed clinical social worker, psychiatric nurse practitioner, or licensed clinical professional counselor). The request for aid-in-dying medication does not proceed unless the mental healthcare professional affirms that the individual is capable of making a rational and informed healthcare decision.

Voluntary Participation

Each law also ensures that individual healthcare providers' values and beliefs are respected; they specifically state participation is voluntary and that no provider is obligated to prescribe or dispense aid-in-dying medication. In other words, if a provider is unable or unwilling to honor a patient's request, they can opt-out and do not have to support the patient in this option.

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[8] Medical Aid in Dying…What safeguards are in place? Compassion & Choices. Available from: https://www.compassionandchoices.org/our-issues/medical-aid-in-dying

The laws provide explicit authorization for qualified healthcare providers to participate in the practice of medical aid in dying. The laws protect both those qualified healthcare providers who choose to and those who choose not to participate in medical aid in dying from criminal liability, civil liability and professional discipline, as long as they comply with the requirements set forth in the law and act in good faith while meeting the standards of medical (end-of-life) care.

Criminal Conduct

While those who comply with all aspects of the law and meet the standard of care are provided immunity from certain criminal prosecution (for example, homicide, assisting suicide or elder abuse) or civil lawsuits (such as malpractice), the jurisdictions retain the ability to hold those who fail to adhere to these strict requirements criminally and civilly liable. Moreover, the existing laws establish that any attempt to pressure or coerce an individual to request or use medical aid in dying is a felony.

Evidence

The growing support for medical aid in dying is attributable, in part, to the fact that it is a proven and time-tested end-of-life care option. Researchers and legal scholars have confirmed that the experience across the 11 authorized jurisdictions "puts to rest most of the arguments that opponents of authorization have made — or at least those that can be settled by empirical data. The most relevant data — namely, those relating to the traditional and more contemporary concerns that opponents of legalization have expressed — do not support and, in fact, dispel the concerns of opponents."[9,10] Additionally, a 2022 sample of Colorado physicians showed that many physicians are both willing and prepared to discuss medical aid in dying with patients and to provide referrals.[11]

The evidence is clear: medical aid-in-dying laws protect terminally ill individuals, while giving them a compassionate option to die peacefully and providing appropriate legal protection for the providers who practice this patient-driven option.

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[9] *A History of the Law of Assisted Dying in the United States.* SMU Law Review, A. Meisel, (2019). Available from: https://scholar.smu.edu/cgi/viewcontent.cgi?article=4837&context=smulr

[10] *Rutgers Study Examines Who Uses Medical Aid in Dying.* Rutgers University, Smith, A. (2022) Available from: https://www.rutgers.edu/news/medical-aid-dying-maid-mostly-used-well-educated-white-patients-cancer

[11] Physicians' Attitudes and Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey. Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. (2022) Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8751472/

Medical Aid in Dying Protects Patients

There have been no documented or substantiated incidents of abuse or coercion across the authorized jurisdictions. The Journal of the American Academy of Psychiatry and Law noted “there appears to be no evidence to support the fear that assisted suicide [medical aid in dying] disproportionately affects vulnerable populations.” Vulnerable populations include the elderly, women, the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses, or racial or ethnic minorities, compared with background populations.[12]

Relatively Few Will Use Medical Aid in Dying, But Many Benefit From These Laws

The use of medical aid in dying by eligible terminally ill people accounts for less than 1% of annual deaths in every one of the 11 jurisdictions where this end-of-life care option is authorized. That said, these laws benefit more than the small number of people who decide to use them. Awareness of the law has a palliative effect, relieving worry about end-of-life suffering. In the jurisdictions that have already authorized medical aid in dying, for example, people report significant relief from worry about future physical and emotional pain just from knowing the option is there should they need it, regardless of whether or not they decide to pursue it. Quite simply, medical aid in dying is a prescription for comfort and peace of mind.

Medical Aid in Dying Improves End-of-Life Care

Oregon has long been on the forefront of end-of-life care, leading the nation in terms of the development of patient-directed practices, adherence to advance directives and hospice utilization. Oregon boasts among the highest number of people who die in their own homes, rather than in hospitals.[13] The experience and data demonstrate that the implementation and availability of medical aid in dying further promote these practices and improve other aspects of end-of-life care.[14]

> A 2001 survey of physicians about their efforts to improve end-of-life care following authorization of the Oregon Death With Dignity Act showed 30% of responding physicians had increased the number of referrals they provided for hospice care, and 76% made efforts to improve their knowledge of pain management.[15]

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[12] *Physician-Assisted Suicide: Considering the Evidence, Existential Distress, and an Emerging Role for Psychiatry*. Journal of the American Academy of Psychiatry and the Law. Gopal, AA. 2015. Vol 43(2): 183-190. Available from http://jaapl.org/content/43/2/183.

[13] *Lessons from Oregon in Embracing Complexity in End-of-Life Care*. New England Journal of Medicine, S.W. Tolle, MD, J.M. Teno, MD, (2017). Available from: https://www.nejm.org/doi/10.1056/NEJMsb1612511

[14] *Oregon's Assisted Suicide Vote: The Silver Lining*. Annals of Internal Medicine, M.A. Lee, S.W. Tolle, (1996). Available from: https://www.acpjournals.org/doi/10.7326/0003-4819-124-2-199601150-00014?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed

[15] *Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act.* JAMA. L. Ganzini, H.D. Nelson, M.A. Lee, D.F. Kraemer, T.A. Schmidt, M.A. Delorit, (2001). Available from: https://pubmed.ncbi.nlm.nih.gov/11343484/

- A 2015 Journal of Palliative Medicine study found that Oregon was the only state both in the highest quartile of overall hospice use and the lowest quartile for potentially concerning patterns of hospice use."[16] Concerning patterns of hospice use" is defined as very short enrollment, very long enrollment or disenrollment. This same study suggested the Oregon medical aid-in-dying law may have contributed to more open conversations between doctors and patients about end-of-life care options, which led to the more appropriate hospice use.
- Hospice programs across Oregon, in fact, reported an increase in referrals following passage of the Oregon Death With Dignity Act.[17] More than 20 years later, more than 90% of individuals who used medical aid in dying were receiving hospice services at the time of their death.[18]

In California, the availability of medical aid in dying has had a profound effect on end-of-life care. On January 24, 2018, slightly more than a year-and-a half after the California law went into effect, the Assembly Select Committee on End of Life Health Care (California Select Committee) held a hearing on the implementation status. The testimony from patients, doctors and health system representatives supported the concept that although the regulatory process was more complicated and burdensome than anticipated, the law has been compassionately implemented, promoted better end-of-life care and provides peace of mind to countless Californians nearing their final days. This message was echoed during the California Select Committee's second hearing on February 25, 2020.[19]

For Some, Comfort Care and Pain Management Are Not Enough to Relieve Suffering

The evidence from scientific studies confirms that despite the wide availability of hospice and palliative medicine, many patients experience pain at the end of life. One study found that the prevalence of pain increases significantly at the end of life, jumping from 26% in the last 24 months of life to 46% in the last four months of life.[20]

Additionally, breakthrough pain — severe pain that erupts even when a patient is already medicated — remains a nightmare experience for many patients. In the National

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[16] *Geographic Variation of Hospice Use Patterns at the End of Life.* Journal of Palliative Medicine, S.Y. Wang, M.D, Aldridge, C.P. Gross, et al. (2015). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4696438/

[17] *Id.*

[18] *Oregon Death with Dignity Act. Annual Report*, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

[19] *California Assembly Select Committee on End of Life Health Care*, Wednesday, January 24, 2018 and Tuesday, February 25th, 2020. Available from: https://www.assembly.ca.gov/media/select-committee-end-life-health-care-20180124/video and https://www.assembly.ca.gov/media/assembly-select-committee-end-life-health-care-20200225/video

[20] *The Epidemiology of Pain During the Last 2 Years of Life.* The Annals of Internal Medicine, A.K. Smith, I.S. Cenzer, S.J. Knight, K.A. Puntillo, E. Widera, B.A. Williams, W.J. Boscardin, K.E. Covinsky, (2010.) Available from: http://annals.org/aim/article/746344/epidemiology-pain-during-last-2-years-life

Breakthrough Pain Study, among respondents who had cancer (at all stages), 83.3% reported breakthrough pain. For those cancer patients who experienced breakthrough pain, only 24.1% reported that using some form of pain management worked every time.[21]

For some people the side effects of pain medication (sedation, nausea, obstructed bowels) are just as bad as the pain from the disease. Some agonies simply cannot be controlled or relieved unless a person is willing to be sedated to complete and deep unconsciousness. Even then, patients sometimes moan and grimace, suggesting pain may still be present. Many value their consciousness so highly that they bear extraordinary pain in order to be somewhat alert during their final days.

People Choose Medical Aid in Dying as well as Hospice and Palliative Care

The majority of individuals who request and obtain aid-in-dying medication are enrolled in hospice services at the time of their death.[22]

Good hospice services and palliative care do not eliminate the need for medical aid in dying as an end-of-life care option. Terminally ill people should have a full range of end-of-life care options, whether for disease-specific treatment, palliative care, refusal of life-sustaining treatment or the right to request medication the patient can decide to take to shorten a prolonged and difficult dying process. Only the dying person can know whether their pain and suffering is too great to withstand. The option of medical aid in dying puts the decision-making power where it belongs: with the dying person.

Patients Involve Their Loved Ones in the Decision

The majority of eligible patients involve their family in their decision-making process and most have someone (family, and sometimes a trusted healthcare provider) present at some point during their planned death, according to the Oregon data.[23]

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[21] *Impact of breakthrough pain on community-dwelling cancer patients: results from the National Breakthrough Pain Study.* Katz, N.P, Gajria, K.L, Shillington, A.C., et. al. (2016). Postgraduate Medicine, 129(1), 32-39. Available from: https://pubmed.ncbi.nlm.nih.gov/27846789/

[22] *Medical Aid-in-Dying Data Across Authorized States, 2023*. Compassion & Choices. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical_aid_in_dying_utilization_report_12-13-2022.pdf?sfvrsn=697faeca_2

[23] *Oregon Death with Dignity Act. Annual Report*, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

Medical Aid in Dying Utilization Report

Currently, public health departments in nine authorized jurisdictions have issued reports regarding the utilization of medical aid-in-dying laws: Oregon[24], Washington[25], Vermont[26], California[27], Colorado[28], Hawai'i[29], the District of Columbia[30], Maine[31], and New Jersey[32]. Compassion & Choices has compiled annual report data from the authorized jurisdictions that collect data[33]. Key highlights include:

> For the past 24 years, starting with Oregon and across all jurisdictions, just 6,378 people have ingested a prescription to end their suffering.

> Over one-third (37%) of people who go through the entire process and obtain the prescription never take it; however, they derived peace of mind from simply knowing that if their suffering became too great, they would have the option.

> The vast majority of terminally ill people who use medical aid in dying — more than 87% — received hospice services at the time of their deaths, according to annual reports for which hospice data is available.

> There is nearly equal utilization of medical aid in dying among men and women.

> Terminal cancer accounts for the vast majority of qualifying diagnoses with neurodegenerative diseases, such as ALS or Huntington's disease, following as the second leading diagnosis.

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[24] *Oregon Death with Dignity Act. Annual Report*, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

[25] *Washington Death with Dignity Act Annual Report* (2020). Available from: https://doh.wa.gov/sites/default/files/2022-02/422-109-DeathWithDignityAct2020.pdf?uid=63463231758e3

[26] *Vermont Patient Choice at the End of Life Data Report* (2020). Available from: https://legislature.vermont.gov/assets/Legislative-Reports/2020-Patient-Choice-Legislative-Report-2.0.pdf

[27] *California End of Life Option Act Annual Report* (2021). Available from: https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH_End_of_Life%20_Option_Act_Report_2021_FINAL.pdf

[28] *Colorado End of Life Options Act Annual Report* (2020). Available from: https://cdphe.colorado.gov/center-for-health-and-environmental-data/registries-and-vital-statistics/medical-aid-in-dying https://drive.google.com/file/d/1FmoyCcL2gHopDO9rCJ2lGFEMUye8FQei/view

[29] *Hawai'i Our Care, Our Choice Act Annual Report* (2020). Available from: https://health.hawaii.gov/opppd/files/2020/01/OPPPD-Our-Care-Our-Choice-Act-Annual-Report-2019-1.pdf

[30] *District of Columbia Death with Dignity Act Annual Report. (*2019). Available from: https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/DWD%20Report%202018%20Final%20%20%208-2-2019.pdf

[31] *Maine Death with Dignity Act Annual Report (2021).* Available from: https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/Patient-Directed%20Care%20%28Death%20with%20Dignity%29%20Annual%20Report%20--%204-2021.pdf

[32] *New Jersey Medical Aid in Dying for the Terminally Ill Act 2020 Data Summary Report* (2021). Available from: https://nj.gov/health/advancedirective/documents/maid/2021.pdf

[33] *Medical Aid-in-Dying Data Across Authorized States, 2023*. Compassion & Choices. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical_aid_in_dying_utilization_report_12-13-2022.pdf.

> Just over 90% of people who use medical aid in dying are able to die at home, which is where most Americans would prefer to die.[34]

The evidence confirms that medical aid-in-dying laws protect patients while offering a much-needed compassionate option.

Medical Ethical Considerations

Among U.S. physicians, support for medical aid in dying is also strong. A 2020 Medscape poll of 5,130 U.S. physicians from 30 specialties demonstrated a significant increase in support for medical aid in dying from 2010. [35] A 2021 Gynecologic Oncology survey showed 69% of respondents believed that medical aid in dying should be legalized, and in a 2020 Oncology Ethics report, 55% of oncologists surveyed said that medical aid in dying should be legalized. [36] A 2022 study of Colorado physicians noted "those who have participated in [medical aid in dying] largely report the experience to be emotionally fulfilling and professionally rewarding," despite barriers to offering the end-of-life care option.[37] Today, 55% of physicians surveyed endorse the idea of medical aid in dying, agreeing that "Physician assisted death should be allowed for terminally ill patients."[38]

Additionally, a 2022 survey of nurses demonstrated that most nurses would care for a patient contemplating medical aid in dying (86%) and that 57% would support the concept of medical aid in dying professionally as a nurse.[39]

During the past six years, dozens of national and state medical and professional associations have endorsed or dropped their opposition to medical aid in dying in response to growing support for this palliative care option among qualified clinicians and the public.

Six national health organizations have taken positions supporting medical aid in dying:

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[34] *Views and Experiences with End-of-Life Medical Care in the U.S.* (2017). Hamel, Wu, and Brodie. Kaiser Family Foundation. Available from: https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings

[35] Medscape Ethics Report 2020: Life, Death, and Pain, (2020). Available from: https://compassionandchoices.org/docs/default-source/fact-sheets/medscape-ethics-report-2020-life-death-and-pain.pdf

[36] Polling on Medical Aid in Dying (2022). Available from: https://compassionandchoices.org/resource/polling-medical-aid-dying

[37] Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. *Physicians' Attitudes and Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey.* J Gen Intern Med. 2022 Oct;37(13):3310-3317. doi: 10.1007/s11606-021-07300-8. Epub 2022 Jan 11. PMID: 35018562; PMCID: PMC8751472.

[38] *Medscape Ethics Report 2020: Life, Death, and Pain*, (2020). Available from: https://compassionandchoices.org/docs/default-source/fact-sheets/medscape-ethics-report-2020-life-death-and-pain.pdf

[39] Polling on Medical Aid in Dying (2022). Available from: https://compassionandchoices.org/resource/polling-medical-aid-dying

> American College of Legal Medicine[40]

> American Medical Student Association[41]

> American Medical Women's Association[42]

> American Public Health Association[43]

> GLMA: Healthcare Professionals Advancing LGBT Equality[44]

> National Student Nurses' Association[45]

Because provider participation is critical to access medical aid in dying, lawmakers look to healthcare associations for input. Neutral positions, including engaged neutrality, recognize differences of opinion among providers and establish that those who participate in medical aid in dying are adhering to their professional, ethical obligations, as are those who decline to participate. Six national healthcare organizations have adopted neutral positions:

> American Academy of Family Physicians[46]

> American Academy of Neurology[47]

> American Academy of Hospice and Palliative Medicine[48]

> American Nurses Association[49]

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[40] *American College of Legal Medicine,* Position on Medical Aid in Dying, (2008). Available from: https://compassionandchoices.org/docs/default-source/policy/american-college-of-legal-medicine-position-statement.pdf

[41] *American Medical Student Association*, Excerpted from: Preambles, Purposes, Principles: Principles Regarding Physician Aid in Dying. (2008). Available from: http://www.amsa.org/wp-content/uploads/2015/03/PPP-2015.pdf

[42] *American Medical Women's Association,* Excerpted from: Position Paper on Aid in Dying (2013/2018). Available from https://www.amwa-doc.org/wp-content/uploads/2018/09/Medical-Aid-in-Dying-Position-Paper.pdf

[43] *American Public Health Association,* Excerpted from: Patient's Rights to Self-Determination at the End. Policy # 20086. (2008). Available from: https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life

[44] *GLMA Letter of Support on AB X2-15*, (2015). Available from: https://compassionandchoices.org/docs/default-source/california/20151002-glma-letter-in-support-of-ca-eoloa.pdf.

[45] *National Student Nurses' Association,* NSNA Resolutions (2018). Available from: https://www.dropbox.com/s/8xwq5f827leqriq/NSNA%20Resolutions%202018.pdf?dl=0

[46] *American Academy of Family Physicians COD Addresses Medical Aid in Dying, Institutional Racism*. (2018). Available from: https://www.aafp.org/news/2018-congress-fmx/20181010cod-hops.html

[47] *American Academy of Neurology position statement on Lawful Physician-Hastened Death.* (2018). Available from: http://n.neurology.org/content/90/9/420

[48] *American Academy of Hospice & Palliative Medicine.* Excerpted from: Statement on Physician-Assisted Death (2007). Available from: http://aahpm.org/positions/pad

[49] *American Nurses Association, The Nurse's Role When a Patient Requests Medical Aid in Dying* (2019). Revised Position Statement. Available from: https://www.nursingworld.org/~49e869/globalassets/practiceandpolicy/nursing-excellence/ana-position-statements/social-causes-and-health-care/the-nurses-role-when-a-patient-requests-medical-aid-in-dying-web-format.pdf

> American Pharmacists Association[50]

> American Society for Health System Pharmacists[51]

> National Association of Social Workers[52]

Medical associations in many of the authorized jurisdictions currently have neutral positions on medical aid in dying, including Oregon[53], California[54], Colorado[55], Vermont[56], Hawai'i[57], Maine [58], New Mexico[59], and the District of Columbia[60]. Seven other state medical societies and a medical resident society in non-authorized jurisdictions (New York, Connecticut, Maryland, Massachusetts, Minnesota, Delaware, and Virginia) have also recently dropped their opposition.[61, 62, 63, 64, 65, 66, 67]

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[50] *American Pharmacists Association, Actions of the 2015 APhA House of Delegates*, Available from: https://docksci.com/report-of-the-2015-apha-house-of-delegates_5a35bf67d64ab2ddfc6de3a7.html

[51] *American Society of Health-System Pharmacists, Board Report on the Joint Council Task Force on Pharmacist Participation in Medical Aid in Dying,* (2016). Available from: https://www.ashp.org/-/media/assets/house-delegates/docs/hod-board-report-on-task-force.ashx

[52] *National Association of Social Workers, NASW Standards for Palliative and End of Life Care*, Available from: https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3D&portalid=0.

[53] *Oregon Medical Association,* Excerpted from: October 27 Board of Trustees Report. Available from: http://bit.ly/2CYT6Dx

[54] *California Medical Association Position on Medical Aid in Dying.* Available from: https://www.cmadocs.org/newsroom/news/view/ArticleId/27210/California-Medical-Association-removes-opposition-to-physician-aid-in-dying-bill

[55] *Colorado Medical Society, Position on Medical Aid in Dying.* Available from: https://www.cms.org/articles/prop-106-may-june

[56] *Vermont Medical Society, Position on Medical Aid in Dying,* (2017). Available from: http://www.vtmd.org/sites/default/files/2017End-of-Life-Care.pdf

[57] *Hawai'i Society of Clinical Oncology, Hawaii Our Care, Our Choice Act Resources* (2018). Available from: https://www.accc-cancer.org/state-societies/Hawaii/resources/medical-aid-in-dying

[58] *Maine Medical Association (MMA) Position on Medical Aid in Dying,* (2017). Available from: http://newsmanager.commpartners.com/mainemed/issues/2017-05-01/index.html

[59] *New Mexico Medical Society Position on Medical Aid in Dying* (2019). Available from: https://d2zhgehghqjuwb.cloudfront.net/accounts/14766/original/2019_1_5_Council_Minutes_-_PENDING_APPROVAL.pdf?1547577653

[60] *Another State Medical Society Stops Fighting Assisted Death* (2017). Lowes, Robert. Medscape. Available from: https://www.medscape.com/viewarticle/889450?reg=1&icd=login_success_gg_match_norm

[61] *New York State Assembly of Family Physicians Position on Medical Aid in Dying,* (2017). Available from: http://www.nysafp.org/NYSAFP/media/PDFs/Policy-Positions-Manual-TOC-links-2017.pdf

[62] *Connecticut State Medical Society Position on Medical Aid in Dying.* (2019). Available from: https://www.cga.ct.gov/2019/PHdata/Tmy/2019HB-05898-R000318-Connecticut%20State%20Medical%20Society-TMY.PDF

[63] *MEDCHI, The Maryland State Medical Society House of Delegates Position on Medical Aid in Dying.* (2016) Available from http://www.medchi.org/Portals/18/files/Events/Resolution%2016-16.pdf?ver=2016-08-26-140448-047

[64] *Massachusetts Medical Society Position on Medical Aid in Dying* (2017). Available from: https://www.massmed.org/About/2017-Annual-Report/

[65] *Minnesota Medical Association Position on Medical Aid in Dying* (2017) Available from: http://www.mnmed.org/news-and-publications/News/MMA-Revises-Its-Policy-on-Physician-Aid-In-Dying

[66] *MSD Support of Engaged Neutrality for Medical Aid in Dying* (2022). Available from: https://files.constantcontact.com/01c210be101/c65122d3-bb72-4b9c-a2f6-8563b3304710.pdf?rdr=true

[67] *2022-2023 Policy Compendium*, (2022). The Medical Society of Virginia. Available from: https://www.msv.org/wp-content/uploads/2022/11/2022-2023-Policy-Compendium.pdf

Additionally, the American Medical Association (AMA) and the National Hospice and Palliative Care Organization (NHPCO), have amended their policies to state that it is ethical for a provider to provide medical aid in dying to qualified patients seeking it.[68] NHPCO went so far as to replace the outdated and pejorative expression, "assisted suicide," with the correct terminology, "medical aid in dying."[69] While the AMA and NHPCO do not yet have a fully supportive policy, these changes are a significant step forward and demonstrate that acceptance within the medical field is gaining momentum.

There is growing recognition within the medical profession and healthcare organizations that patients want, need and deserve this compassionate option at the end of life. This recognition is burgeoning into collaboration. As more jurisdictions authorize medical aid in dying, the healthcare community is coming together and providers are sharing their experiences and fine-tuning their collaborative efforts to better serve dying patients.

Public Support for Medical Aid in Dying as an End-of-Life Care Option

Numerous public opinion polling from a variety of sources, both nationally and at the state level, demonstrates that the American public consistently supports medical aid in dying, with majority support among nearly every demographic group. A 2021 nationwide poll by Susquehanna Polling and Research reported that 68% of voters support medical aid in dying as an end-of-life care option. Additionally, when respondents are asked if they want the option of medical aid in dying personally for themselves, 67% said yes.[70] Gallup's 2020 Values and Beliefs poll shows that a majority of respondents have consistently favored [medical aid in dying] since Gallup first asked about it in 1996.[71]

Thank you for the opportunity to submit evidence for this inquiry. Please feel free to contact me with any questions at [Contact details redacted]

Most sincerely,
Bernadette Nunley
National Director of Policy

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[68] *Report 2 of the Council on Ethical and Judicial Affairs (2-A-19), Physician Assisted Suicide (Resolution 15-A-16 and Resolution 14-A-17)* (2019). American Medical Association. Available from: https://www.ama-assn.org/system/files/2019-05/a19-ceja2.pdf

[69] *Statement on Medical Aid in Dying* (2021). National Hospice and Palliative Care Organization. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical_aid_dying_position_statement_nhpco.pdf

[70] *Nationwide Poll Shows Strong Support for Advance Care-Dementia Planning, Medical Aid in Dying*, Susquehanna Polling and Research, Omnibus Survey (2021). Available from: https://compassionandchoices.org/docs/default-source/default-document-library/usa-omnibus-cross-tabulation-report-final-november-2021-2.pdf?sfvrsn=74705b4b_1

[71] Prevalence of Living Wills in U.S. Up Slightly. Jones, Jeffrey (2020) Gallup. Available from: https://news.gallup.com/poll/312209/prevalence-living-wills-slightly.aspx

Kyam Maher MLC – Submission of Evidence to the UK Parliament's Health and Social Care Select Committee on Voluntary Assisted Dying

My name is Kyam Maher and I am a member of the Legislative Council in the Parliament of South Australia. While I am currently the Attorney-General, Minister for Aboriginal Affairs and Minister for Industrial Relations and Public Sector in the Malinauskas Labor Government, my involvement in South Australia's voluntary assisted dying legislation was as a Private Member of our Parliament in 2020 and 2021. In December 2020, I introduced the legislation and worked closely with medical and legal experts to lead debates in Parliament until the passing of the bill in 2021.

I was invited by Ms Sarah Wootton, Chief Executive of Dignity in Dying UK, to make a submission of evidence to the Health and Social Care Select Committee in light of this experience.

2. What can be learnt from the evidence in countries where assisted dying is legal?

In May 2021, the Voluntary Assisted Dying Act[1] passed South Australian Parliament after 16 previous attempts spanning 27 years. On 31st January 2023, that legislation will begin operation and eligible South Australians will be able to have the choice of dying with dignity. Voluntary assisted dying (VAD) is now legal in every state in Australia.

Victoria was the first state in Australia to pass VAD laws in 2017[2], commencing in 2019. Since implementation, that VAD Scheme has facilitated over 600 Victorians having a dignified death.[3]

Palliative effect of peace of mind

In their most recent publication, the Victorian VAD Review Board[4] have reported that as of 30 June 2022, over 900 permits had been issued under the Victorian VAD Scheme and of those, only 604 permit holders ultimately died from taking the prescribed lethal substance.[5]

Feedback from Victorian applicants and their relatives have reported on the palliative effect of knowing that they have access to the VAD substance if they choose to use it.[6] Families and loved ones are often comforted by witnessing the applicant's wishes being fulfilled and their autonomy respected, regardless of whether the applicant uses the lethal substance.[7]

In Victoria, 81 percent of applicants were accessing palliative care at the time of requesting VAD.[8]

Palliative Care

In Belgium and the Netherlands, research suggests the introduction of VAD has not stunted the development of palliative care, and that government funding grew at a consistent rate with

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[1] Voluntary Assisted Dying Act 2021 | South Australian Legislation
[2] Voluntary Assisted Dying Act 2017 (legislation.vic.gov.au)
[3] Voluntary Assisted Dying Review Board Report of Operations July 2021-June 22_FINAL.pdf (safercare.vic.gov.au) p 5.
[4] Voluntary Assisted Dying Review Board | Safer Care Victoria
[5] Ibid 3, p 22.
[6] Ibid 4, p 1.
[7] Ibid, p 1.
[8] Ibid, p 16.

countries such as the UK that have not legalised VAD.[9] The same year that VAD was implemented in Victoria, the Victorian State Government announced more than $62 million in additional funding to palliative care services.[10]

Incurable disease, illness or medical condition

One of the eligibility criteria for accessing VAD is that the person must have been diagnosed with an incurable disease, illness or medical condition. The Victorian Ministerial Advisory Panel on Voluntary Assisted Dying (Panel) considered 'incurable' to mean the person is suffering from a condition that is causing enduring and unbearable suffering that cannot be cured, and cannot be relieved in a manner *the person deems tolerable*.[11] Therefore, the Panel considers that denying a person access to VAD because they have refused medical treatment options that are available but are not acceptable to them would be inconsistent with the right to refuse life-sustaining medical treatment and may infringe other human rights and amount to discrimination.[12]

Safeguards

Between 1 July 2021 and 30 June 2022, the Victorian VAD Review Board found four cases to be non-compliant with the VAD Act.[13] Three of those were due to a delay in returning the lethal substance to the Statewide Pharmacy. The law requires the contact person to return any outstanding substance within 15 days of the death of an applicant. These delays were for various reasons, but all were found to be absent of concerning behaviour and the Review Board recommended that contact persons are made better aware of this requirement when they are appointed. The other case of non-compliance was where someone signed an application document on behalf of an applicant and was also a witness to the document, which is prohibited by the Act. After investigating the case, the Review Board considered this was an oversight and the case was considered clinically appropriate.[14]

The Victorian VAD model now implemented from the Panel Recommendations is even more rigorous than any existing process in Victoria for medical treatment, and provides greater opportunity to identify instances of elder abuse.[15]

In the South Australian legislation, there are 71 safeguards before a person can administer the lethal substance, which is 3 more than the highly rigorous Victorian legislation.[16]

Language

Another point I wish to make is the importance of language and not referring to VAD as suicide or assisted killing. The Panel recognises that language in the VAD space is often used to imply judgements about something through its description and can be associated with unnecessary stigma.[17] The South Australian VAD Act clarifies that a person who performs an act or omission in relation to the voluntary assisted dying of a person in accordance with this Act will be taken not, by

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[9] 'State of palliative care development in European countries with and without legally regulated physician-assisted dying', *Health Care* 2014 (Ministerial Advisory Panel on Voluntary Assisted Dying Final Report p. 39).
[10] Additional palliative care funding for Victoria announced | Aged Care Guide
[11] Victorian Ministerial Advisory Panel on Voluntary Assisted Dying, Final Report 2017, p 66.
[12] Ibid p 67.
[13] Ibid 4, 25.
[14] Ibid.
[15] Ibid 11, p 88.
[16] Ibid 1.
[17] Ibid 11, pp 7-8.

that act or omission alone, to have aided, abetted, counselled or procured the suicide of the other person.

Suicide in the alternative

As reported in the Parliament of South Australia's Joint Committee on End of Life Choices, the State Coroner David Whittle advised that people who are chronically or terminally ill and experiencing an 'irreversible decline in physical health' have elected to commit suicide rather than endure what palliative care has to offer.[18] The Coroner had identified a number of deaths by suicide, seemingly in response to people suffering 'a deteriorating quality of life' from a disease likely to result in death. South Australia's Assistant Commissioner of Police, Scott Duval, reported that from 1 January until 22 November 2019, ten people had taken their lives as a result of terminal illness, equating to approximately 11 per cent of all suicides during that period. The age of those persons ranged from 63 to 88 years, and most deaths in such circumstances are undignified, violent, and sometimes botched.[19]

Under South Australia's *Criminal Law Consolidation Act 1935*, it is not an offence to commit or attempt to commit suicide.[20] It is however an offence to assist someone in their suicide or suicide attempt. Consequently, the 'vast majority' of suicides in South Australia are committed when the person is alone and 'without their family to comfort them'. This usually leads to the deceased not being found for some time, and often being discovered by a family member.

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[18] Report of the Joint Committee on End of Life Choices, Parliament of South Australia, Second Session, Fifty-Fourth Parliament 2020, p 18.
[19] Ibid, p 19.
[20] Criminal Law Consolidation Act 1935 | South Australian Legislation

Submission to the UK Parliament Health & Social Care Committee-Inquiry into Assisted Dying

Submitter:

Tina McCafferty
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Tōtara Hospice I Te Kahu Pairuri o Tōtara
Auckland
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Reasons for submission

The submission responds to question 2: *What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?*

It is made in support of patient choice in healthcare. In support of patient rights and human rights where they pertain to the terminally ill and in support of excellent palliative care and assisted dying services being a complimentary continuum not opposing ideologies.

Having first-hand experience as a specialist palliative care provider Organisation who also hosts assisted dying to terminally ill patients who meet the legal criteria, we hope to offer some useful insights.

Introduction

Tōtara Hospice **I** Te Kahu Pairuri o Tōtara (TH) is an Aotearoa New Zealand (ANZ) registered charity (CC2168) and specialist palliative care provider (SPCP) offering inpatient, outpatient and at home hospice care across the districts of south and southeast Auckland, serving a community of approximately 600,000 people.

Now in our 40th operating year, we are one of ANZ's largest Hospices and its most culturally diverse; both in workforce and in community served. We actively collaborate across a range of care partnerships with secondary care, tertiary care, general practice, aged residential care and Māori and Pacific providers as well as service alliances with other Hospice providers across our region.

We have provided a hosting assisted death service (HADS) since November 2021.

Background

In October 2020 New Zealanders were given the opportunity to vote in a binding referendum on the End-of-Life Choice Bill 2019, which proposed to give those with a terminal illness (who met certain criteria including cognitive competence) the option of an assisted death. The referendum result was a majority 'yes' vote of 65.1% for the right of individuals with incurable disease to access assisted dying across Aotearoa New Zealand. On November 7th, 2021, the Bill became an Act of Parliament.
https://www.legislation.govt.nz/act/public/2019/0067/latest/DLM7285905.html

As a leadership team of a SPCP (CEO, General Manager Clinical Services, Head of People & Capability, Medical Director, Nursing Director, Clinical Lead for Allied Health and Head of Cultural & Social Support) we had prepared for this outcome for a number of years (3 previous bills had gone through the NZ Parliament) and we chose to acknowledge and respect it. For a number of years in our belief and commitment to specialist palliative care providers working to destigmatise death and dying we ran a regular series of death cafes called the 'Departure Lounge'. We supported the use of Advanced Care Plans. We knew from conversation every other week with patients that this question of 'being able to legally choose' was sitting just under the surface (and often above it).

Contemporaneously, incrementally extensive training, debate information and education forums occurred for all staff (clinical and support) in the 24 months prior to implementation. Information and advice were provided to all volunteers.

The change management process was fundamental, critical and necessary. We had to be and were 100% transparent, we enabled judgment free debate, set clear expectations, recruited and retained for attitude and values. We were and remain explicit about how assisted dying fits with palliative care principles and practices, our service, our culture, our values and philosophy.

We would not have had a successful first year if we had not taken this approach. Clinical managerial leadership partnerships were so vital. Robust debate, inquiry, constructive challenges and the ability to find change campions. Equally vital. All entirely do-able. Not always easy. Totally worth all effort.

We drew upon the Ministry of Health resources, created our own. We developed our own policy and procedure in keeping with the Act. We have been and remain clear with all stakeholders that as an organisation:

- TH expects that any person under its care may ask about assisted dying services or choose to access this service. When a person asks for information about or access to assisted dying services, staff at TH will help the person to access this information or service (within the framework of the Act).

- A person must make their own choice to access assisted dying services and should do so without pressure from anyone else. Staff should be careful to avoid directly or indirectly encouraging someone to choose assisted dying.

- Equally staff should be careful to avoid directly or indirectly discouraging a person from choosing assisted dying. Staff should carry out their responsibilities under the Code of Health and Disability Services Consumers' Rights and ensure that a person is not prevented from accessing lawful medical care.

- Staff should use a person-centred approach during conversations about assisted dying. During these conversations, staff should keep in mind Ngā Paerewa: Health and Disability

Services Standard NZS 8134:2021. In particular, they should consider the criteria in Section 1.4: E whakautetia ana ahau | I am treated with respect and in Section 1.6: Ka kitea ngā whakawhitiwhitinga whai hua | Effective communication occurs.

- If a staff member is not sure about how to respond or feels uncomfortable with something a person has talked to them about, they should speak to their direct line manager in the first practical instance or any of the Clinical Senior Leadership Team.

We studied other jurisdictions and understood that roughly less than 6% of eligible patients apply for an assisted death and only a very small sub percentage of those actually proceed. We understood that this was about autonomy, choice, safeguarding and the desire to control the means within the inevitable. We developed a network of peers from other jurisdictions (Canada, Australia and within ANZ). We knew from the working relationships formed with providers in other jurisdictions that there was little to no evidence of a thin end of the wedge or atrocities being committed. It was not a slippery slope.

In partnership with our Board the decision was made to go public with our deeply considered position via ANZ's most preeminent current affairs news programme:
https://www.youtube.com/watch?v=ztFwS6hBDrs

We commenced a formative evaluation with an independent researcher on lessons from the first year of implementation (results due March 2023).

Our position was contra to that of our peak body and to all other Hospices across ANZ. In summary we stated:

1. As an Organisation we did not conscientiously object to anyone accessing their rights under the Act/the law. We expected and respected differences to occur amongst people and organisations; we would focus on the needs of our patients and their loved ones. We remained united with our sector in our shared view that great palliative care should be accessible

2. We did not believe that the introduction of legal assisted dying had no place in palliative care, nor did we believe that these approaches were in competition or counter ideologies. Both were intervention options in the menu of services for the terminally ill.

3. Our firm support that patient centred care puts the patient in control of their choices regarding their care pathway, including their pathway at the end of their life.

4. Our firm belief that The EOLC Act 2019 has an important place in, and relationship with contemporary Hospice palliative care.

5. Our belief that the W.H.O. definition of palliative care should be updated to reflect societal changes across the world as this pertains to Assisted Death. We acknowledged

that the spirit or intention of the definition is to promote palliative care as care that accepts death as inevitable and is not a curative paradigm. We do not accept that this statement was intended to prohibit patient choice or prohibit palliative care professionals and services working within societal changes/changes to norms/changes in the Law.

Key aspects of the Act that led to our position were that:

a. Only those with a physical terminally ill could access it. This meant that this was an act for the Hospice population. How could we be a Hospice and ignore this or deny patients choice? We shouldn't.

b. Only adults could access it.

c. Cognitive competence was a requirement

d. Transparency levels and the range of controls

e. Assisted death would not be a crime

f. Preventing/prohibiting or abusing patient choice would be a crime

g. The NZ voting public had made their views and their democratic voice clear

Of great significance to us was that the Act did not use the terminology 'suicide/assisted suicide'. This was critical. Patients who could access the service were already dying/ were terminal. They did not want to irrationally kill themselves. They wanted dignity and control in how they would die. Suicide has much stigma for the person and their loved ones and is an irrational act. Suicide prevents the fair pay out of insurance. Suicide should not be on the death certificate of someone who is terminally ill choosing an assisted death as the means of their inevitable death. Significantly we had experienced three suicide attempts from patients over the last couple of years because they could not access an assisted death service. One was successful and the others left the patient and their loved ones in a worse state. Such suffering. This could be prevented in the future. Work on suicide in the terminally ill has just been published in the British Medical Journal, (*BMJ* 2022;377:01014) and makes grim reading on the consequences of lack of options around dignity, control and choice for the terminally ill.

The feedback from community was overwhelmingly positive. We received hundreds of phone calls, letters, emails, texts from the general public, healthcare providers, palliative care providers, academics and even clergy. All thanked us for having the courage to support patient choice and the leadership to implement services. There was a general backlash of various strengths regarding Hospices to objected to assisted dying. This was a shock to them but not to us. Hospices operate within democratic societies. ANZ is a progressive democracy. Hospices often found their roots in religious values. We accepted this and the reality that we TH are a Hospice for all, a progressive Hospice providing contemporary, patient centred palliative care in a complex and socially progressive environment.

Out of all the feedback we received only three (out of hundreds) expressed their disappointment (or stronger) that we would implement HADS. Two were from far right / religious /conservative organisations and one from an individual member of the public.

What has occurred to date

We provided our first HADS in January 2022 and in total have provided HADS to eleven very relived terminally ill, cognitively competent adults to the period closing 31st December 2022.

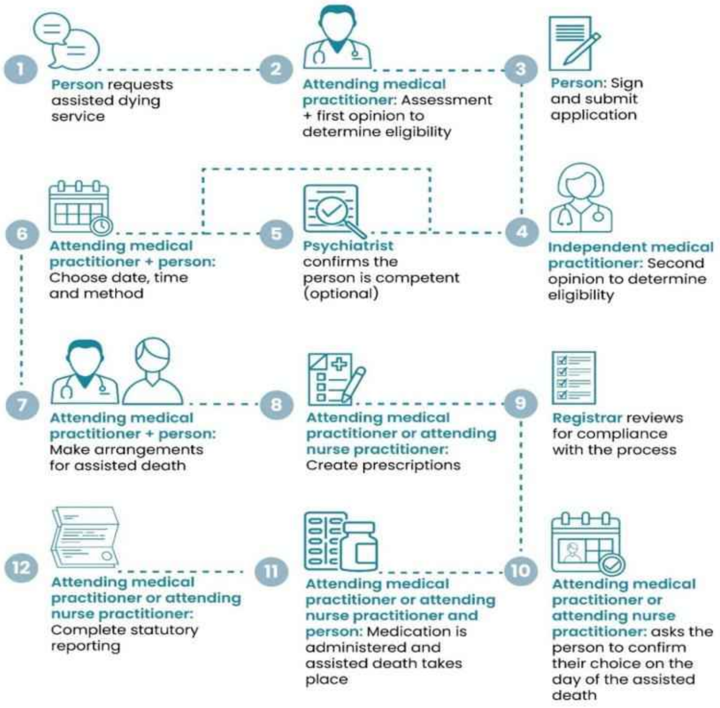
	AD Date	Age	Ethnicity	Gender	Condition
1	01/22	67	NZ European	F	MND
2	02/22	68	Fijian Indian	F	Cancer
3	02/22	58	NZ European	F	MSA
4	04/22	68	South African	F	Cancer
5	04/22	74	Chinese	M	Cancer
6	06/22	68	Dutch	F	Cancer
7	06/22	76	NZ European	F	Cancer
8	06/22	86	NZ European	F	COPD
9	08/22	54	NZ European	F	Cancer
10	11/22	80	NZ European	F	Cancer
11	12/22	72	NZ European	M	Cancer

This shows the number through to final act, not the number who have inquired or inquired and applied but who have died before approval or denied due to cognitive competency. The age range and ethnic/cultural backgrounds have been diverse. Gender is interestingly at this point more female.

We have discussed our position in public forums, conferences, with stakeholders and families, academic institutions. Cultural competence is of great importance. We are thankful to have a number of cultural liaison positions and an expectation of cultural competency in practice from staff as well as a diverse staff. Many Māori patients and family/whānau have been interested and we are supporting independent research on access for Māori. The only group to not appear broadly in the stats across ANZ is Samoan – which may be due to the strong religious orientation of this cultural group of people. It is ethically and socially just and important that wishing an assisted death is now as protected as not wishing one. No-one has to have an assisted death. However, importantly one person's 'no' cannot override another person's 'yes'. Patient choice is paramount.

Our Medical Director, Nursing Director, General Manager Clinical Services, have hands on intimately supported the provision of the eleven assisted deaths. They are supported to ensure a total care approach with patients and support loved ones via the Clinical Lead for Allied Health and the Head of Cultural and Social Support. We are supportive of any eligible TH employee undertaking an AMP role/providing assisted death directly. We actively partner with a network of Attending Medical Practitioners Medical and Nurse Practitioners who provide assisted death.

We are crystal clear on our process for individual conscientious objection both under the Employment Relations Act 2003 and under the End-of-Life Choices Act 2019. In summary our HADS service is provided within the following framework:



At the time of a person’s assisted death, our HADS approach ensures that staff who are willing to participate can help make appropriate arrangements and encourage and support a person in arranging what is important to them. This includes understanding and considering needs specific to the person’s culture and identity, such as needs related to religious beliefs and Te Ao Māori tikanga (e.g., kawa, blessing of rooms, rākau rongoā, mirimiri, karakia).

Staff, including me, have been involved in a number of ways:

- Providing access to a private room with space for whānau or family throughout the time the assisted death is taking place. Making this room available to whānau or family after the assisted death and making them aware of how long this room will be available to them after the person has died.

- Being present at a person’s assisted death and participating/providing direct assistance to the external AMP if needed for the assisted death to take place and ensuring required supports are present for care of the person or their whānau/family, including to undertake post-death care. Staff who are present at an assisted death should have an opportunity to debrief.

- Talking to whānau or family about any cultural practices or rituals they would like to take place before, during or after the assisted death, and supporting these to take place.
- Arranging times and venues with external AMPs to provide care within our facility.
- Our specialist clinical team providing debriefing and supervision to providers with the assisted death provider network.

We are clear that our Duty of Care to a dying person from the process of inquiry, through to service provision of an assisted death does not replace or prevent the specialist palliative care a person is already getting. Instead, it provides another option for terminal patients receiving specialist palliative care.

As the concept-reality gap closed we had a turnover of circa 10% longer serving staff. Yet we had more applications for clinical roles than we ever had in our history. This has continued. Our workforce understands our research approach, and many have participated in providing the independent researcher with views, examples and information. Our research is guided by strict protocol.

Having been directly involved as a leadership team, I can say, with the backing of my team, that for these patients this is the right thing to do and is not at all at odds with our palliative care values, approach and principles. We have been privileged to be with them, support them, help them have their wishes met.

The network of practitioners is compassionate, patient centred, professional. All assisted deaths have occurred in a calm, loving, supported environment – just what a Hospice should do.

An outcome we did not predict was that we would be contacted by patients and providers from all over the country – not only our own coverage area. We have acted more than 50% of the time to provide service to those patients who legally meet the criteria but who have come up against conscientious objection at Organisation level. Who have access to a provider but do not have a venue e.g., they have been denied their right within aged residential care, a hospice, care facility etc. or are homeless or renting accommodation or are in such poverty they are overcrowded and under resourced.

We have been thanked by the Ministry of Health for our stance as otherwise we have been informed these patients were being told to rent a motel room, use a care park, basement or funeral parlour. Horrific.

We remain very well supported by patients, families and wider stakeholders. We are recognised as a pioneering Hospice service for ANZ by many. Other Hospices are beginning to engage with us and inquire about what we do, what it looks like, the response from staff and patients. We welcome this dialogue and hope to see the network expand.

We will be involved in the first-year review with the Ministry of Health's The End-of-Life Review Committee and we will be publishing our own research on organisational impact.

Concluding remarks

Our standard palliative care got better as assisted death made us question and review everything we do.

We had some turnover of staff from very traditional, conservative or religious backgrounds. We recruited and retained great staff also.

We acknowledge the right of conscientious objection of individuals and ensure we have a process. Everyone can have their view. Everyone must know and work with our Organisation approach within the Act and within our policy and procedure. Everyone must respect that we are a pro patient choice Organisaiton. The sky has not fallen in. There has been no drama.

- We must keep talking, training, refreshing, inquiring– maintaining the culture and the reasons are vital.
- Not having suicide at all levels as mentioned above has been fundamental.
- In pushing and leading change, we have respectfully forced conversations across our own and other sectors – we aim to have this continue. Some partner Hospices are now providing social support. It is a beginning
- Ethical questions and forums are critical to progress and change.
- Change management is vital.
- Transparency is vital.
- Education and information are vital. Misinformation is rife and emotive.

Having been directly involved as a leadership team, I can say, with the backing of my team, that for these patients this is the right thing to do and is not at all at odds with our palliative care values, approach and principles. We have been privileged to be with them, support them, help them have their wishes met.

Written Submission to the Government of the Isle of Man, UK

James Downar, MDCM, MHSc (Bioethics), FRCPC
Head and Professor, Division of Palliative Care
University of Ottawa, Ottawa, Canada.

To Whom It May Concern,
I am writing this submission to aid in your consultations regarding Assisted Dying. As a **Canadian Palliative Care Physician and Researcher**, I will not be affected by any change in the UK's laws, and I have no wish to push my own view of Assisted Dying (or Medical Assistance in Dying- MAiD, as we call it) on UK citizens. However, as the prospect of legislation in the UK comes nearer, I am concerned that Britons and Canadians alike have been subjected to a number of **misleading or false public claims** about what is happening in my country. My only purpose in making this submission is to set the record straight about **who is actually receiving Assisted Death in Canada**, and what this says about the drivers of Assisted Death. I respect those who disagree with MAiD on a principled basis, as a number of my friends do, but this does not entitle anyone to make false claims.

Disclaimers

- I do not represent any organization or agency.
- I am an employee of a faith-based institution, so will not address issues where I have a conflict of interest.
- I have previously spoken in favour of the legalization of MAiD, but I have never promoted MAID. I hope for a future where Canadians have access to MAiD, but choose not to use it because we are able to address the suffering that drives it.

Key Points – Focused on the state of Palliative Care in Canada

1. Many Canadians have poor access to Palliative Care, as do many in the UK, but funding/support for clinical palliative care has increased dramatically in much of the country since MAiD became legal, including:

- A large growth in funding and salaried positions for Palliative Care physicians. For example, in the past 4 years, the division I lead in Ottawa has almost doubled in size (~40 physicians).
- $3 billion invested in home care in 2016, much of which went to palliative care services.
- Millions of dollars invested in research at the federal and provincial levels, providing funding for the Pan-Canadian Palliative Care Research Collaborative in Ottawa, and the Palliative Care Institute in Alberta, and announcing dedicated research funding for palliative therapies including psilocybin.
- There has been a large growth in the number of funded community hospice beds in Canada in particular over the past 5 years, mirroring the rapid growth seen in the Benelux countries following MAiD legalization there.[1] Some palliative care services have been transiently reduced as a result of staffing challenges during the pandemic, which has caused similar problems around the world. This is unrelated to MAiD and is already recovering.

2. There is no data suggesting that the practice of MAID in Canada is driven to any degree by poor access to Palliative Care, socioeconomic deprivation or isolation. On the contrary, multiple reports have shown that MAiD is extremely rare in "vulnerable" demographics, indicating that vulnerability is not a driver of MAiD. We do expect people requesting MAiD from every demographic, as suffering is not limited to the privileged. But if vulnerability was driving MAiD requests, MAiD would be more common in structurally vulnerable groups; in reality, MAiD is substantially less common in these groups.

- The second annual report on MAID in Canada (covering 2020)[2] indicated that even during the pandemic, only 126 of 7394 people (1.7%) who received MAID were unable to access palliative care services that they needed. Similarly, only 3.8% of those receiving MAiD were unable to access disability services that were needed.
- This claim is not based on "self-reported data", as is sometimes reported. In Ontario, the Coroner's office reviews every MAID case and their own assessments of Palliative Care involvement concur with the findings of the Health Canada report[3].
- Canadians who receive MAID are much wealthier, more likely to be married and less likely to be widowed, and far less likely to be institutionalized[3] than those who do not receive MAiD.
- In Ontario, the poorest fifth of the population are 40% less likely to receive MAID than the richest fifth[4], even though the prevalence of chronic illness is much higher.
- Bottom line, **there are people who struggle to access palliative care[5,6] and disability services in Canada, but they're rarely if ever receiving MAiD**. We need to improve access to palliative care and disability services, not because it will have any effect on MAiD, but to meet the needs of the 97% of Canadians who do not request MAiD.

3. The interaction between MAiD and Palliative Care doesn't need to be a conflict. MAID is a point of friction in our community- many prominent palliative care providers are opposed to MAID. But **in much of the country a respectful coexistence has evolved, as it has in most of Europe.** Palliative care and MAID have been integrated in many palliative care units and hospices in Canada, and ~20% of Canadian MAiD procedures now take place in a palliative care facility[2]. They are not fully integrated everywhere, but it is incorrect to say that they are incompatible.

- One key concept is that although Palliative Care can be effective for providing comfort, no field of medicine can claim to fix every problem it sees. Even in the best Palliative Care Units in the world, suffering can be substantial and symptoms increase as patients approach death[7]. This does not mean that anyone should request MAiD, but it explains why so many MAiD recipient chose to end their lives despite having good access to PC.
- Palliative Care is generally more effective for addressing quality of life and physical symptoms, and less effective (or even ineffective) for treating **psychological or existential distress**[8]. Our Health Canada reports have clearly shown that this latter type of distress is the main driver of MAiD requests[2].
- **Existential Distress** is not simply a concern about "being a burden" on others, but rather a sense of distress about their inability to do things that they enjoy, the things that define us as people. Existential distress is not caused by a lack of social or emotional support- these individuals often have very good emotional support available, and people to help with their physical needs. The distress is caused by the fact that they need those supports in the first place. We currently have no proven, scalable, effective treatments for relieving existential distress. **We should not trivialize existential suffering** by claiming that it doesn't exist, or that it is an irrational fear, or that we can easily treat it.
- **Admitting that there are limits to what Palliative Care can achieve is not a sign of failure, but a call for more innovation and research into treating all types of suffering.** The benefits

of such research would be felt far beyond any impact on MAiD statistics, because suffering is much more common than MAiD among the dying.

- Ultimately, **the purpose of Palliative Care is not to prevent MAID, and MAID should not be considered a failure of Palliative Care or of the healthcare system**. Legalization of MAiD in Canada has allowed for more open, honest communication about end-of-life options. There are many people who have obtained better palliative care as a result of an honest conversation about MAiD.

4. MAID does not siphon resources from Palliative Care, or pull Palliative Care providers away from patients who are more appropriate. The vast majority of MAID requests in Canada arise in patients who are already followed by Palliative Care providers at the time of the request (75-80%)[3], and most were followed by Palliative Care for months before they received MAID. For the remainder- they are almost always people with end-stage or terminal illnesses, who have intolerable suffering. These are absolutely appropriate referrals for Palliative services, and should not be seen as a burden or a distraction from the mission of Palliative Care. If we make them feel more comfortable even for a short time, and they still request MAID, then that was definitely <u>not</u> a waste of our time or resources. To address some common misconceptions:

- **MAID providers do not receive resources that were intended for PC**. MAID providers use palliative care fee codes in Ontario to be paid, but this doesn't reduce payments to Palliative Care providers in any way.
- Some MAID assessments are performed by salaried Palliative Care providers, but they will usually do MAID assessments for their own patients (which is a minimal additional workload for a provider who already knows the patient), or provisions during their non-clinical time. **It would be false to state that MAID is pulling providers away from their PC duties.**
- **There is no "right" to MAiD in Canada** any more than there is a right to any healthcare service, including Palliative Care. This comment is usually raised during a discussion of access. Access to Palliative Care is a substantial issue for many Canadians, but Canadian data clearly show that the people who struggle to access palliative care and disability services in Canada don't seem to access MAID either.

5. There are many misconceptions about "Track 2" cases, or MAID for people who meet eligibility criteria but do not have a reasonably foreseeable death. To be sure, there are people with chronic, advanced conditions who want to receive MAID and meet eligibility criteria. On the other hand, there are also people who are not eligible but are requesting MAID as a signal for help obtaining social supports. These cases cause distress among caregivers and are challenging to address, as it may not be apparent how much of the suffering would truly be reversible given improved supports. Some key points here are:

- **Nobody is eligible for MAID based on social deprivation**; the eligibility criteria (e.g. serious and incurable condition, advanced state of irreversible decline in capability) are only met by a small proportion of the population and many "track 2" requests are found to be ineligible. There may be eligible individuals living in poverty who request MAID, but financial distress would be only one of a long list of causes of suffering. These cases, and suffering in general, can be highly complicated. It should never be described in the unidimensional, black-and-white way that it has been presented in some media stories.

- **"Track 2" cases are a very small proportion of all MAID cases, and extremely rare overall-** 219 according to Health Canada's report for 2021 (2% of all MAID cases). For comparison, ~150-200 Canadians are struck by lightning every year[9].
- Track 2 is definitely not an easy option to avoid more difficult questions about how we support the disabled and the vulnerable. Clinicians are generally hesitant to take these cases on because of the emotional burden and workload involved, which is why they are so rare.
- We should definitely increase supports that address key social determinants of health, particularly for the vulnerable. We should do this not because of the effect on MAID requests, but because it is the right thing to do as a society. The impacts of social deprivation on health are well-established in Canada, as they are in the UK:
    - More than 4000 people die by suicide in Canada every year (20x the total number of track 2 cases) and much of this is driven by social deprivation.
    - Income inequality is associated with as many as 40,000 deaths per year in Canada (200x the total number of track 2 cases)[10].
- **The legalization of MAiD did not create a link between social deprivation and death. This link was already there and very impactful.** Trying to blame MAiD legislation for mortality among the poor is a cynical and inappropriate distraction from the real issues that drive this problem. Anyone concerned with supporting the vulnerable should focus on things that we know will help improve the lives and survival of the vulnerable, such as better pharmaceutical coverage, increased social assistance, affordable housing, etc.

6. Media reports of "abuses" should be treated with skepticism. As the UK and other jurisdictions have moved closer to legalizing MAID, there has been intense speculation about what is happening in Canada. Broadly speaking these stories fit into one of several categories:

- Claims that people have received MAiD despite being ineligible or incapable of making decisions. These claims are usually made by family members who were estranged, or who are morally opposed to MAiD. In Canada, eligibility is assessed by at least two assessors in every case, and each case is reviewed by a coroner or delegate to confirm eligibility. Some cases reported in the media were even reviewed by the police or the medical regulator. Despite such scrutiny, **I am not aware of any case where these claims were substantiated**.
- Claims that people are seeking MAID due to trivial medical conditions. These claims often derive from the fact that people are asked to indicate a single diagnosis or problem prompting a MAiD request. This may be appropriate for some conditions (e.g. lung cancer) but not for others (e.g. multimorbid frailty- which can be debilitating but is not caused by a single diagnosis). In one well-known case ("AB"), a person requested MAiD due to severe osteoarthritis that had required multiple operations and left her completely bedbound, unable to sit upright, and in nearly constant pain, with no further treatment options[11]. This case was reported by some in the media as "simply arthritis". Of course, not everyone in AB's condition would request MAiD, but **it is wrong to trivialize or misrepresent the suffering of others**.
- Claims that hospital staff members are pressuring patients to receive MAID. This claim stems from a story of a patient in London, Ontario, who was in a dispute with their hospital about the home care that would be provided on discharge. He recorded one of his interactions with an ethicist, and then sent the recording to a reporter who published a story entitled "*Chronically ill man releases audio of hospital staff offering assisted death*"[12]. In fact, the

recording indicated the opposite- that **the ethicist was quite clearly discouraging him from pursuing MAID but this was not picked up by the media outlets**:
  - "Oh, no, no, no," the man is heard saying. "…Don't get me wrong. I'm saying I don't want you to be in here and wanting to take your life."

Needless to say, privacy rules prevent many MAID assessors and providers from coming forward to discuss these cases and provide the missing information. In such a context, it is easy for misinformation to persist and get amplified by those with an agenda.

7. Changes in MAiD eligibility criteria in Canada do not represent a "Slippery Slope". Canada's Supreme Court was very clear and unanimous in the initial *Carter* ruling about who should be eligible to request and receive MAiD. Following this ruling, **Canada's Parliament initially attempted to restrict eligibility more than the court intended**, passing a MAiD Bill (C14) in 2016 that specifically excluded:

- …those with a reasonably foreseeable death- this part of the law was struck down by a Quebec Superior Court decision (*Truchon*), which simply reflected the original *Carter* decision.
- …those with mental illness as an incurable condition- this part of the law was removed by a subsequent Bill (C7) passed in 2021, which takes effect in March 2023.

Of course, every country that has legalized MAiD has chosen a slightly different set of eligibility criteria. But in Canada, the criteria set out in the Carter decision have never been changed, and the Quebec superior court has simply upheld the precedent set in the *Carter* decision. This is evidence of a Constitutional Democracy, not a slippery slope.

My Brief CV (Relevant to Palliative Care)

- Professor and Head, Division of Palliative Care, University of Ottawa
- Clinical Research Chair (Tier 2), Palliative and End of Life Care, University of Ottawa
  - Founder, co-chair of the Pan-Canadian Palliative Care Research Collaborative
  - Authored or co-authored >115 scientific publications
    - International guidelines on end-of-life care in the ICU
    - Communication and decision-making for people with serious illness
  - $24 million in peer-reviewed grant funding
- Lead, Hospital-Based Models of Care (Adult) working group in the Ontario Palliative Care Network (part of Ontario Health).
- Former Member, Palliative Medicine Subspecialty Working Group at the Royal College of Physicians and Surgeons of Canada (established the standards of subspecialty training in Palliative Care in Canada).
- Former Chair, Postgraduate education committee of the Canadian Society of Palliative Care Physicians and the Education Committee of the Ontario Palliative Care Network.
- Founder, former director of the first accredited subspecialty palliative care residency training program in Canada at the University of Toronto (2016).

Specific Relevance to MAID

- Former Co-Chair of Physician Advisory Committee, Dying with Dignity Canada

- Expert witness for prosecution in *Truchon* case, also called as a witness in *Lamb*
- Developed Canadian Medical Association educational material to train MAID assessors and providers in Canada, also used in educational material in Australia
- Advised on legislation developed in Australia and New Zealand
- Lead study on demographics of MAID recipients in Ontario, and compared them to people who died without receiving MAID. MAID recipients are much wealthier, more likely to be married and less likely to be widowed, and far less likely to be institutionalized than those who do not receive MAID (referenced above).

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The Isle of Man: Assisted dying bill consultation

January 2023

While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal care.
– Palliative Care Australia

Dad didn't choose death. Dad chose life over and over again. He chose it when he knew he would have his sides ripped out. He chose it when he knew he would have chemotherapy that would make him sick for another six months. He chose life, he chose life, he chose life. And when life was no longer a choice, he decided to die on his own terms.
– Katie Harley, whose father Phil, 70, metastatic bowel cancer, elected to have an assisted death in Victoria in 2019.

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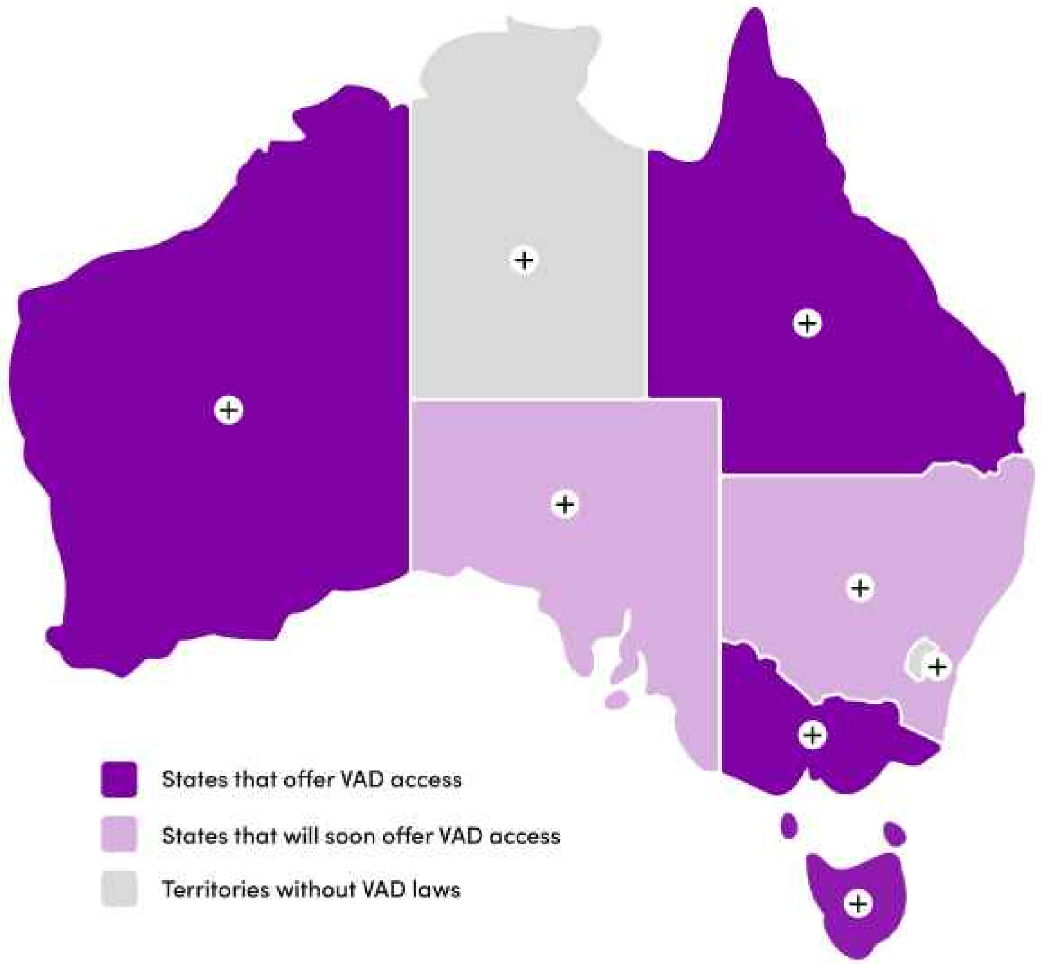
Introduction

Go Gentle Australia is a national charity established in 2016 to promote choice at the end of life. We empower people to choose the end-of-life care that is right for them, including the option of voluntary assisted dying (VAD). We have played a critical role in the introduction of VAD legislation in Australia, where all six states have now passed laws. We believe the voices of dying people should be heard and their decisions respected.

This submission will focus on: **What can be learnt from the evidence in countries where assisted dying is legal?**

Voluntary Assisted Dying in Australia



Australia's embrace of VAD began in 2017 when Victoria became the first state to pass a law. It was described as "the most conservative law of its kind in the world."[1]

Since then, all state parliaments have passed their own legislation; Western Australia in 2019, Tasmania, South Australia and Queensland in 2021 and New South Wales in 2022.

Each state's law came about after significant levels of public consultation. Each built on the strengths (and addresses the weaknesses) of laws that came before. The result is similar, but not uniform, legislation across the country.

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[1] 'Assisted dying law a credit to Victoria's Parliament; now for federal change' 29 Nov 2017, The Age https://www.theage.com.au/national/victoria/assisted-dying-law-a-credit-to-victorias-parliament-now-for-federal-change-20171129-gzvct2.html

All the laws have had at least 18-month implementation periods before they take effect, to establish processes and train healthcare professionals. Victoria, Western Australia, Tasmania and Queensland's laws are all currently effective.

By the end of 2023, all state laws will be operating (South Australia's law commences operation on 31 January and the NSW law will begin on 23 November). This means all Australians, bar the 700,000 people in the Northern Territory and Australian Capital Territory (ACT), will be able to access VAD if they become terminally ill (and they meet strict eligibility criteria).

The ACT government has begun public consultation with the aim of introducing legislation in mid 2023.[2]

The Australian model

Although each state's law differs slightly, all Australian VAD legislation follows a similar framework, which has become known as the 'Australian model' of VAD. This limits medical assistance to die to terminally ill adults of sound mind who are suffering intolerably.

Broadly, to use VAD in Australia a person must be:

- **Diagnosed with an incurable disease, illness or medical condition** that
    - is advanced, progressive and will cause death within 6-12 months (depending on the nature of a person's disease)
    - is causing suffering that cannot be relieved in a manner the person finds tolerable
- **Capable of making decisions** about their medical treatment and communicate those decisions throughout the assessment process
- **Acting freely and without coercion**
- **Aged 18+**
- **An Australian citizen or permanent resident** who has lived in their chosen state for at least 12 months
- **Request VAD** at least three times
- **Be assessed and approved** by at least two doctors

Disability, mental illness and advanced age alone do not meet the above criteria; to access VAD in Australia, a person must also be terminally ill.

There is a rigorous request and assessment process and the process can be stopped at any time - by the individual, or by a VAD practitioner if any duress or coercion is suspected.

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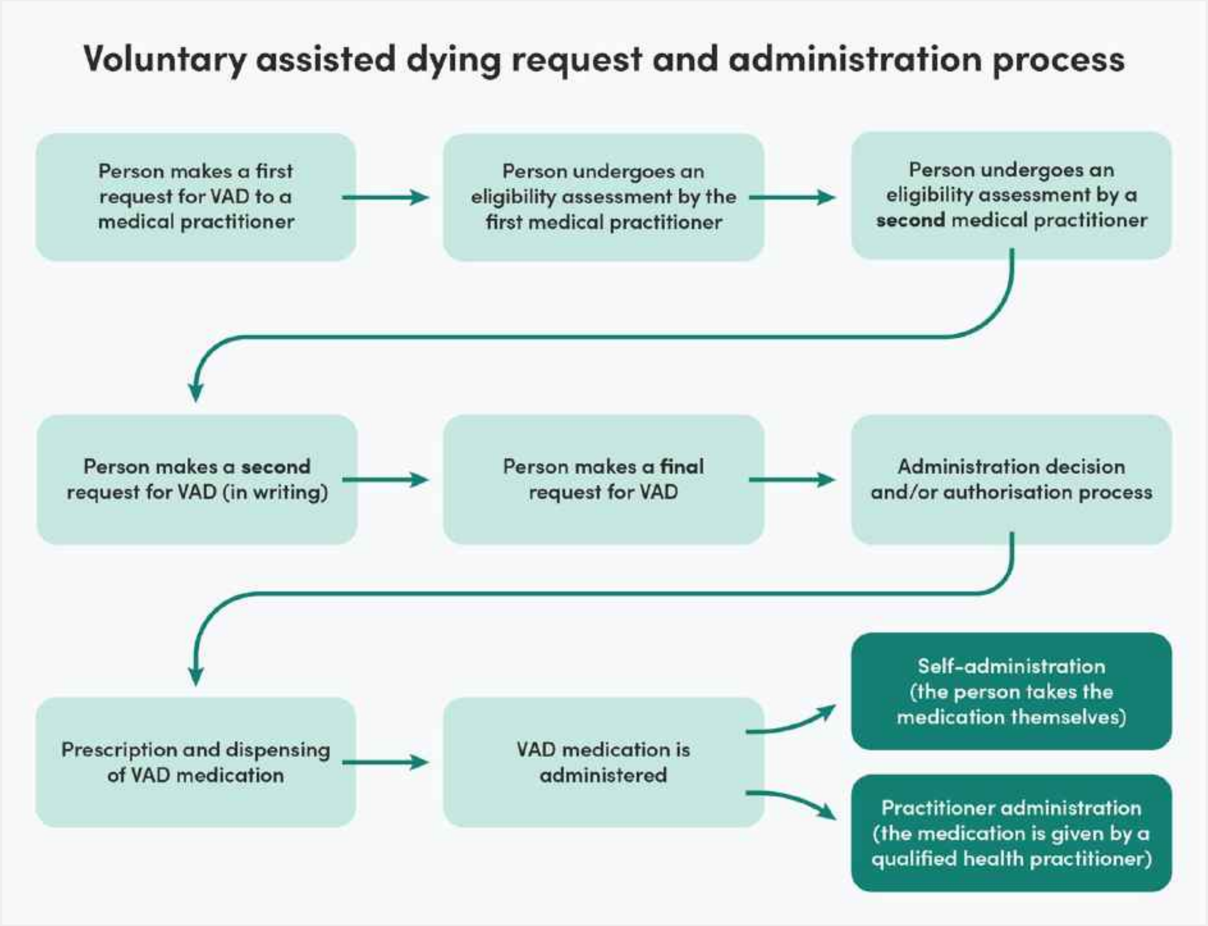
[2] 'Andrew Barr says ACT to introduce voluntary assisted dying laws in 2023' 1 Dec 2022, Canberra Times https://www.canberratimes.com.au/story/8002335/barr-outlines-path-to-acts-voluntary-assisted-dying-laws/

The diagram below summarises the process, as designed by ELDAC[3]:



Safeguards

The safeguards as proposed by the Isle of Man broadly reflect those included in the ‘Australian model’ of VAD. However, we strongly recommend additional attention be given to the number of required witnesses, the length of time for the ‘‘cooling off period’ and the mandated method of administration.

Safeguard 6 says: **The person signs a written declaration of their request, which is witnessed and signed by both doctors and an independent witness.**

Getting two doctors in one location to witness and sign the written declaration is burdensome. It is enough to have one doctor – the coordinating practitioner – and an independent witness present.

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[3] End of Life Direction for Aged Care https://www.eldac.com.au/Portals/12/Documents/Factsheet/Legal/Toolkit-Voluntary-assisted-dying_v11_2022.pdf

Safeguard 7 says: **A suggested waiting period of 14 days allows the person time to reflect on their decision. This timeframe could be shortened if the person is expected to die within 30 days.**

While a cooling off period can be useful, it should not be unnecessarily long. In Australia, the minimum time between first and final request is between 4 and 9 days, depending on the jurisdiction. We consider this timeframe more than adequate. Experience shows that the entire VAD process can take several weeks – even months – to navigate, depending on doctor availability and access to paperwork. This is more than ample time for a person to reflect on their decision, without mandating additional waiting periods.

The final safeguard says: **The person must administer the life-ending medication themselves.**

All laws in Australia contain a provision for practitioner administration, as well as self-administration.

In Victoria and South Australia, self-administration is the default method but if people are incapable of taking or ingesting the medication, a doctor can administer it for them. In all other states, it's a choice. If the intention of these laws is to help dying people then their needs should be at the forefront of any provision. What is to happen to a dying person, for example a patient with MND, if they cannot self-administer? They should not be forced to suffer a painful and distressing death – the very death they sought so desperately to avoid – simply because of the severity of their illness? The option to choose between self and practitioner administration is working well in Australia. We recommend amending this safeguard to include both options.

What we've learnt from Victoria and Western Australia

Victoria's law has been in operation since June 2019, providing more than three years of robust evidence of how VAD works in an Australian context. Crucially, the Victorian experience makes it possible to examine the concerns raised about VAD (for example, vulnerable people would be killed, or that palliative care would be damaged) and determine whether they have turned out to be true.

Victoria's Voluntary Assisted Dying Review Board, the statutory body tasked with monitoring the law, have published biannual reports[4] containing data and feedback from those who have chosen to use the law, and those who were with them when they died, including family, friends, doctors and carers.

The reports show that the Victorian legislation is operating safely and as intended. Terminally ill people are being helped to die under the circumstances of their choosing with a

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[4] Victorian Assisted Dying Review Board reports available here: https://www.safercare.vic.gov.au/publications?f%5B0%5D=agency%3A751&search=voluntary%20assisted%20dying%20review%20board

deep level of compassion, integrity and care. **They also make clear that none of the dark predictions about VAD have come to pass**. The law is operating within the strict eligibility criteria and safeguards determined by parliament, with a compliance rate close to 100%.

Assisted deaths in Victoria account for a tiny proportion of total deaths each year – less than 0.5%. There have been no 'wrongful' deaths referred to police, no rogue doctors abusing the system and no evidence of coercion of the vulnerable.

Feedback from Western Australia[5], where a similar VAD scheme has been operating for 18 months, mirrors the positive Victorian experience. In its first annual report, the independent Review Board noted that the Voluntary Assisted Dying Act is working well and that "medical practitioners, care navigators and pharmacists have given beyond the normal call of duty to provide comprehensive end of life care to those Western Australians who have made [this] choice". The WA Board noted that demand for VAD had been greater than in Victoria, with VAD deaths representing 1.1% of all deaths in the time period. The Board's recommendations centred on ensuring equity of access for people in rural areas by increasing the number of trained VAD practitioners and ensuring doctors are properly remunerated for the hours - and often significant travel time - they put into VAD assessments.

Laws in Tasmania and Queensland have been effective for less than six months and as such there has been no release of official data. However, given the similarities of the laws, their performance is expected to mirror the positive experiences in other states.

Why legislate for VAD?

Key points

Palliative care works for most - but not all

While palliative care is excellent and accommodates the needs of the majority of dying people, even the best-resourced care cannot relieve the extreme suffering some people endure. Palliative Care Australia acknowledges this:

> *While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal care.*[6]

It's not about pain, it's about suffering

Pain isn't the only suffering experienced at the end of life. Depending on your condition, there can also be bone metastases, distention, open sores, weight loss, odour, disfigurement, incontinence, fatigue, disfigurement, a sense of suffocation, continuous

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[5] Western Australia Voluntary Assisted Dying Reports available here: https://ww2.health.wa.gov.au/Articles/U_Z/Voluntary-Assisted-Dying-Board

[6] Palliative Care Australia, 'Policy Statement on voluntary euthanasia', Canberra , 2006, p.2 Quoted by Neil Francis, Dying For Choice, 'AMA Uncovered: How its own review exposed its assisted dying policy as indefensible' p. 20 https://www.dyingforchoice.com/docs/AMAuncoveredFullReport27Mar2017.pdf

bleeding and paralysis. It is hard to imagine why a modern health system would abandon patients to these horrors when there exists a means to relieve them.

Palliative care and assisted dying work together
It is not a choice between palliative care OR assisted dying. The two can, and do, coexist. Evidence from Victoria and WA shows around 80-85% of people who choose VAD are also receiving excellent palliative care. VAD is simply another option.

Moreover, the existence of VAD laws does not result in a decline in palliative care. In fact the opposite is true. A 2018 report commissioned by Palliative Care Australia, looking at the impact of VAD on palliative care internationally, found:

> *"There is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards… if anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced*.[7]

The Australian experience reinforces this. Since the first VAD law was passed in Victoria in 2017, more than $1 billion in extra funding has gone to palliative care across Australia, including a $743 million boost in NSW, the last state to pass a law.

Australians' experiences of VAD

Families of those who have used VAD laws in Victoria and Western Australia have described the peace of mind and relief that having choice and control gives to dying loved ones.

The words they most commonly use to describe these VAD deaths are "peaceful", "dignified" and "perfect."

The extent to which the laws are working safely and compassionately is revealed by the case studies of the first people to use VAD in each state.

The stories of Kerry Robertson & Mary Ellen Passmore

'She left this world with courage and grace'

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[7] Aspex Consulting, 'Experience internationally of the legislation of assisted dying on the palliative care sector – Final Report, Palliative Care Australia, October 2018 https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-the-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

Kerry Robertson was the first person to use Victoria's VAD law. The following account was written after an extensive interview with her daughters.[8] A version can also be read in *The Age*.[9]

> *Kerry Robertson, 61, died in a nursing home in Bendigo on 15 July (2019) of metastatic breast cancer.*
>
> *Her daughters said: "It was a beautiful, positive experience. It was the empowered death that she wanted".*
>
> *"We were there with her; her favourite music was playing in the background and she was surrounded by love," Jacqui said.*
>
> *"That was the greatest part, knowing that we did everything we could to make her happy in life and comfortable in death," Nicole said.*
>
> *Ms Robertson was diagnosed with breast cancer in 2010. Despite treatment, the cancer metastasized into her bones, lungs and brain. When the disease had also spread to her liver and the side effects from the chemo were no longer manageable, she made the decision to stop all treatment. Jacqui and Nicole said their mother had always known what she wanted.*
>
> *"Mum already had an appointment booked to see her specialist the day the legislation came into effect, she made her first request that same day," Nicole said.*
>
> *"Mum had always been brave, a real 'Feel the fear then do it anyway' mentality to life; it's the legacy she leaves with us."*
>
> *The sisters said the assisted dying application process went smoothly and took 26 days. Ms Robertson took the medication on the same day it was dispensed by the statewide pharmacy.*
>
> *"It was quick, she was ready to go. Her body was failing her and she was in incredible pain. She'd been in pain for a long time," Jacqui said. "Palliative care did its job as well as it could. But it had been a long battle. She was tired, the pain was intolerable and there was no quality of life left for her."*

'Eternally thankful'

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[8] Interview with Nicole Robertson and Jacqui Hicks, Go Gentle Australia, 29 July 2019 https://www.gogentleaustralia.org.au/the_first_to_use_voluntary_assisted_dying_law

[9] Melissa Cunningham 'She left with courage and grace': Daughters farewell Victoria's first person to access assisted dying' The Age Aug 4 2019 https://www.theage.com.au/national/victoria/she-left-with-courage-and-grace-daughters-farewell-victoria-s-first-person-to-access-assisted-dying-20190802-p52d97.html

In July 2021, a 63-year-old Indigenous woman from Perth became the first identified Western Australian to use the state's Voluntary Assisted Dying law. Her story was told to Go Gentle Australia by her family[10]. It was also published in *The West Australian*[11] and *SBS Online*[12].

> *Mary-Ellen Passmore, a Wongatha-Yamatji woman, died in Perth on 29 July from motor neurone disease (MND). Her family described her death as "beautiful".*
>
> *"All were singing along to 'Hallelujah', including her doctors," her sister said.*
>
> *The family said Mrs Passmore had confirmed her choice multiple times before accepting the medication. She thanked her doctors and VAD coordinator and "gave them her love".*
>
> *Mrs Passmore had applied to be assessed for VAD soon after the law came into effect on 1 July and said she was profoundly grateful.*
>
> *"I feel very honoured to choose when and where I can die," Mrs Passmore said. "I am excited because I won't have to suffer any more."*
>
> *Her family said: "We wish to express our gratitude that our proud Black mother, daughter, grandmother, sister, aunty, niece, cousin, godmother, friend, and mentor Mary-Ellen Passmore has been able to have her choice of a dignified death, voluntary assisted dying, finally fulfilled.*
>
> *"We wish to thank the campaigners, the medical professionals, the families, and the state politicians who fought for the right thing - for the law to catch up and allow for choice and dignity.*
>
> *Mrs Passmore had lived with MND, a degenerative neurological condition, for up to 12 years and received a formal diagnosis in 2015. In the past few months her pain had become unbearable.*
>
> *She had become totally bedridden, had difficulty speaking and swallowing and was fed through a tube.*

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[10] Interview with Mary Ellen Passmore's family, Go Gentle Australia, 30 July 2021 https://www.gogentleaustralia.org.au/indigenous_woman_among_first_to_use_western_australia_voluntary_assisted_dying

[11] Rangi Hirini, First known Aboriginal voluntary assisted dying (VAD) patient Mary-Ellen Passmore dies in Perth hospital, July 30 2021, The West Australian https://thewest.com.au/news/health/first-known-aboriginal-voluntary-assisted-dying-vad-patient-mary-ellen-passmore-dies-in-perth-hospital-ng-b881946986z

[12] Aaron Fernandes. 'I'm at peace': Aboriginal grandmother among first to use WA's new voluntary assisted dying laws, July 30 2021, SBS. https://www.sbs.com.au/nitv/article/2021/07/30/im-peace-aboriginal-grandmother-among-first-use-was-new-voluntary-assisted-dying

> *"It is terrifying being trapped by your own body and it's a relief to know there will be an end to my suffering," she said.*

Medical perspectives

Voluntary assisted dying is increasingly accepted by the Australian medical community. In 2017, only two medical bodies openly supported VAD and 15 were opposed. By 2021, the number in support had risen to six, with 15 declaring a neutral position.

Medical practitioners in Victoria and WA also describe the benefits of being involved in the assisted dying process.

<u>Gentle and peaceful deaths</u>

Dr Nick Carr, GP (VIC)

For the people who have gone through the process – and I have been there for a number of people who have taken the medication – it has been, it sounds odd really to describe dying as beautiful, but it has actually been a beautiful experience… It's been a positive experience for myself as a doctor.

Dr Simon Towler (WA)

I am amazed by how hard the VAD providers are working, driving and striving with little financial reward and putting significant pressure on their own families. In the end, the energy that drives the community of practice comes from the enormous privilege of looking after people who are showing all of us that facing your own death is an important part of living.

The patients have given so much more back and we have given to them. They are the heroes in the story and will continue to provide for them even if there are impediments. We respect, admire and applaud every VAD patient. It has been an absolute privilege to be part of the process.

Dr Clare Fellingham, Consultant Anaesthetist (WA)

Overwhelmingly, voluntary assisted dying deaths are peaceful, they're dignified, they’re calm, they’re gentle and compassionate, and they are truly, truly patient centred.

Personally, I found it an immense privilege to be involved so deeply and intimately in another person's life and experiences that I've gained and conversations that I've had with people. And what they've imparted in me has allowed me to cherish the time that I have, and appreciate my own life even more. I now choose to live more broadly, and actively look to seek out the joy in everything. And that is with an immense debt of gratitude to all the people who've shared all of their experiences with me.

Professionally rewarding

Dr Gareth Wahl, emergency physician (WA)

I had previously seen a very large number of unplanned deaths with things left unsaid and with both patient and family profoundly distressed and sometimes in pain. These [VAD] deaths are the complete opposite.

One patient chose to die with no one in the room except myself and my required witness. Mostly they've been surrounded by their closest family and on occasion, up to 30 of their closest friends. They've been surrounded by love. And most importantly, it's been how they've wanted. These people have died well. What I get back from this is really tremendously professionally satisfying. I walk away from this feeling that I've helped people. And that is something that my patients are giving me, that is worth much more than what I'm giving them. So yes, there is a cost, but there's a greater personal and professional gain.

Dr Peter Lange, geriatrician (VIC)

You’re required to ask people the nature of their suffering, and I was a bit ashamed to see that my practice had unconsciously been to direct people to the suffering that I could relieve. So, I might have talked about suffering but the next immediate follow up question might have been how is your pain, how is nausea and those kinds of things which are more amenable to treatment. So, after starting to assess patients I realised that the nature of their suffering was often not those immediate symptoms but might well be a loss of purpose and dignity. I think it has changed my practice outside VAD.

Powerful palliative effect

Dr Philip Parente, oncologist (VIC)

Voluntary Assisted Dying is exceptionally patient-centred. We're allowing patients to take control when all the appropriate conditions are met in a very controlled way.

It's quite an amazing sight. They feel definitely more at ease, less anxiety, and they feel more in control. It doesn't necessarily mean they take it. Just having the option there gives them control and gives them hope.

Fiona Jane, Clinical Hospice Manager, Albany Community Hospice (WA)

In our experience of patients requesting VAD, we've seen improved patient-related symptom control of previously difficult to manage symptoms such as fatigue and anxiety. And this has happened almost as soon as the first assessment has been completed.

The process of VAD assessment acknowledges suffering caused by the burden of the disease process and the patient feels heard that their fear of increased disability, suffering and being a burden on their family is acknowledged.

Conclusion

VAD is working safely, as intended and with extraordinary integrity, care and compassion in Australia. It is increasingly recognised as a much-needed and powerful addition to end-of-life care. Given medical services and palliative care provision in Australia is comparable with the Isle of Man, we see no reason why the island’s patients cannot also benefit from this same end-of-life choice.

20 January 2023

Submission to Isle of Man Consultation on Assisted Dying

Thank you for the opportunity to make a submission in relation to the Isle of Man's consultation exercise into assisted dying. We make this submission as Australian academics who have been conducting research into assisted dying and end-of-life law, policy and practice for over 20 years (including in relation to assisted dying systems internationally).

Because models of assisted dying from other countries are generally included in debates about assisted dying law reform, we wish to share evidence about the Australian experience of assisted dying. We also make some observations law reform generally on this topic, based on our research into the law-making process in the end-of-life area.

We would be pleased to provide any further information if that would be of assistance.

Yours sincerely

[Signature redacted]

[Signature redacted]

Professor Ben White

Professor of End-of-Life Law and Regulation
Australian Centre for Health Law Research
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Professor Lindy Willmott

Professor of Law
Australian Centre for Health Law Research
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Submission to Isle of Man Consultation on Assisted Dying

Professors Ben White and Lindy Willmott, Australian Centre for Health Law Research, Queensland University of Technology, Australia

Executive Summary

- We are academics whose research focuses on assisted dying. We have been working on end-of-life law, policy and practice for the last 20 years.
- We support law reform to permit access to assisted dying under strict conditions and with robust oversight.
- We provide evidence, based on reliable research and reports of the oversight bodies, about how assisted dying systems are operating in Australia.
- The Australian assisted dying systems are operating safely. There is no evidence of ineligible patients gaining access to assisted dying. Instead, the evidence suggests that some patients who are eligible are not able to access this choice because of the system's complexity and design.
- Law-making on assisted dying must be evidence-based. This requires evaluating the evidence underpinning factual claims so that the debate is informed by accurate and reliable evidence.

Background and expertise

We are health law academics whose principal area of research expertise is end-of-life law, particularly assisted dying. We have each been researching in the end-of-life area for over 20 years. We have published over 150 publications on end-of-life decision-making and received over $45 million (Australian dollars) for our end-of-life research and training programs.

Our research on assisted dying includes a body of work on comparative and legal analysis of the various international assisted dying regimes. This includes developing a Model Voluntary Assisted Dying Bill which has been cited widely and also adopted as the basis for law reform in one Australian reform report.

Our current work includes a four-year project 'Optimal Regulation of Voluntary Assisted Dying' which includes research into assisted dying systems in Australia, Canada and Belgium: https://research.qut.edu.au/voluntary-assisted-dying-regulation/. This project will make recommendations about how best to safely regulate assisted dying.

We were also commissioned by the state governments of Victoria, Western Australia and Queensland to design and deliver the legislatively-mandated training for practitioners wishing to provide assisted dying. One of us, Lindy Willmott, is a member of the oversight body for assisted dying in Queensland, the Voluntary Assisted Dying Review Board, while the other, Ben White, is a member of the relevant review tribunal, the Queensland Civil and Administrative Tribunal. (We note, however, that we make this submission only in our capacity as academics.)

In terms of law reform, we have been consulted and participated in various assisted dying law reform exercises in Australia and overseas. We also edited the book *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021). This is a collection of ten case studies from six jurisdictions (the United Kingdom, the United States, Canada, Australia, Belgium and the Netherlands) analysing different aspects of end-of-life law reform.

Finally, we note our global position on assisted dying. We support law reform to permit access to assisted dying under strict conditions and with robust oversight. Some discussion of our views on this is available here:

- Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson, *Tensions and Traumas in Health Law* (Federation Press, 2017).

More background information is available here:
https://www.qut.edu.au/about/our-people/academic-profiles/bp.white
https://www.qut.edu.au/about/our-people/academic-profiles/l.willmott

The Australian experience of assisted dying

Because models of assisted dying from other countries are generally included in debates about assisted dying law reform, we wish to share evidence about the Australian experience of assisted dying.

Sources of evidence

We base our comments below on two main sources of evidence. The first is the reports of the oversight bodies in the Australian states of Victoria and Western Australia. These are the two systems that have been in operation the longest – Victoria for over three years and Western Australia for more than one year. The other state systems are newer and so the oversight bodies have not yet reported.

The second type of evidence is the research that we have undertaken about the law, policy and practice of assisted dying systems in Australia. This includes articles:

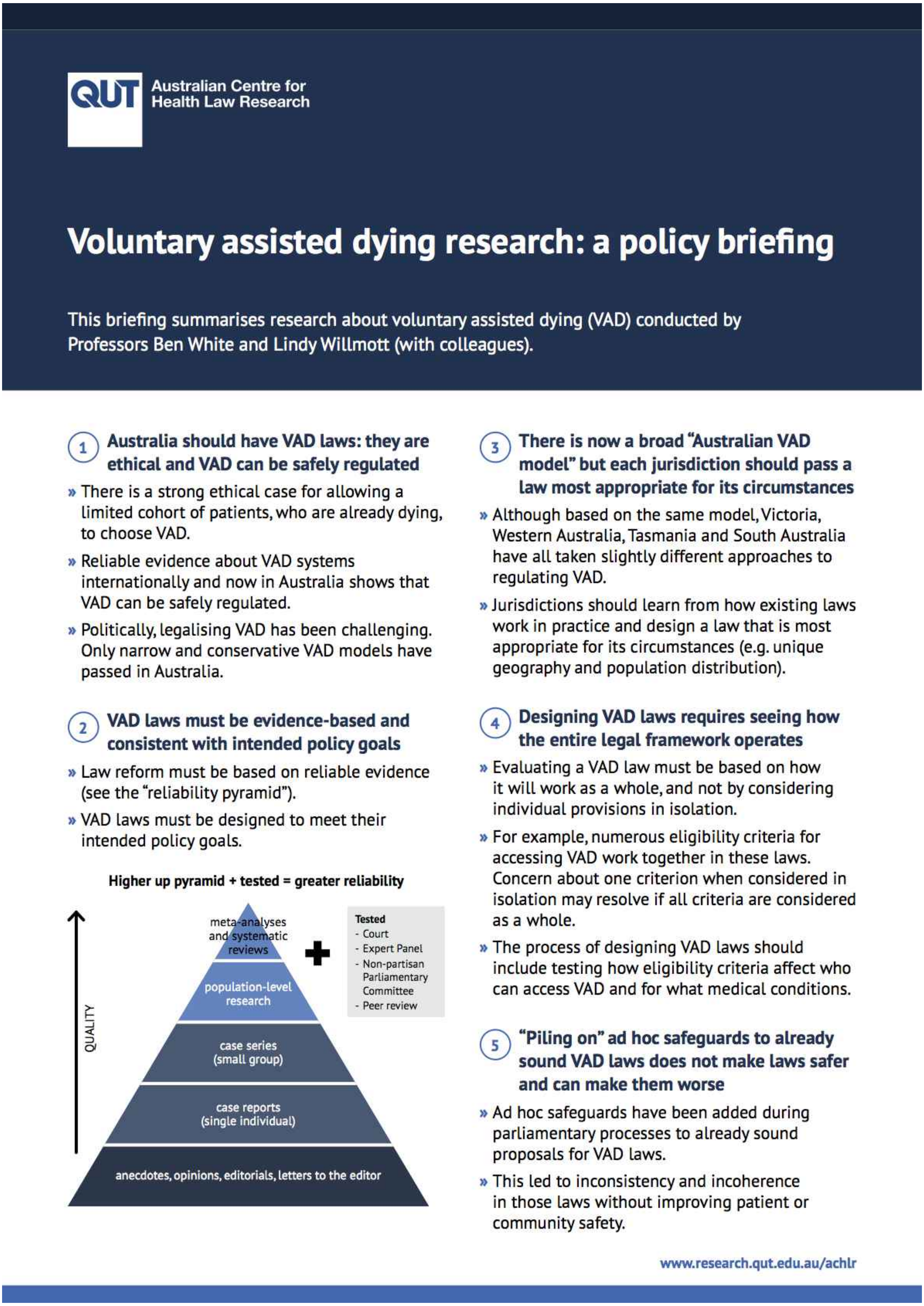
- Analysing the assisted dying models from a legal and regulatory perspective
- Analysing the policies produced by government and non-government bodies about assisted dying
- Reporting on the development and utilisation of the legislatively-mandated assisted dying training
- Reporting on empirical research about how the assisted dying models are operating in practice.

In relation to empirical research, we have conducted over 100 qualitative interviews with patients, families, doctors and regulators in the Australian states of Victoria and Western Australia to understand how these assisted dying models are working in practice. Some of this research has been published, some is under review, and some data are currently being analysed. Because some of this research is not yet in the public domain, it is discussed in general terms. We would be happy to provide more information about specific findings if that would be of assistance, including providing in confidence access to unpublished or under review work.

The published academic research is available here: https://eprints.qut.edu.au/view/person/White,_Ben.html.

A policy briefing (August 2021)

To inform parliamentary debates in Australia, we produced a policy briefing which summarised the key findings from our research about assisted dying over a period of almost two decades. The briefing is reproduced in full below and may also be accessed at the following link: https://research.qut.edu.au/voluntary-assisted-dying-regulation/other-resources/. Also available at that website is the research that underpins this policy briefing (see the PDFs extracted into five volumes).



Australian Centre for
Health Law Research

Voluntary assisted dying research: a policy briefing

This briefing summarises research about voluntary assisted dying (VAD) conducted by Professors Ben White and Lindy Willmott (with colleagues).

1 Australia should have VAD laws: they are ethical and VAD can be safely regulated

- There is a strong ethical case for allowing a limited cohort of patients, who are already dying, to choose VAD.
- Reliable evidence about VAD systems internationally and now in Australia shows that VAD can be safely regulated.
- Politically, legalising VAD has been challenging. Only narrow and conservative VAD models have passed in Australia.

2 VAD laws must be evidence-based and consistent with intended policy goals

- Law reform must be based on reliable evidence (see the "reliability pyramid").
- VAD laws must be designed to meet their intended policy goals.

Higher up pyramid + tested = greater reliability

3 There is now a broad "Australian VAD model" but each jurisdiction should pass a law most appropriate for its circumstances

- Although based on the same model, Victoria, Western Australia, Tasmania and South Australia have all taken slightly different approaches to regulating VAD.
- Jurisdictions should learn from how existing laws work in practice and design a law that is most appropriate for its circumstances (e.g. unique geography and population distribution).

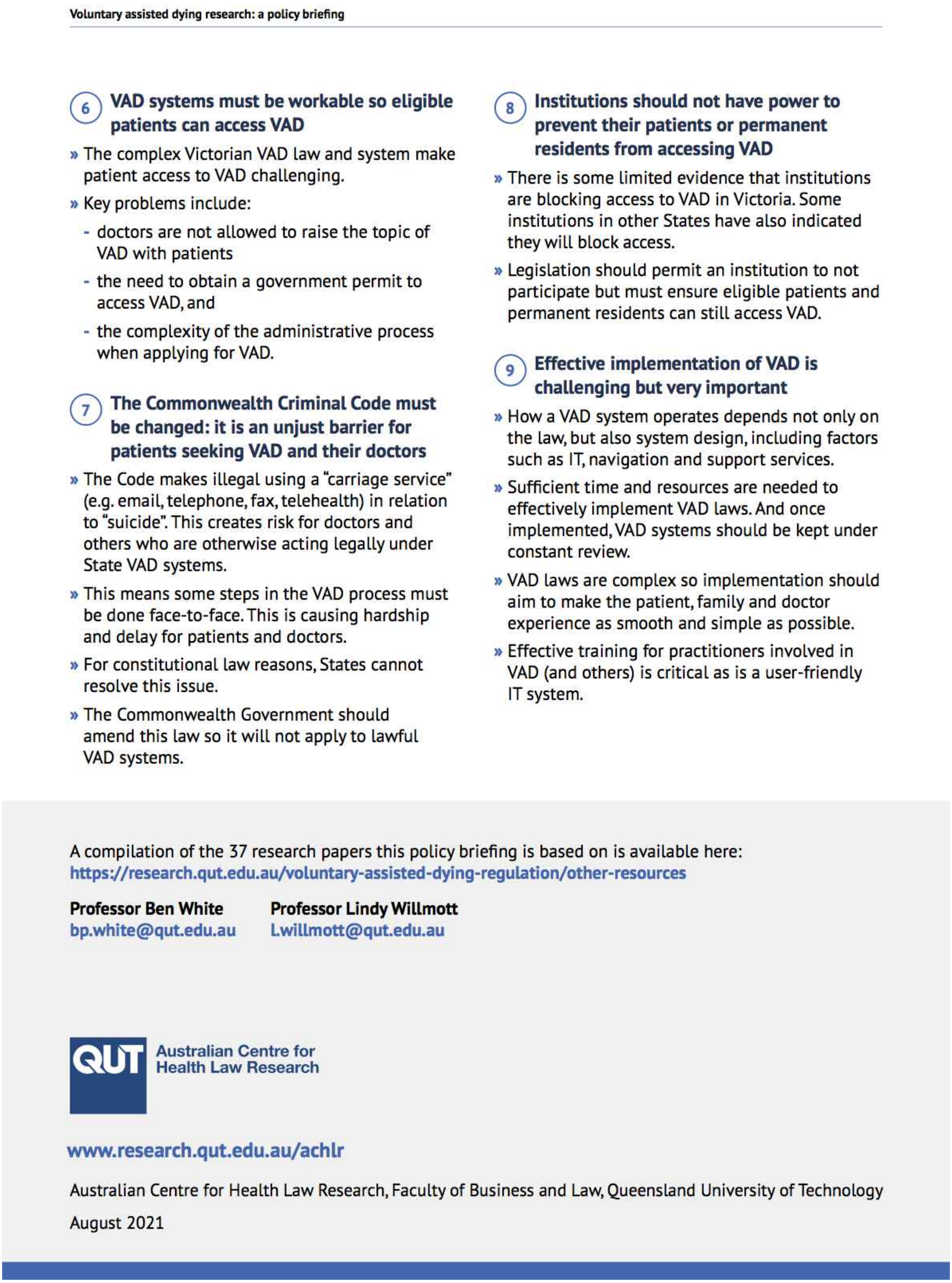
4 Designing VAD laws requires seeing how the entire legal framework operates

- Evaluating a VAD law must be based on how it will work as a whole, and not by considering individual provisions in isolation.
- For example, numerous eligibility criteria for accessing VAD work together in these laws. Concern about one criterion when considered in isolation may resolve if all criteria are considered as a whole.
- The process of designing VAD laws should include testing how eligibility criteria affect who can access VAD and for what medical conditions.

5 "Piling on" ad hoc safeguards to already sound VAD laws does not make laws safer and can make them worse

- Ad hoc safeguards have been added during parliamentary processes to already sound proposals for VAD laws.
- This led to inconsistency and incoherence in those laws without improving patient or community safety.

www.research.qut.edu.au/achlr



⑥ VAD systems must be workable so eligible patients can access VAD

- The complex Victorian VAD law and system make patient access to VAD challenging.
- Key problems include:
  - doctors are not allowed to raise the topic of VAD with patients
  - the need to obtain a government permit to access VAD, and
  - the complexity of the administrative process when applying for VAD.

⑦ The Commonwealth Criminal Code must be changed: it is an unjust barrier for patients seeking VAD and their doctors

- The Code makes illegal using a "carriage service" (e.g. email, telephone, fax, telehealth) in relation to "suicide". This creates risk for doctors and others who are otherwise acting legally under State VAD systems.
- This means some steps in the VAD process must be done face-to-face. This is causing hardship and delay for patients and doctors.
- For constitutional law reasons, States cannot resolve this issue.
- The Commonwealth Government should amend this law so it will not apply to lawful VAD systems.

⑧ Institutions should not have power to prevent their patients or permanent residents from accessing VAD

- There is some limited evidence that institutions are blocking access to VAD in Victoria. Some institutions in other States have also indicated they will block access.
- Legislation should permit an institution to not participate but must ensure eligible patients and permanent residents can still access VAD.

⑨ Effective implementation of VAD is challenging but very important

- How a VAD system operates depends not only on the law, but also system design, including factors such as IT, navigation and support services.
- Sufficient time and resources are needed to effectively implement VAD laws. And once implemented, VAD systems should be kept under constant review.
- VAD laws are complex so implementation should aim to make the patient, family and doctor experience as smooth and simple as possible.
- Effective training for practitioners involved in VAD (and others) is critical as is a user-friendly IT system.

A compilation of the 37 research papers this policy briefing is based on is available here:
https://research.qut.edu.au/voluntary-assisted-dying-regulation/other-resources

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August 2021

Further observations about Australia's assisted dying systems

In addition to the findings summarised in the policy briefing, we make the following further observations based on the two sources of evidence identified above:

- The Victorian and Western Australian oversight bodies' reports show that their assisted dying systems are operating safely. There have not been cases of ineligible patients being wrongly granted access to the assisted dying system. Research participants interviewed have also repeatedly observed how safe the system is.
- Indeed, there appear to be challenges with assisted dying not being sufficiently accessible for terminally-ill eligible patients who want this choice (particularly in Victoria). Although the many safeguards in these systems are ensuring the system operates safely, there is evidence that people are dying or losing capacity during the rigorous assessment process, and applying for assisted dying is very challenging. While continued focus on safety is essential, work is needed to ensure assisted dying systems can be effectively used by the patients they are designed to help.
- In particular, the requirement for prospective review and approval in Victoria (e.g. via a government permit) has been a cause of delay in accessing assisted dying.
- The Victorian prohibition on being able to raise assisted dying with patients has generally been seen as problematic as it impedes frank conversations about end-of-life choices.
- To date, there are a relatively small pool of doctors (and nurses where permitted) who have trained and are available to provide assisted dying. This can make access to assisted dying difficult, particularly in some areas.
- Some institutions have objected to assisted dying occurring on its premises. This has led to adverse consequences for some terminally-ill patients and their families.
- The thorough and planned implementation processes prior to the law coming into force ensured assisted dying operated safely as soon as the law began.
- The assisted dying care navigators have been pivotal to the effective operation of the assisted dying system.

Law reform and assisted dying

In this section, we make some observations based on our research into law reform and assisted dying, as well as our participation in the six law reform exercises in the Australian states which have legalised assisted dying.

Law reform processes and assisted dying

We commend the Isle of Man undertaking a consultation process as part of its deliberations on assisted dying. We share the below book chapter on law reform processes in the end-of-life area. This chapter was a collaborative effort with international end-of-life scholars on law making and law reform which draws on ten case studies in six countries to identify features that support law reform in this area.

- White, Ben, Willmott, Lindy, Downie, Jocelyn, Lewis, Penney, Kitzinger, Celia, Kitzinger, Jenny, et al., 'International Perspectives on Reforming End-of-Life Law' in White, Ben P. & Willmott, Lindy (Eds.) *International Perspectives on*

End-of-Life Law Reform: Politics, Persuasion and Persistence (Cambridge University Press, 2021) pp. 250-275.

Law-making on assisted dying must be evidence-based

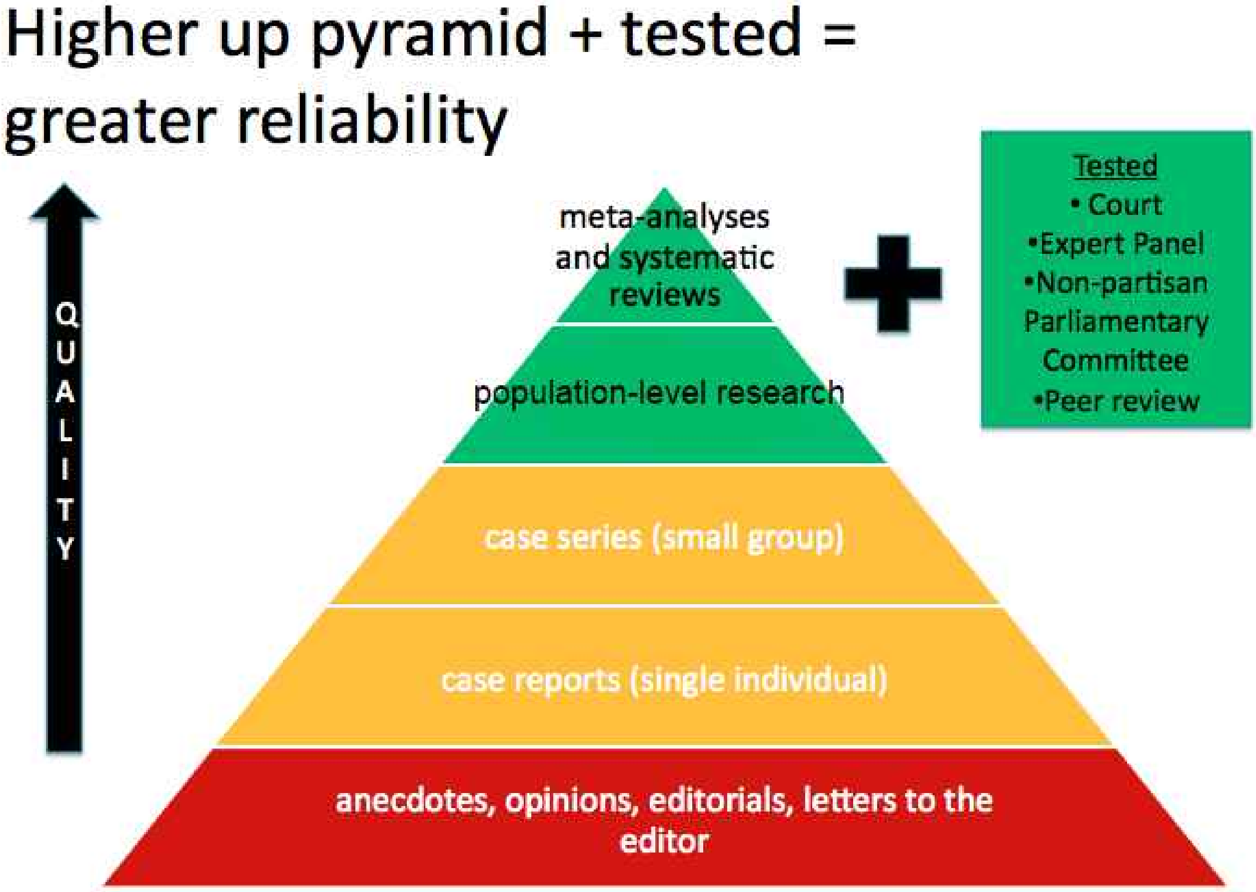
We advocate for evidence-based law-making, and consider this is particularly important in relation to a contested social policy area such as assisted dying. For example, there is a large body of reliable evidence about how assisted dying systems operate internationally. We outline the case for evidence-based law-making in:

- Ben White and Lindy Willmott, ‘Evidence-based law making on voluntary assisted dying’ (2020) 44(4) *Australian Health Review* 544-546

There is also evidence which is not reliable. For an example of a critical analysis of research which claimed to be reliable evidence for the New Zealand assisted dying referendum – but was in fact not reliable evidence, see:

- Ben White, Lindy Willmott, Jocelyn Downie, Andrew Geddis and Colin Gavaghan, ‘Assisted dying and evidence-based law-making: A critical analysis of an article’s role in New Zealand’s referendum’ (2020) 133(1520) *New Zealand Medical Journal* 83-90

In particular, we note the utility of an evidence pyramid (see below and in the two above-mentioned articles) to critically evaluate factual claims about assisted dying.



** Originally developed by Professor Jocelyn Downie (see above-mentioned articles)*

Concrete testing of eligibility criteria

We also recommend the concrete testing of eligibility criteria to understand properly the boundaries of a proposed assisted dying law. We undertook (with colleagues) an analysis of five assisted dying laws (three Australia models, Oregon and Canada) across nine different medical conditions to determine which models might permit access to assisted dying and for whom.

One key finding was that access to assisted dying under the Australian models like Victoria and Western Australia, and Oregon, which include a proposed time until death is likely to be the same when compared to our Model Bill (which does not have a time frame) regardless of the patient's medical condition. Those two papers also include a range of recommendations about law and regulation that we consider are important for parliaments and law-makers considering assisted dying laws:

- Ben White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663.
- Ben White et al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* 401.

Avoid incoherent law by ad hoc addition of safeguards

A final observation about the law-making process, based on what we have seen in the six Australian law reform processes, is the need to avoid the ad hoc addition of safeguards which are awkwardly tacked on to already sound law. This leads to the assisted dying law being incoherent or inconsistent in important ways.

An example of this in Australia is eligibility for assisted dying depending on a variable time period – 6 or 12 months until expected death – depending on the nature of a patient's illness (the longer period is only available for neurodegenerative conditions). This change in timing was a political compromise in Victoria which has since been uncritically adopted and replicated in all other states in Australia except Queensland. Yet this was only a last-minute addition to the Victorian Bill as a result of political compromise.

Our research has shown that the Victorian assisted dying law fails to meet its own stated policy goals in important respects, sometimes because of these later ad hoc additions during the law-making process:

- Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.

For this reason, we argue that any proposed changes to an assisted dying Bill must be carefully scrutinised in light of the Bill as a whole: [VAD here refers to voluntary assisted dying, the term used in Australia]

> 'When thinking about the politics of reform, it can be tempting to only consider each safeguard or process individually. Each may have merit and advance a particular policy goal. It may also be difficult politically to argue that a specific

> safeguard is not needed, particularly if it appears to achieve at least some useful purpose. However, when the safeguards are aggregated, the VAD system as a whole can become very complex and unwieldly, and slowly take the legislation away from its policy goals. This “policy drift by a thousand cuts” – the incremental loss of policy focus through accumulation of individual safeguards without reference to the whole – is a key issue for other states to consider when evaluating their proposed VAD reforms. It is suggested that each part of the law be evaluated both on its own, and also for its impact on the functioning of the overall system. This is needed to enable VAD laws to meet their policy goals, in particular, the two key goals at the core of the design of the VAD Act: safeguarding the vulnerable while respecting the autonomy of eligible persons who wish to access to VAD.’[1]

We have also written on this point in ‘Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks’:

> ‘Taking a holistic view is also an important consideration more generally when designing VAD regulation. While it may be politically attractive to add numerous safeguards to VAD legislation, including in the eligibility criteria, there is a risk of what we have called elsewhere “policy drift by a thousand cuts” if the cumulative effect of these individual safeguards is not properly considered. For example, it is possible that a series of provisions designed to make VAD legislation safe, when aggregated, can in fact make access to VAD cumbersome or even unworkable.’[2]

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[1] Ben White, Katrine Del Villar, Eliana Close and Lindy Willmott, ‘Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?’ (2020) 43(2) *University of New South Wales Law Journal* 417, 451.

[2] Ben P White et al, ‘Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks’ (2021) 44(4) *University of New South Wales Law Journal* 1663, 1699.

APPENDIX – PUBLISHED RESEARCH REFERRED TO ABOVE

The below list of publications is presented in the order in which they are cited.

- Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson, *Tensions and Traumas in Health Law* (Federation Press, 2017).
- White, Ben, Willmott, Lindy, Downie, Jocelyn, Lewis, Penney, Kitzinger, Celia, Kitzinger, Jenny, et al., 'International Perspectives on Reforming End-of-Life Law' in White, Ben P. & Willmott, Lindy (Eds.) *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021) pp. 250-275.
- Ben White and Lindy Willmott, 'Evidence-based law making on voluntary assisted dying' (2020) 44(4) *Australian Health Review* 544-546
- Ben White, Lindy Willmott, Jocelyn Downie, Andrew Geddis and Colin Gavaghan, 'Assisted dying and evidence-based law-making: A critical analysis of an article's role in New Zealand's referendum' (2020) 133(1520) *New Zealand Medical Journal* 83-90
- Ben White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663.
- Ben White et al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* 401.
- Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.

Our other assisted dying research is available here:

https://eprints.qut.edu.au/view/person/White,_Ben.html.

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Assisted Dying in Australia: A Values-based Model for Reform

Lindy Willmott and Ben White[*]

Introduction

Assisted dying demonstrates starkly the tensions and traumas of health law as Australia, like jurisdictions around the world, wrestles with proposed changes to make voluntary euthanasia and/or assisted suicide lawful. Tensions are evident in the entrenched and opposing policy positions of individuals and organisations about whether reform should occur. And even those advocating for a change in the law will disagree about what should and should not be permitted and how a permissive regime should be regulated. These different positions are often driven by different ideological perspectives and are embedded in deeply held personal values and beliefs.

Assisted dying debates raise issues of trauma too. In our sophisticated health system which boasts a very high standard of palliative care,[1] death is generally well managed with the patient's pain and symptoms being adequately controlled. Yet, this is not always possible. There is trauma for a small cohort of people whose suffering (whether physical, psychological or existential) cannot be satisfactorily alleviated and who seek assistance to die. This trauma can extend to their loved ones and their treating teams.

The debate over whether we should reform our law on euthanasia and assisted suicide has been particularly prominent in Australia over recent years. We have seen Bills drafted in all but one Australian State,[2] parliamentary committee inquiries,[3] police

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[*] The authors thank our colleagues, Professor Jocelyn Downie and Professor Ian Freckelton QC, for their valuable contributions and comments on an earlier draft. Their insightful comments sharpened our thinking and improved the quality of this chapter. Of course, the views expressed in this chapter are of the authors alone and not necessarily shared by others. We also thank Juliet Davis and Penny Neller for their research assistance.

[1] The Economist Intelligence Unit, *The 2015 Quality of Death Index: Ranking palliative care across the world* (2015) 7, 15, 23, 26, <https://www.eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf>.

[2] Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) *University of New South Wales Law Journal* 1, 11.

[3] Most recently, see the Joint Select Committee on End of Life Choices which was established by the Western Australian Parliament on 23 August 2017, <http://www.parliament.wa.gov.au/Parliament/commit.nsf/WCurrentNameNew/023DFCF05E82695948258186001A2106?OpenDocument>. See also the review of end-of-life choices in Victoria: Legislative Council Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report* (June 2016), <https://www.parliament.vic.gov.au/file_uploads/LSIC_pF3XBb2L.pdf>.

investigations, action by medical regulators,[4] and a media-fuelled public debate. There has also been considerable movement towards liberalising euthanasia and assisted suicide internationally. We will expand on both Australian and international developments shortly.

The goal of this chapter is not to rehearse all of the arguments for and against reform. Instead, we advance a values-based model for assisted dying. These values – life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable, and reducing human suffering – are based on existing Australian legal principle, for example, as reflected in common law, legislation or conventions or treaties that have been ratified by Australia. Drawing on these values, we conclude that the current criminal law prohibition on assisted dying cannot be justified and instead propose a model that permits and regulates assisted dying in certain circumstances. Our model is guided by the values identified but also draws on arguments based on reason and practice (consistent with the values), including the experience of assisted dying in other jurisdictions.

We acknowledge at this point two limitations of this chapter. First, there is not space here to articulate comprehensively and defend the values we propose. Nor is there scope to outline in detail the model that follows. That more detailed project will have to wait. Our purpose here is to put forward these values and this model for discussion and critique, and we do so with an awareness that a more robust case (including discussion of a wider body of literature) is not possible here.

The second limitation is that there are three important issues that have not been considered in developing our model and therefore fall outside the scope of this chapter. They are outside scope for two reasons. First, they are complex issues that require more detailed consideration than is possible in this chapter. The second reason is that they are not currently part of the mainstream Australian assisted dying debate, and so it is justifiable and appropriate to leave them to another time. We do not address the issue of assisted dying through advance directives. This issue requires a conceptual analysis (for example, whether a present competent self should have the authority to bind a future incompetent person) as well as answers to implementation questions (for example, rules about revocation, relationship to current advance care planning systems). We also do not address the issue of assisted dying requested by substitute decision-makers as this involves a different formulation of autonomy than that used in this chapter, and shifts the discussion of the balancing of the competing values in a way that also exceeds the space constraints of this chapter. Finally, we do not consider the position of *Gillick*-competent minors, as Australian court authority recognising limits on the power of this cohort to refuse life-sustaining treatment would require detailed analysis which is not possible here.[5]

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[4] See, eg, *Nitschke v Medical Board of Australia* [2015] NTSC 39; *Syme v Medical Board of Australia* [2016] VCAT 2150.

[5] See, eg, *X v Sydney Children's Hospitals Network* (2013) 85 NSWLR 294 (an application from the New South Wales Court of Appeal for special leave to the High Court was dismissed as moot after the child in question turned 18 years of age: *X v Sydney Children's Hospitals Network* [2014] HCASL 97); *Royal Alexandra Hospital for Children Trading as Children's Hospital at Westmead v J* (2005) 33 Fam LR 448; *Minister for Health v AS* (2004) 33 Fam LR 223. See further Freckelton and McGregor, this volume, Chapter 12.

A final point about terminology. We define 'euthanasia' in the following way:

> For the purpose of relieving suffering, a person performs a lethal action[6] with the intention of ending the life of another person.[7]

And 'voluntary euthanasia' as where:

> Euthanasia is performed at the request of the person whose life is ended, and that person is competent.[8]

'Assisted suicide' is defined as follows:

> A competent person dies after being provided by another with the means or knowledge to kill him or herself.[9]

'Physician-assisted suicide' is 'where a doctor acts as the assistant'.[10]

For the purpose of this chapter, unless we indicate to the contrary, we will use the term 'assisted dying' to refer to both 'voluntary euthanasia' and 'physician-assisted suicide' as defined above.

A short history of Australian assisted dying reform

The Northern Territory was the first jurisdiction in the world to legalise voluntary euthanasia with the enactment of the *Rights of the Terminally Ill Act 1995* (NT) (ROTTIA).[11] Although ground-breaking reform, the Act was short-lived, and the Commonwealth overturned it a short time later by enacting the *Euthanasia Laws Act 1997* (Cth). Since the enactment (and repeal) of ROTTIA, there have been dozens of attempts at the State, Territory and Commonwealth level to: legalise euthanasia (the majority of Bills), to overturn the Commonwealth *Euthanasia Laws Act 1997* (Cth) to enable Territories to legislate on the topic, and to hold a referendum on law reform.[12] Bills have been introduced in all Australian jurisdictions except Queensland.[13] In the past, the majority of the proponents of reform have been independent members of parliament, or members of the Australian Greens or the Australian Democrats.[14] More recently, private members' Bills have been proposed by Labor Party and Liberal Party politicians as well.[15] Conscience votes have always been allowed when the Bills have been considered in parliament.

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[6] Note that the authors do not include within this definition positive steps taken by a person to stop treatment which action results in death (such as removing a breathing tube).

[7] Willmott et al, above n 2, 6.

[8] Ibid.

[9] Ibid 7.

[10] Ibid.

[11] For background regarding the passage of the Bill and its repeal, see ibid 8-9.

[12] Ibid 11.

[13] Though no Bill has been introduced in Queensland, in October 2016 Queensland Independent MP Peter Wellington called for a parliamentary inquiry into voluntary euthanasia and end-of-life choices: Felicity Caldwell, 'Voluntary euthanasia: Calls for Queensland Parliamentary Inquiry', *Brisbane Times* (online), 17 October 2016, <http://www.brisbanetimes.com.au/queensland/voluntary-euthanasia-calls-for-queensland-parliamentary-inquiry-20161017-gs44ri.html>.

[14] Willmott et al, above n 2, 11-13.

[15] For example, in October 2016 South Australian Liberal MP Dr Duncan McFetridge introduced the *Death with Dignity Bill 2016*, which was defeated in the South Australian Parliament following a close conscience vote: ABC News, 'Voluntary euthanasia: South Australian parliament

Despite the large number of Bills introduced, they have rarely reached the Committee or third reading stage. As such, there has been only limited detailed analysis of proposed legislation by our parliamentarians. More Bills have lapsed rather than been defeated.[16]

A recent analysis of the Bills that have been proposed revealed common features:[17]

- Most allow both euthanasia and physician-assisted suicide (including the ROTTIA).
- The overwhelming majority of the Bills (including the ROTTIA) propose permissive models, that is, providing a legislative framework containing eligibility requirements and integrating safeguards which *allow* euthanasia in the described circumstances. (Other models provide defences while continuing to retain the offence of killing, and still other models provide for mitigation of penalties if killing occurs in certain circumstances.)
- All permissive models (including the ROTTIA) provide that assistance to die would only be available to an adult who is enduring intolerable suffering and/or has a terminal illness. The person needs to be competent and the request voluntary. (Under some models, a person could receive assistance to die if they no longer had capacity, but the request was made when he or she did have capacity.)
- Generally, the person could determine for themselves whether the suffering was of a level acceptable to them, and most Bills adopt a broad interpretation of the categories of suffering (often including physical, psychological and existential).
- Most Bills (including the ROTTIA) contain safeguards including requirements that the person obtain information from a range of specialists and specify a cooling-off period.
- Most Bills (including the ROTTIA) contain oversight mechanisms, commonly reporting to the Coroner.

So, despite many attempts to reform the law, assisted dying remains unlawful in Australia. This has not, however, prevented people from assisting others to end their lives. From time to time, doctors have admitted to providing such assistance to patients who are approaching the end of their lives and are experiencing unbearable suffering. For the most part, such admissions by doctors have not resulted in police investigation or prosecution.[18] Also at risk are individuals who respond to requests from a terminally ill family member or friend who seeks their assistance to die. There are reasonably

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knocks back Death with Dignity euthanasia bill', *ABC News* (online), 17 November 2016, <http://www.abc.net.au/news/2016-11-16/voluntary-euthanasia-debate-in-south-australia-goes-to-committee/8031776>. In February 2016 South Australian Labor MP Stephanie Key introduced the *Voluntary Euthanasia Bill 2016*, but withdrew the Bill in March 2017: South Australia, *Parliamentary Debates*, House of Assembly, 2 March 2017, 8775 (Stephanie Key, MP, Ashford).

[16] Willmott et al, above n 2, 5-20.

[17] Ibid 39-41.

[18] See, eg, admissions by Dr Rodney Syme about providing assistance to die: Norman Hermant, 'Euthanasia debate: Doctor confirms he helped patients die, wants to be charged', *ABC News* (online), 8 May 2014, <http://www.abc.net.au/news/2014-05-07/doctor-confirms-he-helped-patient-die/5437686>. Despite that report, Dr Syme was not arrested or prosecuted for a criminal offence.

regular prosecutions in such cases,[19] although judges frequently hand down sentences less than the maximum permitted, and often do not impose a custodial sentence on the accused in these cases.[20]

Pressure to change the law continues to build. Media interest in reform has been unparalleled, perhaps fuelled by the campaign for reform spearheaded by Andrew Denton, the high profile entertainer. Media attention is also sparked, and public debate ensues, when health professionals are investigated for assisting one of their terminally ill patients to die (as is reportedly the case for Dr Alida Lancee in Western Australia)[21],or conditions are imposed on their ability to practise medicine (as in the case of Dr Rodney Syme in Victoria).[22] We have also seen a great deal of political activity by members of parliament federally and in all Australian States. At the Commonwealth level, the Australian Greens plan to table a Bill during the current term of parliament.[23] At State level, there has been recent political activity through tabling of bills, establishing Committees to review the law or calls to do so in all Australian States. In South Australia, the State where there have been more reform attempts than in any other Australian jurisdiction, the *Death with Dignity Bill* was defeated in November 2016 by just one vote.[24] More recently, in Tasmania in May 2017, the *Voluntary Assisted Dying Bill 2016* was defeated in the House of Assembly.[25] In Western Australia, a Joint Select Committee on End of Life Choices was established on 23 August 2017.[26] Even in Queensland, where an assisted dying Bill has never been introduced, Peter Wellington (an independent member of parliament) has recently called for a parliamentary inquiry into end-of-life decision-making with a goal of providing individuals with more choice.[27]

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[19] Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16(1) *QUT Law Review* 84, 103-104.

[20] Ibid.

[21] Nicolas Perpitch, 'Perth doctor investigated by police after admitting hastening patient's death', *ABC News* (online), 24 August 2016, <http://www.abc.net.au/news/2016-08-24/doctor-alida-lancee-investigated-after-hastening-patient-death/7780788>. At the time of writing, there are no media reports that Dr Lancee has been charged.

[22] In 2016, the Medical Board of Australia imposed a condition on the registration of Victorian doctor, Dr Rodney Syme, following a mandatory notification from a general practitioner that Dr Syme was to assist a terminally ill patient to end his life: Julia Medew, 'Medical Board of Australia investigates euthanasia doctor Rodney Syme', *The Age* (online), 7 March 2016, <http://www.theage.com.au/victoria/medical-board-of-australia-investigates-euthanasia-doctor-rodney-syme-20160307-gnca3j.html>. The condition prevented him from engaging in 'the provision of any form of medical care, or any professional conduct in his capacity as a medical practitioner that has the primary purpose of ending a person's life'. On appeal, the Victorian Civil and Administrative Tribunal set aside the condition 'on the basis the Tribunal is not able ... to form a reasonable belief that Dr Syme's conduct places persons at serious risk or that it is necessary to take immediate action to protect public safety': *Syme v Medical Board of Australia* [2016] VCAT 2150, [185].

[23] The Greens, 'Don't punish doctors for voluntary euthanasia: Greens' (Media Release, 25 August 2016), <http://greens.org.au/sites/greens.org.au/files/20160627_Dying%20with%20Dignity_0.pdf>. See also the *Medical Services (Dying with Dignity) Exposure Draft Bill 2014* which was released for consultation in 2014 by Greens Senator Richard Di Natale, <http://www.aph.gov.au/~/media/Committees/Senate/committee/legcon_ctte/dying_with_dignity/Exposure%20draft%20dying%20with%20dignity.pdf>.

[24] 23 votes were in favour and 24 votes opposed the Bill.

[25] 8 votes were in favour and 16 votes opposed the Bill.

[26] See <http://www.parliament.wa.gov.au/Parliament/commit.nsf/WCurrentNameNew/023DFCF05E8269594825818600 1A2106?OpenDocument>.

[27] Caldwell, above n 13.

At the time this book goes to print, bills to legalise assisted dying have just been introduced into the New South Wales and Victorian parliaments. On 21 September 2017, the *Voluntary Assisted Dying Bill 2017* was introduced into the Legislative Council of New South Wales by National Party MP, Trevor Khan.[28] Only a day earlier on 20 September 2017, a bill of the same name was introduced into the Legislative Assembly of the Victorian Legislative Assembly by the Health Minister, Jill Hennessy.[29] The introduction of the Victorian bill followed an extensive consultation and review process by the Victorian Parliament Legislative Council Legal and Social Issues Committee[30] and, more recently, the Expert Panel which was charged by the Victorian Premier to draft legislation to legalise assisted dying.[31]

After initially leading the world, Australia has not had an assisted dying law for over 20 years, despite repeated efforts to change the law. This may soon change with momentum for reform building. If the law does change in one Australian jurisdiction to allow assisted dying, other States and Territories are likely to follow. This follows a trend of liberalisation internationally, to which we now turn.

A brief snapshot of international assisted dying regimes

This section provides a brief overview of the international jurisdictions that permit assisted dying. The focus is on the three main areas in the world that have legislated to permit assisted dying – Europe, the United States and Canada.

Europe

There are four jurisdictions in Europe where assisted dying is lawful: the Netherlands, Belgium, Luxembourg and Switzerland. The focus of the below discussion is the Netherlands and Belgium as they have been in operation longest (and the Luxembourg regime is similar to that which operates in Belgium). There is also a brief discussion of the Swiss approach.

The Netherlands

Both voluntary euthanasia and physician-assisted suicide are permitted in the Netherlands. Under the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002*[32] doctors are protected from criminal charges provided that they adhere to the stipulated requirements for assisting patients to die. When a voluntary and well-considered request is made by a patient for assistance to bring about their

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[28] See <https://www.parliament.nsw.gov.au/Hansard/Pages/HansardResult.aspx#/docid/HANSARD-1820781676-74390>.

[29] See <https://www.parliament.vic.gov.au/images/stories/daily-hansard/Assembly_2017/Assembly_Weekly_Aug-Dec_2017_Book_12.pdf>.

[30] The Committee's report was tabled in Victorian Parliament on 9 June 2016: Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices Final Report* (2016).

[31] The Expert Panel released its final report in July 2017: Victoria, Ministerial Advisory Panel on Voluntary Assisted Dying, *Final Report* (2017).

[32] *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002* (Netherlands).

death, a doctor concludes that their suffering is lasting and unbearable, and the patient holds the conviction that there is no other reasonable solution to their situation, a doctor is legally permitted to provide them with assistance to bring about their death (Art 2). It is obligatory for the doctor to have informed the patient about their situation and their options, and for the practitioner to have consulted at least one other doctor (Art 2). If the patient is between 16 and 18 years old, and has a reasonable understanding of their interests, their parents must be involved in the decision process although there is no requirement for them to agree with their child's request. If they are between 12 and 16, and have a reasonable understanding of the process, the doctor can only act on the patient's request if the parents agree. If the patient is aged 16 years or older and is no longer capable of expressing their wishes, the doctor can act on their earlier wishes if, before reaching this condition, the patient, who had a reasonable understanding of their interests, made a written request for assisted dying.

The Netherlands has established Regional Review Committees for assisted dying.[33] Their role is to assess whether doctors who have terminated a life on request or assisted in a suicide have acted in accordance with the requirement of due care (Art 8). The Committees can provide information to prosecutors as they deem appropriate (Art 10).

Belgium

Belgium legalised voluntary euthanasia in designated circumstances in 2002.[34] The *Belgian Act on Euthanasia 2002* permits euthanasia[35] if the person is in 'a medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated, resulting from a serious and incurable disorder caused by illness or accident'.[36] The patient's request must be in writing and signed by the patient[37] and must be 'durable'.[38] The doctor must explain to the patient information regarding his or her health condition and life expectancy.[39] The doctor and patient must consider there to be no reasonable alternative to the patient's situation.[40] The doctor must also be satisfied that the patient's request is completely voluntary and that the patient is in a state of constant physical or mental suffering.[41] Belgium's Federal Control and Evaluation Committee on Euthanasia undertakes monitoring of the application of the law.

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[33] See Regional Euthanasia Review Committees, *Annual Report 2013* (2014), <https://english.euthanasiecommissie.nl/documents/publications/annual-reports/2002/annual-reports/annual-reports>; Guy Widdershoven, 'Euthanasia in the Netherlands: Experiences in a Review Committee' (2004) 23(3) *Medicine and Law* 687.

[34] See Neera Bhatia, Ben White and Luc Deliens, 'How Should Australia Respond to Media-Publicised Developments on Euthanasia in Belgium?' (2016) 23(4) *Journal of Law and Medicine* 835 for a discussion of the operation of the law.

[35] 'Euthanasia' is defined as 'intentionally terminating life by someone other than the person concerned, at the latter's request': *Belgian Act on Euthanasia 2002* s 2.

[36] *Belgian Act on Euthanasia 2002* s 3§(1).

[37] *Belgian Act on Euthanasia 2002* s 3§(4).

[38] *Belgian Act on Euthanasia 2002* s 3§(2).

[39] *Belgian Act on Euthanasia 2002* s 3§(2).

[40] *Belgian Act on Euthanasia 2002* s 3§(2).

[41] *Belgian Act on Euthanasia 2002* s 3§(2).

In 2013, the law was extended to permit access for children provided they have the 'capacity of discernment', that is, are able to demonstrate an understanding of the absolute consequences of such a request.[42] This is analogous to the Australian law concept of *Gillick* competence. Other requirements include that the child's parents approve the decision, the child's illness must be such that death is expected in the short term and 'they must be in great pain, with no available treatment to alleviate their distress'.[43] The doctor assisting the minor must also consult a child psychiatrist or psychologist to discuss the case.

Switzerland

The legislative regime in Switzerland differs from those in the Netherlands and Belgium in that Switzerland has not passed legislation to make either euthanasia or assisting a suicide lawful in specific circumstances.

Instead, the law in Switzerland is governed by its *Criminal Code* and, under that Code, both of these acts are unlawful (euthanasia – in all circumstances; and assisted suicide – if done for selfish motives).[44] Under Art 114, any person who for commendable motives, and in particular out of compassion for the victim, causes the death of a person at that person's own genuine and insistent request shall be liable to a custodial sentence not exceeding three years or to a monetary penalty.[45] Article 115 deals with assisting another to commit suicide and provides that 'any person who for *selfish motives* incites or assists another to commit or attempt to commit suicide shall, if that other person thereafter commits or attempts to commit suicide, be liable to a custodial sentence not exceeding five years or to a monetary penalty' (emphasis added).[46]

The effect of Art 114 is that voluntary euthanasia is unlawful and the person performing the act commits a crime, even if the act is done for 'commendable motives' at the other's request. On the other hand, not all cases of assisting a suicide will be illegal. Assisting a suicide is only an offence if it is done for 'selfish' motives. There is unlikely to be a breach of Art 115 where a person has a medical condition which causes unbearable pain and suffering, forms a desire to end his or her life to relieve that pain and suffering, and seeks assistance to achieve that goal.

The United States

In most of the United States, physician-assisted suicide is illegal. However, it is legal in some circumstances in six jurisdictions: Oregon,[47] Washington,[48] Vermont,[49] Calif-

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[42] There is no official English translation available of the recent Belgian amendments relating to children. The examination of the law here is based on this unauthorised version: Christian Munthe, 'Legalised Euthanasia for Children Regardless of Age in Belgium: The Actual Law in English', Philosophical Comment (28 August 2015), <http:// philosophicalcomment.blogspot.com.au/2014/02/legalised-euthanasia-for-children.html>.

[43] Bhatia, White and Deliens, above n 34, 842.

[44] *Criminal Code 1937* (Switzerland).

[45] *Criminal Code 1937* (Switzerland) Art 114.

[46] *Criminal Code 1937* (Switzerland) Art 115.

[47] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994).

[48] *Death with Dignity Act*, Wash Rev Code §§ 70.245.010–70.245.904 (2008).

[49] *Patient Choice and Control at End of Life Act*, Vt Stat Ann §§ 5281–93 (2013).

ornia[50] and Colorado[51] through legislation,[52] and in Montana by way of court decision which concluded that consent provides a statutory defence to a charge of homicide.[53] In the legislative jurisdictions, the statutes are closely modelled on Oregon so we focus here on that jurisdiction given its two-decade history of physician-assisted suicide.

Since 1997, an Oregon law (passed in 1994)[54] has permitted residents of Oregon to receive prescriptions for self-administered lethal medication from their doctors provided the patient is 'capable', namely able to make and communicate decisions about their health care, and has an illness expected to lead to death within six months.[55] The patient must make one written and two oral requests to their physician, the latter separated by at least 15 days.[56] The patient's primary physician and a consultant must confirm the diagnosis of a terminal condition and the prognosis, determine that the patient is capable,[57] and refer the patient for counselling, if either believes that the patient's judgment is impaired by depression or some other psychiatric or psychological disorder.[58] The primary physician must also inform the patient of all feasible alternatives, such as comfort care, hospice care, and pain-control options.[59] Physicians must report all prescriptions that they write for lethal medications to the Oregon Health Division.[60]

Canada

There has been considerable judicial and legislative activity in Canada over recent years. Legislation was first enacted in Quebec with *An Act Respecting End-of-Life Care*,[61] commencing operation in December 2015. The stated objective of the Act is 'to ensure that end-of-life patients are provided care that is respectful of their dignity and their autonomy'.[62] Unlike the European models, the Act regulates end-of-life care more broadly and includes both palliative care and medical aid in dying.[63]

The second development affected the entire country. In *Carter v Canada (Attorney General)*,[64] the constitutionality of the provisions of the Canadian *Criminal Code* that prohibited voluntary euthanasia and assisted suicide was challenged on the basis of breaching ss 7 (the right to life, liberty and security of the person) and 15 (the right to equality) of the *Canadian Charter of Rights and Freedoms*. The case originated with Kay

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[50] *End of Life Option Act*, Cal Health and Safety Code §§ 443–443.22 (2015).

[51] *End-of-Life Options Act*, Colo Rev Stat §§ 25-48-101 – 25-48-123 (2016).

[52] It should also be noted that assisted dying legislation has also been enacted in the District of Columbia (*Death with Dignity Act*, Law 21-577 DC (2016)). However, at the time this book goes to print, the federal House of Representatives is taking steps to repeal that law.

[53] *Baxter v Montana* 224 P 3d 1211 (2009).

[54] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994). See Joan Woolfrey, 'What Happens Now? Oregon and Physician-Assisted Suicide' (1998) 28(3) *Hastings Center Report* 9; Linda Ganzini, 'Legalised Physician-Assisted Death in Oregon' (2016) 16(1) *QUT Law Review* 76.

[55] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) s 2.01.

[56] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) s 3.06.

[57] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) ss 3.01 and 3.02.

[58] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) s 3.03.

[59] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) s 3.01.

[60] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) s 3.11.

[61] *An Act Respecting End-of-Life Care*, RSQ c S-32.0001.

[62] *An Act Respecting End-of-Life Care*, RSQ c S-32.0001, s 1.

[63] *An Act Respecting End-of-Life Care*, RSQ c S-32.0001, s 3.

[64] [2015] 1 SCR 331. For commentary on this case, see Downie, above n 19.

Carter, a woman who had a severe case of spinal stenosis. She asked her family to take her to Switzerland so that she could end her life, and they did so. Her daughter and son-in-law became the first plaintiffs in the case. Gloria Taylor subsequently joined the case as another central plaintiff. She was a woman who suffered from amyotrophic lateral sclerosis which causes progressive and fatal muscle weakness. She asked the court to strike down the *Criminal Code* barriers to physician-assisted death.

The Supreme Court held that the *Criminal Code* breached s 7 of the *Canadian Charter of Rights and Freedoms*, which protects 'the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice'. The prohibitions imposed by the *Criminal Code* were overbroad and thus not in accordance with the principles of fundamental justice – that is, the prohibitions were broader than was necessary to achieve the objective of the provision, namely the protection of the vulnerable from being induced to end their lives by suicide in times of weakness. The violation of s 7 was not 'demonstrably justified in a free and democratic society' (because the provisions limit the rights more than necessary to achieve the objectives) and so the provisions were unconstitutional. The Supreme Court issued a declaration that the relevant provisions of the *Criminal Code* were void in so far as they prohibited physician-assisted death for a competent adult who clearly consented to the termination of life and had a grievous and irremediable medical condition (including an illness, disease or disability) that caused enduring suffering that was intolerable to the individual in the circumstances of their condition. The Supreme Court also declared that 'irremediable' did not require the patient to undertake treatments that were not acceptable to him or her.

In response to the *Carter* decision, the Canadian Parliament passed a law which came into force on 17 June 2016.[65] The legislation contains a range of eligibility criteria and procedural safeguards. In terms of eligibility, the person must be an adult, be capable of making health decisions, have made a voluntary request, have given informed consent, and have a grievous and irremediable condition. The legislation provides that to have such a condition:

- the person must have a serious and incurable illness, disease or disability;
- the person must be in an advanced state of irreversible decline of capability;
- the person must have enduring physical or psychological suffering that is intolerable to them which cannot be relieved under conditions that are acceptable to them; and
- the person's natural death must be reasonably foreseeable.

Core values that should underpin this area of law[66]

There will never be total agreement on whether permissive assisted dying laws should be enacted in Australia. People hold positions which are shaped by deeply

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[65] *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)* SC 2016.

[66] In this section we draw heavily on the descriptions of values previously set out by two of the authors in Jocelyn Downie, Lindy Wilmott and Ben White, 'Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining treatment' (2014) 26(1) *New Zealand Universities Law Review* 24.

held personal values and beliefs. Individuals have different value systems which will result in different positions about whether it should ever be lawful to assist another person to end his or her life. However, the law must ultimately take a position on this issue – retain the prohibition full stop, retain the prohibition but introduce a defence, or adopt a permissive regime. In this section, we articulate the core values that we contend should underpin the law: life, autonomy, freedom of conscience, equality, the rule of law, protecting the vulnerable, and reducing human suffering.[67] These values are derived from existing Australian legal principle, as reflected in common law, legislation or conventions or treaties that have been ratified by Australia. In the section that follows, we then draw on these values to determine what the legal position should be in relation to assisted dying in Australia.

Life

The fundamental importance of human life is recognised by our legal system. The criminal law in all States and Territories makes the killing of another person unlawful unless it is authorised, justified or excused.[68] It also makes assisting another person to commit suicide unlawful.[69] Further, the value of human life is recognised by the common law, as revealed in court decisions about whether to permit the withholding or withdrawal of potentially life-sustaining treatment. In the landmark case of *Airedale NHS Trust v Bland*,[70] for example, the House of Lords accepted that 'sanctity of life' formed part of the English legal system and Australian courts have also recognised the state's interest in preserving human life.[71]

The value of life can be upheld through prohibiting assisted dying and this is the principal way in which this value is drawn upon in current debates. However, there is a sense in which the value of life can be advanced through *permitting* assisted dying. This was recognised by the Supreme Court of Canada in *Carter v Canada (Attorney General)*,[72] which held that the current blanket prohibition on assisted suicide breached the right to life. The court's reasoning included that, where suicide is legally permitted but assisted dying is not, some individuals may die earlier than they would if assisted dying were permitted – that is, they may commit suicide before they would request

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[67] We do not, here, discuss the value 'dignity' because it is relied on to justify opposite conclusions on end-of-life issues by all sides of the debate. There is also no agreed on definition. We believe that the debate about end-of-life decision-making can more usefully proceed by setting aside the term 'dignity' and instead focusing on the concepts that most commonly lie behind it – that is, equality and autonomy. We take this position for the reasons articulated in Udo Schuklenk et al, 'End of Life Decision Making in Canada: The Report by the Royal Society of Canada Expert Panel on End of Life Decision-Making' (2011) 25 *Bioethics* 1, 38-45.

[68] LexisNexis, *Halsbury's Laws of Australia* (at 18 November 2016) 130 Criminal Law, '3 Homicide' [130-3000].

[69] LexisNexis, *Halsbury's Laws of Australia* (at 5 September 2016) 80 Civil and Political Rights, '2 Civil Rights', '2 Right to Life' [80-920].

[70] [1993] AC 789, 859.

[71] See, eg, *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, [5]-[16]; and more recently a reference by a majority of the Australian High Court in *Patel v The Queen* (2012) 247 CLR 531, [87] to 'the value the law places on human life'.

[72] [2015] 1 SCR 331.

assisted dying because they fear losing the physical capacity to commit suicide and being trapped with no way out.[73]

Furthermore, preserving human life is not an absolute value. The law in Australia (and indeed in many common law jurisdictions throughout the world) recognises that the value of an individual's life can sometimes be outweighed by the disvalue of their suffering. In other words, a person may decide that life is no longer worth living to them. For this reason, the law allows a competent individual to refuse treatment, even if that treatment is necessary to preserve life and is recommended by doctors.[74] Where a person has completed a valid advance directive,[75] and, in some cases, where a substitute decision-maker refuses treatment,[76] the law also allows treatment to be withheld from a person who lacks decision-making capacity. While we, as a society, recognise the intrinsic value of life and the possibility of instrumental value for life (for the individual and those the individual cares about), we already acknowledge that, for some individuals who are enduring suffering that is unacceptable to them, other values can outweigh the intrinsic and instrumental value of their life.

Autonomy

The principle of respect for autonomy is a fundamental part of Australian common law. In the High Court case of *Stuart v Kirkland-Veenstra*,[77] Gummow, Heydon and Hayne JJ recognised, in the context of a negligence action, 'an underlying value of the common law which gives primacy to personal autonomy' and observed that personal autonomy is 'a value that informs much of the common law'.[78] The value of autonomy is also a core value in the context of health law. It prevails over the value of life when a competent adult, for whatever reason, refuses medical treatment even if that treatment is needed to stay alive. In *Brightwater Care Group (Inc) v Rossiter*,[79] Martin CJ refers to the 'common law principle of autonomy and self-determination' and also notes that the principle is 'well established at common law'.[80] In that case, a man with quadriplegia was being kept alive by the delivery of artificial nutrition and hydration, and decided that he no longer wished to receive such medical treatment. The Western Australian

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[73] Ibid [57]-[58].

[74] See, eg, *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84; *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449; *Auckland Area Health Board v Attorney-General (NZ)s* [1993] 1 NZLR 235, 245; *Smith v Auckland Hospital Board* [1965] NZLR 191, 219.

[75] See generally Lindy Willmott, Ben White and Shih-Ning Then, 'Withholding and Withdrawing Life-Sustaining Medical Treatment' in Ben White, Fiona McDonald and Lindy Willmott (eds), *Health Law in Australia* (Thomson Reuters, 2nd ed, 2014) [14.100] (the common law), [14.150]-[14.170]; Lindy Willmott, Ben White and Ben Matthews, 'Law, Autonomy and Advance Directives' (2010) 18 *Journal of Law and Medicine* 366. See also *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88 which recognised the right of a competent adult to make a binding advance directive.

[76] See generally Willmott, White and Then, above n 75, [14.180]-[14.230].

[77] (2009) 237 CLR 215, [87].

[78] Ibid [88]. See also, eg, *Cole v South Tweed Heads Rugby Club* (2004) 217 CLR 469, [14] (Gleeson CJ); *Perre v Apand Pty Ltd* (1999) 198 CLR 180, [88] (McHugh J).

[79] (2009) 40 WAR 84, [48].

[80] Ibid [24]. For other examples, see *H Ltd v J* (2010) 107 SASR 352, 369 and the heading 'Common law right to self-determination' at 364; and *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, [5].

Supreme Court recognised his right to self-determination and that this prevailed over the state's interest in keeping him alive.

Although the law prioritises autonomy over life in decisions to refuse medical treatment, the current legal position is reversed if a competent adult seeks assistance to end his or her life in the context of assisted dying. The criminal law prohibits this assistance, and the fact that the person requests help to end his or her life (in the exercise of his or her autonomy) does not alter the legal position. This anomaly begs the question about the different possible meanings of the term 'autonomy' in law.[81] In the context of refusals of treatment, autonomy has generally been interpreted in Australia as the narrow right to prevent physical interference with one's bodily integrity.[82] This is what requires a refusal of treatment to be respected at law. A wider view, a right to self-determination, involves having one's will respected and acted upon and would include the ability to receive assistance to die.[83]

These different views about what autonomy might mean do not detract from accepting autonomy as an appropriate value to underpin decisions about regulation of assisted dying; rather, they point to the need to clarify which sense of respecting autonomy is meant. We consider that it is the latter view of autonomy – as self-determination – that should inform regulation of decision-making for a person who is approaching the end of their life and enduring intolerable suffering. The case for embracing autonomy as self-determination starts with how autonomy is understood in contemporary Australian society. It is unlikely that Australians understand autonomy in the narrow sense of only preserving bodily integrity; if asked, they would talk in terms of the broader concept of self-determination. We note that this wider approach was also adopted by the Victorian Legislative Council Legal and Social Issues Committee when articulating the core values that they believed should underpin end-of-life care.[84] And while the narrow view has received firm and unwavering support in law, this has occurred in the context of cases involving *refusals of treatment*. The narrow view is sufficient for deciding these cases so it is not surprising that they have been confined in this way. Judges are inclined to

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[81] In philosophy, it has even more different meanings. For example, contrast the conception of autonomy articulated by John Stuart Mill (a liberal individualist) in *On Liberty* (Longman, Roberts & Green, Edinburgh, 4th ed, 1869) with that articulated by Susan Sherwin (a feminist relational theorist) in 'A Relational Approach to Autonomy in Health Care' in Susan Sherwin (ed), *The Politics of Women's Health: Exploring Agency and Autonomy* (Temple University Press, Philadelphia, 1998) 19.

[82] See, eg, *Secretary, Department of Health and Community Services (NT) v JWB and SMB (Marion's Case)* (1992) 175 CLR 218, 232-233, 265, 309-310; *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, [5], [17]; *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84, [23], [24], [26], [31]-[32].

[83] Although in the context of decisions to withhold or withdraw potentially life-sustaining medical treatment, see Loane Skene, 'Disputes about the Withdrawal of Treatment: the Role of the Courts' (2004) 32 *Journal of Law Medicine and Ethics* 701, where she comments on the narrow and wide interpretations of the concept of autonomy. The wider approach to autonomy, again in the context of requesting potentially life-sustaining treatment, was adopted by Munby J at first instance in *R (Burke) v General Medical Council* [2005] QB 424, [130] where he commented that Art 8 of the *Human Rights Act 1998* (UK) means that it is for a competent patient to decide the treatment he or she should or should not be given. Note, however, Munby J's decision and this more expansive approach to autonomy were overturned by the Court of Appeal: *R (Burke) v General Medical Council* [2006] QB 273.

[84] Legislative Council Legal and Social Issues Committee (Vic), above n 3, xxi.

decide cases on the narrowest possible basis and so this should be taken only as silence about, and not rejection of, autonomy as self-determination.[85]

We consider that, given society's understanding of autonomy as self-determination (which is reflected in the approach of the Victorian Parliamentary Committee),[86] the value of autonomy proposed here should be understood in the wider sense of having one's will respected and acted upon. As with all values, however, promoting self-determination is not unqualified and is subject to the claims of other competing values.

Freedom of conscience

Conscience is a value recognised generally by the Australian legal system[87] and respecting the conscience of health professionals in particular is also reflected in law.[88] Further support for conscience is found in position statements of peak medical bodies which endorse the need for doctors to be able to practise medicine in accordance with their conscientiously held beliefs.[89] The value of conscience suggests that doctors (and other health professionals) should not be required to participate in assisted dying where doing so is contrary to their conscience.

While the conscience of health professionals who oppose assisted dying and the need to protect them from an obligation to practise contrary to their beliefs are important and have been prominent in the Australian debate, the right to act according to conscience is not absolute. It can be overridden where competing values require. An example is a competent refusal of potentially life-sustaining treatment. Here, the law requires that such treatment not be given, notwithstanding that a doctor may conscientiously believe that this is wrong because the patient will die without treatment.[90]

We also note that conscience can tilt toward *permitting* assisted dying. Some health professionals want to be able to provide assisted dying as they believe it is a part of good end-of-life care.[91] Some believe that they would fail in their duty to their patient

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[85] For example, in *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84, [20], the judge explicitly noted that 'I should only answer questions directly and explicitly raised by the facts of this particular case, and refrain from making any observations with respect to any other hypothetical scenarios'.

[86] Legislative Council Legal and Social Issues Committee (Vic), above n 3, xxi.

[87] *International Covenant on Civil and Political Rights*, opened for signature 16 December 1966, 999 UNTS 171 (entered into force 23 March 1976) Art 18 (signed by Australia on 18 December 1972 and ratified on 13 August 1980); *Charter of Human Rights and Responsibilities Act 2006* (Vic) s 14; *Human Rights Act 2004* (ACT) s 14.

[88] See, eg, the following with respect to abortion: *Criminal Law Consolidation Act 1935* (SA) s 82A(5)-(6); *Health Act 1911* (WA) s 334(2); *Health Act 1993* (ACT) s 84; *Medical Services Act* (NT) s 11(6)-(7).

[89] See, eg, Australian Medical Association, *Position Statement on Conscientious Objection* (28 November 2013), <https://ama.com.au/position-statement/conscientious-objection-2013>; Australian Nursing and Midwifery Federation, *Policy on Conscientious Objection* (February 2015), <http://anmf.org.au/documents/policies/P_Conscientious_Objection.pdf>; Medical Board of Australia, *Good medical practice: a code of conduct for doctors in Australia* (March 2014) [2.4.6], <http://www.medicalboard.gov.au/Codes-Guidelines-Policies/Code-of-conduct.aspx>.

[90] *Re B (Adult: Refusal of Medical Treatment)* [2002] 2 All ER 449, 475; *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84, [24]-[25]; *Hunter and New England Area Health Service v A* (2009) 74 NSWLR 88, [17].

[91] See, eg, College des Medicins du Quebec *Physicians, Appropriate Care and the Debate on Euthanasia: A Reflection* (2009) 2, 7, <http://www.cmq.org/publications-pdf/p-1-2009-10-01-en-medecin-soins-appropries-debat-euthanasie.pdf>.

not to assist them to die. Even in Australia where the practice is unlawful, a small number of doctors have admitted to assisting their patients to die in a bid to relieve their suffering.[92] In a rare (and famous) case a doctor, Dr Cox, was prosecuted and ultimately convicted of attempted murder following the death of his patient. Five days before her death, Dr Cox's patient pleaded for an injection to end her life. Three days later, Dr Cox wrote in his notes: 'She still wants out and I don't think we can reasonably disagree'.[93] The current law prohibits these health professionals from following their conscience and assisting their patients to die.

Thus, while respecting conscience is important,[94] we need to recognise that everyone's consciences are implicated in assisted dying policy decisions. This points to a permissive regime that does not compel health professionals to assist individuals to die, but also does not prevent health professionals from providing that assistance in certain circumstances.

Equality

The Australian legal system has made significant commitments to the value of equality through becoming a signatory to the Convention on the Rights of Persons with Disabilities,[95] and passing human rights[96] and anti-discrimination legislation.[97] These instruments endorse equality and reject discrimination, including discrimination on the basis of disability. The rule of law (which underpins the Australian legal system and itself a core value which is discussed below) also requires that the law treat people equally.[98]

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[92] See, eg, the media report by Julia Medew, 'Doctor admits giving dying man the drugs to end his life' that Dr Rodney Syme admitted giving a terminally-ill man Nembutal before the man's death: *The Age* (online), 28 April 2014, <http://www.theage.com.au/victoria/doctor-admits-giving-dying-man-the-drugs-to-end-his-life-20140427-zr07i.html>. See also an open letter to *The Age* newspaper calling for euthanasia law reform by seven Melbourne doctors in which they wrote: 'It cannot be right to tolerate this totally unsatisfactory situation, where it is a matter of chance whether patients will receive the treatment which they so desperately seek and where it must be only a matter of time before some doctor is prosecuted by the state for following the dictates of his conscience': 'Helping Patients to Die', *The Age*, 25 March 1995.

[93] Dr Cox's patient, Mrs Boyes, had suffered from acute rheumatoid arthritis for 20 years, had 'developed ulcers and abscesses on her arms and legs, a rectal sore penetrating to the bone, fractured vertebrae, deformed hands and feet, swollen joints, and gangrene from steroid treatment': C Dyer, 'Rheumatologist Convicted of Attempted Murder' (1992) 305 *British Medical Journal* 731, as cited in Roger Magnusson, *Angels of Death: Exploring the Euthanasia Underground* (Melbourne University Press, Melbourne, 2002) 25.

[94] Jocelyn Downie and Francoise Baylis, 'A test for freedom of conscience under the Canadian Charter of Rights and Freedoms: Regulating and litigating conscientious refusals in health care' (2017) 11(1) *McGill Journal of Law and Health* 51.

[95] The *Convention on the Rights of Persons with Disabilities*, opened for signature 30 March 2007, 2515 UNTS 3 (entered into force 3 May 2008), signed by Australia on 30 March 2007 and ratified on 17 July 2008. Pursuant to this Convention, States Parties agree to prohibit all discrimination on the basis of disability (Art 5: Equality and Non-Discrimination).

[96] *Charter of Human Rights and Responsibilities Act 2006* (Vic); *Human Rights Act 2004* (ACT).

[97] See, eg, *Disability Discrimination Act 1992* (Cth); *Anti-Discrimination Act 1977* (NSW); *Anti-Discrimination Act 1991* (Qld); *Equal Opportunity Act 1984* (SA); *Equal Opportunity Act 1984* (WA).

[98] See, eg, the second key principle identified by the Law Council of Australia in their Policy Statement on the Rule of Law: Law Council of Australia, *Policy Statement: Rule of Law Principles* (March 2011), <https://www.lawcouncil.asn.au/lawcouncil/images/LCA-PDF/a-z-docs/PolicyStatementRuleofLaw.pdf> (discussed further below). See also Thomas Bingham, *The Rule of Law* (Penguin, London, 2010) ch 5.

Equality is implicated in the assisted dying discussion in various ways – both in terms of whether assisted dying laws should be introduced, and also the substantive content of those laws. In terms of whether assisted dying should be allowed, we note that individuals without disabilities are able to end their suffering through suicide. But this option may not be open to some individuals who have a physical disability that prevents them from doing so. Prohibiting assisted dying can thus be seen as offending the value of equality through discrimination on the basis of physical disability.[99]

We turn next to how the value of equality can influence the nature of regulation. First, similar to the point above, a legislative framework that is limited to physician-assisted suicide, and so requires the individual to administer the medication themselves, discriminates against those whose disability does not allow them to do this. Limiting assisted dying in this way would be inconsistent with the value of equality. Secondly, we believe that having a disability should not of itself prevent a person from receiving assistance under assisted dying legislation. That is, if the person satisfies the eligibility requirement of 'medical condition', he or she should not be regarded as ineligible because that medical condition results from a disability. More will be said on this later.

Rule of law

The Australian legal system is built upon the rule of law.[100] There is no universally accepted definition of the rule of law, and the concept is generally regarded as incorporating a range of principles that are fundamental to a liberal western democracy. The rule of law has ancient origins, but the modern concept encompasses important principles including the separation of powers between the judiciary, executive and legislature; the equal application of laws to all; and procedural requirements, such as the availability of a fair hearing.[101] In 2011, the Law Council of Australia produced a

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[99] Support for this position can be found in the judgment of Smith J at first instance in *Carter v Canada (Attorney General)* [2012] BCSC 886, [1158]-[1159]: 'The law, viewed as a whole, embodies the following principles: (1) persons who seek to take their own lives, but fail, are not subject to criminal sanction because there is no longer a criminal offence of suicide or attempted suicide; (2) persons who are rendered unable, by physical disability, to take their own lives are precluded from receiving assistance in order to do so by the *Criminal Code* offence of assistance with suicide. Those principles create a distinction based on physical disability. The effect of the distinction is felt particularly acutely by a subset of persons with physical disabilities represented by the plaintiff Gloria Taylor and others such as Mr Fenker (now deceased), Mr Morcos and Ms Shapray – persons who are grievously and irremediably ill and physically disabled or will soon become so, are mentally competent, have full cognitive capacity, and wish to have a measure of control over their circumstances at the end of their lives. They may not wish to experience prolonged pain. They may wish to avoid the anxiety that comes with fear that future pain will become unbearable at a time when they are helpless. They may not wish to undergo palliative sedation without hydration or nutrition for reasons including concern for their families, fear for themselves or reaction against the total loss of independence at the end of their lives.'

[100] Westlaw AU, *The Laws of Australia* (at 26 April 2017) 21 Human Rights, '1 Development and Recognition of Human Rights' [21.1.140]; Peter Bailey, *The Human Rights Enterprise in Australia and Internationally* (LexisNexis, Sydney, 2009) 242-253; John Toohey, 'A Government of Laws, and Not of Men?' (1993) 4 *Public Law Review* 158, 168-169. See also *Patel v Chief Executive of Department of Labour* [1997] 1 NZLR 102, 110-111; *Australian Communist Party v Commonwealth* (1951) 83 CLR 1, 60-61.

[101] Brian Z Tamanaha, *On the Rule of Law: History Politics and Theory* (Cambridge University Press, Cambridge, 2004) 33. See also Bingham, above n 98.

policy statement setting out its formulation of the key principles comprising the rule of law in the Australian context.[102]

There are two important dimensions to the rule of law that are particularly important to the assisted dying debate: key principles one and two from the Law Council's policy statement. The first key principle is that the 'law must be both readily known and available, and certain and clear'.[103] This principle continues:

> The intended scope and operation of offence provisions should be unambiguous and key terms should be defined. Offence provisions should not be so broadly drafted that they inadvertently capture a wide range of benign conduct and are thus overly dependent on police and prosecutorial discretion to determine, in practice, what type of conduct should or should not be subject to sanction.[104]

This component of the rule of law is important if a decision is made to allow assisted dying. Any regulatory regime should provide sufficient clarity so individuals (health professionals and those seeking assistance) understand how the regime operates and can assess the implications of the regime for him or herself. That is, the scheme should have clearly expressed legal parameters.

Allied to this requirement is the need for regulation to have in-built protections to ensure that it is operating in the manner intended by parliament. For example, there would need to be appropriate safeguards to ensure that only individuals who are eligible receive assistance to die. Further, there should be robust oversight systems in place both in terms of reviewing individual cases for regulatory compliance, but also to address any systemic issues that may arise in relation to non-compliance.

The second key principle identified by the Law Council is that the 'law should be applied to all people equally and should not discriminate between people on arbitrary or irrational grounds'.[105] There are two aspects of this principle that are relevant in the assisted dying context. The first is determining who should be eligible to receive assistance under the legislation. For example, if a decision is made that individuals with a specified 'medical condition' are eligible, there would need to be 'a demonstrable and rational basis'[106] for excluding people who had such a medical condition from the ambit of the legislation. Different treatment of a person or group of individuals (such as those with a disability) without a rational basis would breach the rule of law. This aspect of the rule of law links with, and supports, the value of equality outlined above.

The second aspect of this principle is that 'no one should be regarded as above the law and all people should be held to account for a breach of law, regardless of rank or station'.[107] This means that compliance with law matters and further supports the case for safeguards and oversight to ensure that the law is being followed.

Protecting the vulnerable

A further value found within Australian law is protecting vulnerable persons within the community. For example, the High Court has recognised that vulnerability, albeit a

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[102] Law Council of Australia, *Policy Statement: Rule of Law Principles*, above n 98.

[103] Ibid Key Principle 1.

[104] Ibid.

[105] Ibid Key Principle 2. See also Bingham, above n 98, ch 5.

[106] Law Council of Australia, above n 98, Key Principle 2.

[107] Ibid.

wider meaning of vulnerability in terms of an inability to protect oneself from another's failure to take reasonable care, is an important feature of tort law.[108] A narrower form of vulnerability and one more akin to that raised in assisted dying debates is also protected by the common law through the equitable doctrines that permit transactions involving undue influence and unconscionable transactions to be set aside.[109] Australian law also recognises the importance of protecting the vulnerable through adult guardianship law with all Australian States and Territories recognising only decisions made by competent adults and imposing duties on others to safeguard the interests of persons who are not able to make their own decisions.[110]

But it is the criminal law, with one of its central purposes being protection of the community,[111] which provides the strongest statement about the importance of protecting the vulnerable. An illustration of this are the criminal law duties imposed on certain people to provide the 'necessaries of life' to various vulnerable groups in their care who cannot secure these necessaries themselves.[112] Protecting the vulnerable from taking their own life through the encouragement or coercion of others is also at the heart of the criminal law prohibition on assisting a suicide.[113]

The nature of vulnerability and who is vulnerable are contested.[114] Vulnerability could arise in a range of ways including because of: personal (eg, family) or institutional (eg, treating health professionals or hospitals) relationships that could possibly lead to coercion or undue influence; age or disability (including cognitive disability); or inadequate access to resources including financial resources or medical care. This value aims to protect those who are vulnerable to ensure they are not accessing assisted dying regimes where that is not a genuine desire on their part. Caution is needed, however, to ensure that a person is not regarded as incapable of choosing assisted death just because they belong to a group that has traditionally been regarded as vulnerable. For example, there is a risk of paternalism and not respecting autonomy and equality if a person with a disability is judged as too vulnerable to be able to access the scheme simply by virtue of that disability.[115]

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[108] See, eg, the High Court cases of *Woolcock Street Investments Pty Ltd v CDG Pty Ltd* (2004) 216 CLR 515 and *Barclay v Penberthy* (2012) 246 CLR 258. See also Jane Stapleton, 'The Golden Thread at the Heart of Tort Law: Protection of the Vulnerable' (2003) 24 *Australian Bar Review* 135, 141-149.

[109] LexisNexis, *Halsbury's Laws of Australia* (at 29 October 2015) 185 Equity, '5 Unconscionable Transactions' [185-875].

[110] For an overview of the principles that govern how decisions are made on behalf of others under guardianship legislation, see Ben White, Lindy Willmott and Shih-Ning Then, 'Adults who Lack Capacity: Substitute Decision-Making' in White, McDonald and Willmott (eds), above n 75, [7.80]-[7.95].

[111] David Lanham et al, *Criminal Laws in Australia* (Federation Press, Sydney, 2006) ch 1B 'The Purposes of Criminal Law'.

[112] In relation to the common law, see *R v Taktak* (1988) 14 NSWLR 226. For the Code jurisdictions: Queensland: *Criminal Code* (Qld) s 285; Tasmania: *Criminal Code* (Tas) s 144; and Western Australia: *Criminal Code* (WA) s 262; Northern Territory: *Criminal Code* (NT) s 149.

[113] Margaret Otlowski, *Voluntary Euthanasia and the Common Law* (Oxford University Press, Oxford, 2000) 88, discussing the Canadian Supreme Court reasoning in *Rodriguez v Attorney General of British Columbia, Attorney General of Canada* [1993] 3 SCR 519.

[114] See, eg, *Seales v Attorney-General* [2015] NZHC 1239, [77]-[79]; David Mayo and Martine Gunderson, 'Vitalism Revitalized: Vulnerable Populations, Prejudice and Physician Assisted Death' (2002) July-August *Hastings Center Report* 17.

[115] Anita Silvers, 'Protecting the Innocents from Physician-Assisted Suicide: Disability Discrimination and the Duty to Protect Otherwise Vulnerable Groups' in Margaret P Battin et

This value requires that any legal response to assisted dying protect the vulnerable.[116] This justifies eligibility criteria and procedural safeguards to ensure that a person seeking assistance to die is able to make their own decision and does so free from pressure or coercion. However, the need to protect the vulnerable does not justify an absolute ban on assisted dying. Individuals who may be regarded as 'vulnerable' may want access to assistance to die, and the empirical evidence from permissive regimes around the world does not support the claim that the vulnerable cannot be protected.[117] While relevant studies have employed significantly different methods to gather data, they consistently find that groups who are generally regarded as 'vulnerable' are not more likely to access euthanasia or assisted dying:

In 2012, Rietjens et al published their findings from a systematic review of articles published over an 11-year period (1998-2009) that collected data about end-of-life decision-making and social factors of those who died.[118] They concluded that the administration of medication with a potential or certain life-shortening effect 'seemed generally to be practiced [sic] less often among the elderly, females and less-educated patients compared with younger, male or more educated patients'.[119] Another review of evidence was carried out more recently by Emanuel and colleagues.[120] Their study collected evidence about various aspects of euthanasia and assisted dying practices from a range of sources.[121] In terms of who is likely to access assistance to die, the researchers concluded that 'typical patients are older, white, and well-educated'.[122] Finally, a very recent published study by Blanke et al analysed 18 years of data collected in Oregon since the commencement of its legislation.[123] During this time, of

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al (eds), *Physician Assisted Suicide: Expanding the Debate* (Routledge, New York, 1998) 133, 133, 135.

[116] This is also the view of the Victorian Parliamentary Committee in its Core Values: Legislative Council Legal and Social Issues Committee (Vic), xxi.

[117] In addition to the studies described next, this also represents the view of the trial judge in *Carter v Canada (Attorney General)* [2012] BCSC 886, [852], [1242] (these findings were not disturbed by the Canadian Supreme Court who noted that the trial judge's findings were 'reasonable and open to her': *Carter v Canada (Attorney General)* [2015] 1 SCR 331, [109]).

[118] Judith AC Rietjens et al, 'Medical End-of-life Decisions: Does its Use Differ in Vulnerable Patient Groups? A Systematic Review and Meta-analysis' (2012) 74(8) *Social Science and Medicine* 1282. Note that, for the purpose of this study, 'the administration of medication with a potential or certain life-shortening effect' included the provision of medication for pain relief that could also have ended life, as well as euthanasia and assisting a suicide.

[119] Ibid 1282. Note that these findings are consistent with an earlier study by Margaret P Battin et al, 'Legal Physician-Assisted Dying in Oregon and the Netherlands: Evidence Concerning the Impact on Patients in Vulnerable Groups' (2007) 33(10) *Journal of Medical Ethics* 591, 594-596 which reviewed data in Oregon and the Netherlands over 9 years and 15 years respectively (the latter data drawing on four death certificate surveys conducted during this period). This study concluded that those who received assistance to die 'appeared to enjoy comparative social, economic, educational, professional and other privileges': ibid 591.

[120] Ezekiel J Emanuel et al, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada and Europe' (2016) 316(1) *Journal of American Medical Association* 79.

[121] The public literature was searched, including surveys from 1947 to 2016, with a focus on original data from three main sources: surveys providing data on attitudes and practices; data from jurisdictions that have legalised euthanasia and assisted suicide that have data on prevalence and practices; and death certificate studies in the Netherlands and Belgium: ibid 80.

[122] Ibid 79.

[123] Charles Blanke et al, 'Characterizing 18 years of the Death with Dignity Act in Oregon' (2017) *JAMA Oncology* (doi: 10.1001/jamaoncol.2017.0243).

the 1545 prescriptions that were written, 991 (64%) individuals died from ingesting the medication. Of those 991 individuals, 51.4% were men, 96.6% were white and 71.9% had some form of tertiary education.[124]

Reducing human suffering

The value of reducing human suffering is different from the preceding values in that it is specific to the end-of-life setting and is not a higher level concept that applies across a legal system like the values of autonomy, life or freedom of conscience. As such, its recognition in law derives from analysing the particular legal areas that deal with palliative care and the relief of pain and symptom management. The common law has given great weight to the relief of pain through the doctrine of double effect which permits the hastening of death through medication provided this is necessary to relieve pain and suffering, and it is the health professional's intention to relieve pain rather than cause the person's death.[125] As such, the doctrine recognises that the value of reducing human suffering may trump that of life in some circumstances.

The doctrine of double effect is likely to be part of Australian common law[126] and appears to have been recognised in the case of *Re Baby D (No 2)*.[127] Some States have also enacted a statutory excuse for criminal responsibility to ensure appropriate palliative care can be provided where that is needed to relieve pain.[128] The Australian Capital Territory even enacted a limited right to 'receive relief from pain, suffering and discomfort to the maximum extent that is reasonable in the circumstances'.[129]

These laws show clear policy support in Australian law for the value of reducing human suffering and this is also reflected in the Victorian Standing Committee on Legal and Social Issues report which included alleviating pain and suffering as one of its core values for end-of-life regulation.[130] This legal recognition is further bolstered by widespread medical,[131] ethical[132] and policy[133] endorsement of reducing pain and managing symptoms as being critical to good end-of-life care.

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[124] Ibid E3. Note that there was a typographical error in the version of the article published online on 6 April 2017. The corrected figure for the percentage of individuals who had some form of tertiary education was published on 4 May 2017: <http://jamanetwork.com/journals/jamaoncology/fullarticle/2624528>.

[125] Ben White and Lindy Willmott, 'Double Effect and Palliative Care Excuses' in White, McDonald and Willmott (eds), above n 75, [15.20].

[126] Ibid.

[127] (2011) 45 Fam LR 313.

[128] White and Willmott, above n 125, [15.30]-[15.110].

[129] *Powers of Attorney Act 2006* (ACT) s 86 and *Medical Treatment (Health Directions) Act 2006* (ACT) s 17. For a discussion of the likely interpretation of this 'right to pain relief', see White and Willmott, above n 125, [15.30].

[130] Legislative Council Legal and Social Issues Committee (Vic), above n 3, xxi.

[131] Australian Medical Association, *Position Statement on End of Life Care and Advance Care Planning* (5 September 2014) [1.2.3] and [3.5], <https://ama.com.au/system/tdf/documents/AMA_position_statement_on_end_of_life_care_and_advance_care_planning_2014.pdf?file=1&type=node&id=40573>.

[132] See, eg, the Australian Medical Association, *Code of Ethics* (2016) [2.1.15], <https://ama.com.au/system/tdf/documents/AMA%20Code%20of%20Ethics%202004.%20Editorially%20Revised%202006.%20Revised%202016.pdf?file=1&type=node&id=46014>.

[133] Australian Commission on Safety and Quality in Health Care, *National Consensus Statement: Essential Elements for Safe High Quality End of Life Care* (27 May 2015) [3.10], <https://www.

While recognising the value of reducing human suffering is not controversial, the weight it carries and how it interacts with other values can be. As has been already noted, the law has prioritised relieving pain (where that is the primary intention) even if this may hasten death, but it has stopped short of allowing suffering to be a justification for intentionally ending a person's life. As we explain further below, we consider that, in some circumstances, the value of reducing human suffering supports making assisted dying lawful.

A regulatory model that reflects core values

Legislative reform is needed to make assisted dying lawful

After considering the above core values, we consider reform is needed. Allowing assistance to die enables a competent adult to assess and balance the value of their life and the disvalue of their suffering and to exercise their autonomy. This promotes both the values of life and autonomy. The value of conscience can be promoted by allowing health professionals the freedom not to participate in assisted dying as well as through an appropriately constructed system for transfers of care. The regime should ensure access to assisted dying for competent adults (autonomy) and eligibility criteria must avoid unjustifiable discrimination, including on the basis of disability (equality and the rule of law). The value of the rule of law can also be promoted through clearly expressed legal parameters about access to assisted dying and establishing safeguards and oversight mechanisms to ensure the law is followed. A regime with adequate safeguards (which empirical evidence demonstrates can be effective) can also serve the value of protecting the vulnerable. By respecting a person's decision to seek assistance to end their life when they are experiencing intolerable suffering, the value of reducing suffering, as assessed by that person, is also promoted. In summary, these values demonstrate the need for reform and that their sometimes competing claims can be accommodated in a regime that permits and regulates assisted dying. We favour reform by way of legislation rather than prosecutorial guidelines or evolution through case law.[134] A carefully drafted statute is more likely to provide the clarity and certainty that is critical here (promoting the rule of law).

In the remainder of this section, we outline a proposed model for assisted dying that reflects and promotes the core values. In some cases, these values push in different directions and so we explain how we have balanced them against each other in arriving at a position (expanding on some of the discussion in the values section). We also note that, for some issues, the values provide a higher policy level direction for a legislative regime but do not provide guidance in relation to its specific details. To inform our thinking in these instances, we have reflected on all of the international legislative models, as well as the Act that operated briefly in the Northern Territory. We have also drawn on two of the proposals for reform that have currency in Australia: the *Death*

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safetyandquality.gov.au/wp-content/uploads/2015/05/National-Consensus-Statement-Essential-Elements-forsafe-high-quality-end-of-life-care.pdf>.

[134] Different ways in which changes to the law or practice could be achieved are discussed in Ben White and Lindy Willmott, 'How Should Australia Regulate Voluntary Euthanasia and Assisted Suicide?' (2012) 20 *Journal of Law and Medicine* 410, 427-432.

with Dignity Bill which was narrowly defeated in South Australia in November 2016, and the *Voluntary Assisted Dying Bill* which was tabled in the Victorian Legislative Assembly in September 2017 after an extensive process of consultation and review.

Nature of the model

Permissive or defence model[135]

A permissive decriminalisation model allows a person to assist another to end their life, but regulates the circumstances in which this will be lawful by setting out eligibility and procedural requirements as well as other safeguards. Most jurisdictions where assisted dying can be lawful adopt this model: the Netherlands, Belgium, Luxembourg, some jurisdictions in the United States (Oregon, Washington, Vermont, California and Colorado, Canada federally (amendments to their *Criminal Code*) as well as Quebec (under its separate legislation), and previously in the Northern Territory. Under the defence model, as in Montana, assisting someone to die remains unlawful, but a defence is created in certain circumstances.[136]

We favour a permissive model for the reasons outlined above as to why assisted dying should be permitted and regulated. In particular, we rely on the values of autonomy and reducing human suffering. Because allowing assisted dying is justified, we favour an approach that treats it as a lawful activity. By contrast, the defence model treats this assistance as prima facie criminal conduct. The framing of assisted dying as potentially lawful in a permissive model is also likely to provide more comfort to health professionals who are assisting people to die within the criteria prescribed by the regime. This model removes the stigma of the criminal law, and also the requirement of health professionals to satisfy an onus of proof to raise the relevant defence to avoid liability. Such an approach therefore removes a potential barrier for patients gaining access to what the core values conclude is a lawful and appropriate form of care.

Voluntary euthanasia, physician-assisted suicide, or both

Some models allow (or did allow) a doctor to participate in both voluntary euthanasia and physician-assisted suicide (see, eg, Canada, the Netherlands, and the Northern Territory). In the United States, however, the legislatures have adopted the more restrictive model of physician-assisted suicide. The Belgium and Quebec legislation, on the other hand, provides for voluntary euthanasia only (at least on its face).[137]

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[135] The authors note that a 'penalty mitigation' model has also been proposed under which minor fines are imposed for conduct that remains unlawful,provided certain procedural safeguards are observed: Willmott et al, above n 2, 33. Such models have not been in any enacted legislative regime to date.

[136] See, eg, *Criminal Law Consolidation (Medical Defences – End of Life Arrangements) Amendment Bill 2011* (SA). Note also Switzerland where, as discussed above, assisting a suicide for 'selfish' motives is an offence. If a person assists another to die and is charged under this provision, he or she must demonstrate that the assistance was provided for 'selfless' motives. Although the legislation does not contain a formal 'defence' provision, the legislation is more akin to a 'defence' model as it does not provide a regulatory framework to govern assisted death as occurs under the permissive models.

[137] Note that, in Quebec, this is referred to as 'medical aid in dying': *An Act Respecting End-of-Life Care*, RSQ c S-32.0001, s 3(6). In relation to Belgium, although the law does not expressly permit

The authors favour permitting both voluntary euthanasia and physician-assisted suicide. The value of autonomy grounds the suggestion that a person be able to choose to receive assistance to die either by a doctor directly providing that assistance or by enabling the person to bring about his or her own death. The value of equality would also favour access to both. Providing only physician-assisted suicide would unfairly exclude individuals who lack the physical ability to end their own life from assisted dying regimes. The value of life would also favour access to both as limiting access to assisted suicide could lead individuals to kill themselves earlier than they otherwise would in order not to become trapped in a body incapable of ending their own life.

Eligibility

There are four important aspects of eligibility to consider: competence; age; medical condition; and suffering.

Competence

It is the value of autonomy that primarily underpins our recommendation that assisted dying be permitted and a person must be competent to exercise that autonomous choice. This approach reflects most legislative models including those in the United States, Canada (both the federal and Quebec legislation),[138] and the repealed Northern Territory legislation which apply only to competent persons. However, this is not universally the case and in the Netherlands and Belgium, for example, a person can make a request for assistance to die in advance of losing their capacity. Despite the breadth of their legislation, however, we note that in practice it is not common for doctors to end a person's life after he or she has lost decision-making capacity and is not able to make a competent request for assistance to die.[139]

We consider that competent adults should be able to request assistance to die. Assisted dying for individuals who make a competent request to end their lives and later lose capacity is a complex issue, and is beyond the scope of this chapter.[140]

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assisted suicide, the practice does occur and is reported to the Federal Control and Evaluation Commission as such: see Bhatia, White and Deliens, above n 34, 836.

[138] We note though that in Canada the issue of advance requests for assisted dying is included in a statutorily mandated review the results of which must be placed before Parliament by December 2018.

[139] See, eg, Mette L Rurup, 'The First Five Years of Euthanasia Legislation in Belgium and the Netherlands: Description and Comparison Cases' (2011) 26(1) *Palliative Medicine* 43, 45. More recently, however, it was noted that in 2013 euthanasia based on an advance directive rose to 5.5% of all cases: Kenneth Chambaere et al, 'Recent Trends in Euthanasia and Other End-of-life Practices in Belgium' (2015) 372(12) *New England Journal of Medicine* 1179 (Supplementary Index).

[140] Some argue that a competent self does not have the moral authority to bind a (different) incompetent self: see, eg, Rebecca Dresser, 'Precommitment: A misguided strategy for securing death with dignity' (2003) 81 *Texas Law Review* 7; Rebecca Dresser, 'Dworkin on dementia: Elegant theory, questionable policy' (1995) 25(6) *Hastings Center Report* 32; Rebecca Dresser, 'Missing persons: Legal perceptions of incompetent patients' (1994) 46 *Rutgers Law Review* 609; Rebecca Dresser, 'Life, death, and incompetent patients: Conceptual infirmities and hidden values in the law' (1986) 28 *Arizona Law Review* 373. Others argue that the choice of the competent self should prevail over the later incompetent self: see, eg, Ronald Dworkin, *Life's Dominion: An Argument about Abortion and Euthanasia* (Harper Collins, London, 1993) and Ronald Dworkin, 'Autonomy and the demented self' (1986) 64 (Suppl 2) *Milbank Quarterly* 4. Other values can also be engaged

However, in this regard we observe that, over the past few decades in Australia, the focus of the debate has been on whether assisted dying should be allowed for competent adults, and there has been only very limited discussion about advance requests for assistance to die.

Age

Most of the legislative models limit (or limited) access to assisted dying to adults: Canada,[141] the United States jurisdictions and the Northern Territory. It is only in the Netherlands[142] and Belgium[143] where this is not the case. As argued above, we believe that a person seeking assistance to die should be competent. Because adults are presumed by our legal system to be competent, all adults would prima facie be eligible to access the regime unless doctors were satisfied of incompetence.

The more challenging issue of whether assistance to die should be available to children who satisfy the test of *Gillick* competence is, as noted in the introduction, beyond the scope of this chapter given the complexity of issues raised and that it has not been part of the Australian debate.

Medical condition

The values of autonomy and life are integral in determining when a person is sufficiently unwell to qualify for assistance to die.[144] Autonomy unfettered could suggest that any competent person[145] should be able to receive assistance to die if that were his or her choice regardless of whether or not they have a medical condition. But autonomy is constrained by the value of life (and other values such as the protection of the vulnerable), and so a more nuanced approach is needed. Allowing assisted dying is also partly grounded in the value of reducing suffering and so the regime should include suffering as an eligibility criterion.

We argue that the balancing exercise involving the value of life can change as circumstances change. A justifiable approach is to recognise that the state's interest in preserving life is weighty where a person is healthy, well and free from pain. But that interest is outweighed by other values such as autonomy and reducing suffering

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such as the value of protecting the vulnerable when considering providing assistance to die for a person who no longer has capacity to make that decision, or who may even express an (incompetent) desire to continue living.

[141] The Quebec legislation is also limited to adults. In Canada, the issue of mature minors is also part of the statutorily mandated review the results of which must be placed before Parliament by December 2018.

[142] As discussed above, pursuant to Art 2 of the *Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2002* (Netherlands), assistance is available to a minor between 16 and 18 years if the minor has a reasonable understanding of his or her interests and parents are involved in the decision-making, and also to a minor between 12 and 16 years if the child has a reasonable understanding and the parents agree with the decision.

[143] As discussed above, in 2013 the Belgian legislation was extended to permit access for children provided they have the 'capacity of discernment'.

[144] We note that the value of protecting the vulnerable is a critical value when formulating a legislative model around assisted dying. However, that value is better protected when considering 'safeguards' underpinning the regime and is dealt with below.

[145] Bearing in mind the restrictions suggested regarding age above.

when both: (1) the person has a condition that will inevitably cause death, and (2) the person too has formed the view that the value of his or her life is outweighed by the disvalue of his or her suffering (this second aspect is discussed further below). So the state's interest in preserving life would prevent a healthy and well person who is free from pain from having assistance to die as the value of life would prevail over autonomy and reducing suffering. However, the balance between these values shifts where a person has a medical condition that will cause their death and they do not want to continue living due to their suffering. In such a case, the value of life would yield to the collective weight of the values of autonomy (as expressed in that person's choice to die) and reducing suffering.

Drawing on this balancing exercise, we argue it is justifiable, based on the values expressed, to permit assisted dying but limit access to those who have a *medical condition that will cause their death* (we also propose that there must be intolerable suffering as well and this is discussed below). The values do not, however, provide guidance as to how this medical condition criterion should be operationalised. To do this, we consider existing assisted dying models and how they have functioned in practice.

There is considerable variation in the legislative models about the qualifying medical condition that a person must have, and whether the condition must result in the death of the person (or their death within a certain period). In some jurisdictions, there is a requirement that the person have a terminal illness and be expected to die within a specified period (often six months) as in the United States jurisdictions.[146] A causal and temporal requirement is also contained in the Victorian Bill as the person must have an 'incurable' condition that is 'advanced, progressive and will cause death', and is expected to cause death within 12 months. Other models require that the person have a serious and incurable condition *and* that the person be at the end of their life, without expressly requiring that there be a causal link between the two (Quebec). The relevant medical condition in Canada is that the person has a 'grievous and irremediable condition'. This condition is defined to mean that the person (among other things) has a 'serious and incurable illness', is in an 'advanced state of irreversible decline' and his or her 'natural death' is 'reasonably foreseeable'. In the South Australian Bill, the person had to have an 'incurable medical condition' that would cause the person's death. In Belgium, the person must have a 'medically futile condition' while in Netherlands legislation does not contain a required condition.

We favour requiring a 'serious and incurable medical condition that will cause the person's death'. A medical condition should be regarded as 'incurable' by reference to available medical treatment of a kind that is acceptable to the person. For example, if a patient with cancer has already undergone two rounds of chemotherapy, the condition should not be regarded as 'curable' if he or she does not wish to undergo further chemotherapy. For a range of reasons, we also do not impose a time limit or require a particular proximity to death. First, the balancing of values exercise undertaken above does not point to the need for a specified period of time. Secondly, it is difficult

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[146] In Oregon, for example, a person may request medication for the purpose of ending life only if he or she has a 'terminal illness'; 'terminal illness' is defined to mean 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months': *Death with Dignity Act*, Or Rev Stat § 127.80 2.01 and 1.01 (1994).

to predict with any certainty when a person is likely to die, making the eligibility certification a challenging if not impossible task for the doctor.[147] Thirdly, a practical harm that can occur when temporal limits are imposed is that people who have a relevant medical condition that will cause their death but are outside the relevant time period may choose to starve themselves until they are close enough to death that the time condition is satisfied.[148]

The proposed criterion will enable people with fatal illnesses such as cancer, motor neurone disease (MND) and dementia (provided he or she retains capacity) to obtain assistance to die. We note that the application of our proposed criterion would also include a person with a medical condition such as quadriplegia who required artificial nutrition and hydration to survive.[149] In such a case, the medical condition of quadriplegia would, without medical intervention (namely the artificial hydration and nutrition), result in the person's death. This criterion would therefore be satisfied if that person was of the view that the medical treatment was unacceptable to him or her and he or she would die as a result of not having it. This may be troubling to some, for example, on the basis that allowing access for people with a disability in this way would devalue their lives and those of others. However, the values of equality and the rule of law would argue against excluding a group of people who would otherwise fall within this criterion on the basis of disability. If a person with a disability has a medical condition which, if untreated, would result in death, and that person satisfies the other eligibility requirements, we consider there to be no justification for excluding that person from assisted dying should they choose it.

Nature of suffering

In our model, the person must be 'suffering' as well as meeting the 'medical condition' criterion to qualify for assistance to die. This is because, as noted above, where these criteria are both met, the values of autonomy and reducing suffering are engaged together to outweigh the value of life. Focusing on the issue of suffering, we argue that, where a person has intolerable suffering, it is open to them to conclude that the disvalue of continued life diminishes the weight that should be attached to the value of life and/or that the value of reducing suffering takes on increasing weight when balanced against the value of life.

The balancing of these values can also shed some light on how this criterion of 'suffering' should be conceptualised. First, because the above rationale for eligibility requires *both* suffering *and* a particular medical condition, it is appropriate to require that the suffering be *caused* by the medical condition or, we would argue, the treatment

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[147] See, eg, Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311; Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337; James Downar et al, 'The 'surprise question' for predicting death in seriously ill patients: a systematic review and meta-analysis' (2017) 189(13) *Canadian Medical Association Journal* E484.

[148] This issue is raised in Jocelyn Downie, 'Medical Assistance in Dying: Lessons for Australia from Canada' (2017) 16(1) *QUT Law Review* 84. See also Kate McKenna, 'Doctor-assisted death obtained by Sherbrooke man who starved himself to qualify', *CBC News* (online), 13 April 2016, <http://www.cbc.ca/news/canada/montreal/sherbrooke-man-hunger-strike-death-1.3529392>.

[149] This was the condition of Mr Rossiter in the case of *Brightwater Care Group (Inc) v Rossiter* (2009) 40 WAR 84 (discussed above).

of the medical condition. Suffering that arises from a cause unrelated to the medical condition that will lead to death is not sufficient to outweigh the value of life. Secondly, the degree of suffering must be sufficiently high and of an enduring nature for the values of autonomy and reducing suffering to trump the value of life. Suffering that is fleeting and not sustained would be insufficient. Similarly, suffering that is not significant, as judged by the individual (see further below), would not qualify.

We suggest 'intolerability' as an appropriate standard, but note that the legislative models employ a variety of different expressions to describe the standard of suffering required including 'unbearable' (Quebec, Netherlands and Belgium), 'severe' (Northern Territory), and 'intolerable' (South Australia and Canada).The requisite level of suffering is not set out in the Victorian Bill with the only requirement being that the relevant condition causes 'suffering'. For the most part,[150] relevant regimes recognise (either expressly or implicitly) that the patient should be the one to assess whether that standard of suffering is met, and we endorse this approach. Only a subjective assessment of the relevant standard of suffering promotes the value of autonomy.

Most models also require the suffering to be enduring, for example by stating that the suffering be 'constant' (Belgium and Quebec) or 'lasting' (Netherlands). The authors favour a model that requires the suffering to be 'enduring'.

The final issue to be resolved here is the nature of the suffering required (physical or broader). Here, the value of reducing human suffering is engaged. As a society, we care about individuals who are suffering as a result of a serious medical condition, and we strive to reduce their suffering. People can and do suffer in different ways: some physically and others psychologically. We argue that we should not distinguish between different kinds of suffering. Recognising only physical suffering would fail to adequately reduce suffering. We therefore favour a model that recognises suffering, whether that be physical, psychological, or existential, that is intolerable to the person. We note that this reflects the approach in most of the legislative models. Some models refer only to the term 'suffering' and it is clear from the context that the term encompasses more than physical pain (Northern Territory, Netherlands, Victoria and South Australia). Other models use express terms to include mental (Belgium) or psychological (Canada and Quebec) suffering.

To summarise then, we propose that the relevant threshold be that of 'intolerable' and 'enduring' suffering which can be physical, psychological or existential, caused by either the medical condition or the available treatment, and assessed by the individual him or herself. Only if these conditions are satisfied, would the values of autonomy and reducing suffering justifiably prevail over that of life.

Safeguards

A legislative framework permitting assisted dying must have appropriate checks and balances to ensure that only individuals meeting the eligibility criteria outlined above can receive assistance. These safeguards promote the value of the rule of law by establishing processes to ensure legal criteria are met. They also provide assurance that the value of life is promoted, and only overtaken by the values of autonomy

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[150] Note that, in the United States jurisdictions where the individual must have a 'terminal illness', there is no requirement for the person to demonstrate 'suffering'.

and reducing suffering for the limited class of individuals who satisfy the eligibility criteria. In so doing, these safeguards also play an important role in protecting the vulnerable so that only competent individuals acting voluntarily, having access to all relevant information, can seek assistance to die. Further, they ensure the request is truly an autonomous one and so promote the value of autonomy. Balance in designing safeguards is important. If they are too prescriptive (difficult to satisfy), the value of autonomy will not be promoted. And if they are too easily satisfied, there will be no confidence that the criteria of the legislation are being complied with which will undermine values such as those of life, protecting the vulnerable and the rule of law.

While the values lead us to the conclusion that robust safeguards are needed, they are of limited use in articulating precisely what those safeguards should be. So, in making the recommendations below, we are guided both by various legislative models as well as international experience regarding the effectiveness and operation of those safeguards. We address a number of safeguards that are routinely found in assisted dying models: who should be involved with ensuring that the eligibility requirements are satisfied and that the request is voluntary; information that should be provided to the person; and waiting periods or other measures for assessing the enduring nature of the request.

Assessment of eligibility regarding medical condition and suffering

International models have similar safeguards to ensure eligibility regarding the medical condition. In the Victorian, South Australian and Northern Territory models, two doctors must independently confirm the diagnosis and prognosis; in the Netherlands, Oregon and Quebec, two doctors must be involved (and under the federal Canadian law, the two practitioners can be either a doctor or a nurse practitioner); and in Belgium, two doctors assess eligibility although a third doctor is required if the person is not expected to die in the near future. In terms of suffering, although we recommend a model that intolerable suffering be assessed by the person, the doctors must also be satisfied that the person has reached this view. We favour a model which requires eligibility regarding the medical condition to be confirmed by two doctors who are independent of each other following an examination of the patient and review of the patient's medical record by each doctor. Both doctors should also confirm that the patient has assessed his or her suffering as intolerable.

Assessment of capacity and voluntariness of the request

Under the legislative models described above, this assessment is generally undertaken when eligibility about the medical condition is being considered. There is some variation across models though. For example, under the South Australian model, a psychiatrist must also be involved if there are concerns about capacity or the voluntariness of the request. Under the Victorian Bill, a referral must be made to a health practitioner who has 'appropriate skill and training' if there are concerns about decision-making capacity.[151] The authors recommend that two doctors must confirm the capacity of

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[151] There is no equivalent obligation to refer if the doctor has concerns about the voluntariness of the request.

the patient and the voluntariness of the request but, if there is doubt regarding either, a doctor with relevant expertise should also be involved to assess the patient and their request. Most cases will not give rise to such doubts so the two doctors dealing with other eligibility issues can adequately assess these matters. However, further and specialised assessment is needed to ensure the decision is truly autonomous where there are doubts about the person's capacity and/or the voluntary nature of his or her decision. This may be undertaken by a psychiatrist where he or she possesses the necessary expertise required for the case but it could also be undertaken by, for example, a geriatrician with particular experience in assessing capacity of older people.

Assessment of the enduring nature of the request

Autonomy is advanced where requests for assistance to die are settled and non-ambivalent. A model which acted on a fleeting or ambivalent request would also not uphold the values of life and protecting the vulnerable. We argue therefore that the request for assistance to die must be enduring. Most legislative models contain some mechanism to prevent assistance being given to a person after just one request. Some of the models (Northern Territory, South Australia, Oregon and Canada) set out waiting periods, while others indicate that the request must be settled in other ways (Victoria – request must be 'enduring'; Quebec – the wish is 'unchanged' and the doctor must talk to the patient 'at reasonably spaced intervals'; Belgium – request must be 'durable'). There is no waiting period in the Netherlands, the only requirement being that the request is 'well-considered'.

We propose that a person must make a formal request after doctors have assessed that person to be eligible, and that assistance to die be provided only after a specified time period passes after that request and the individual then reconfirms their desire for assistance. This delay and reconfirmation would provide confidence that the request was enduring. A period of 15 days is common in other legislative regimes and may be an appropriate time between an eligible request and the provision of assistance to die after reconfirmation.

However, the model should also contain discretion in limited cases both in relation to the specified period and the reconfirmation requirement where the doctors are satisfied that the request is enduring. For example, if the patient is expected to die before the specified period has passed, that time could be abridged if the doctor were satisfied that the request was an enduring one. Also, if the person loses capacity after making the formal request, for example as a result of receiving high doses of medication to relieve their pain, and so reconfirmation is not possible,[152] assistance should still be allowed provided the doctor remains satisfied of the enduring nature of the request.

Information to be provided

To promote the value of autonomy, the person should be provided with relevant information so that a request to receive assistance to die is fully informed. This is a feature of all legislative models. Although there are some minor variations across jurisdictions, generally doctors must provide the following information to the patient:

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[152] This issue is raised in Downie, above n 148.

the patient's diagnosis and prognosis; treatment options available and their likely results; palliative care options and their likely results; the medical procedure that will be used to assist a person to die and the likely risks and results; and that the person is able to rescind the request at any time. We recommend that legislation contain a requirement for two doctors to be satisfied that this information has been provided to the patient.

Oversight

An assisting dying regime needs robust oversight mechanisms to ensure that the framework operates as parliament intends. In doing so, this oversight promotes all of the values that underpin our proposed legislative model. But robust oversight mechanisms especially advance particular values. One is the rule of law. This value is promoted where oversight mechanisms monitor not only individual deaths but also any systemic issues that may arise when a legislative model is implemented. Oversight mechanisms also promote the values of life and protecting the vulnerable by reviewing the circumstances surrounding each death to ensure that assistance is provided only in accordance with the requirements of the legislation. The value of autonomy is promoted by reviewing evidence of an autonomous choice to seek assistance to die.

There are two main options for oversight mechanisms: prospective or retrospective review. As their description suggests, a prospective oversight mechanism requires an independent party to review the facts *before* the provision of assistance to die, while a retrospective model will review evidence after death occurs. There are also a range of possibilities in terms of the body that is charged with the oversight: should existing structures be used, or new bodies established?

As was the case for safeguards, while the articulated values point to establishing robust oversight mechanisms, they do not necessarily provide precise guidance as to what that system might look like. That said, we suggest that one value – reducing suffering – is relevant to the question of the timing of the review of decision-making. The proposed legislative model requires at least two independent doctors to be satisfied of eligibility, part of which is to be satisfied of the intolerable nature of the patient's suffering. Given this safeguard, the value of reducing suffering points us towards a retrospective model rather than requiring further delay for the person who is in this intolerable state while yet another body be satisfied that he or she is eligible to receive assistance.

In terms of the body charged with oversight, we considered a variety of established or proposed models. Under the Northern Territory and proposed South Australian models, deaths are monitored by the Coroner while, in Victoria, the Bill requires the doctor to notify the Registrar of Births, Deaths and Marriages of the death and the Registrar must, in turn, notify the Voluntary Assisted Dying Review Board. International models include reporting to a Regional Review Committee through a municipal pathologist (Netherlands), the Federal Control and Evaluation Commission (Belgium), the Department of Human Services (Oregon) and the Commission on End of Life Care (Quebec). Under all of these models, reporting of the assisted dying occurs retrospectively.

We favour the establishment of a new retrospective review body dedicated to overseeing an assisted dying regime. We do note that responsibilities for reviewing individual deaths and also systemic issues around the operation of the legislation align well with the existing responsibilities of the Office of Coroner. Coroners also currently have duties and powers in relation to investigating certain types of deaths as well as making recommendations about systems improvement arising from the deaths investigated. However, oversight by the Coroner is not our favoured approach primarily because we do not consider deaths that result from a practice that is recognised as lawful should be in the same category as 'reportable deaths' currently investigated by Coroners (which sometimes includes connotations of these deaths being 'suspicious').

By contrast, there are advantages of establishing a dedicated body (such as a review board) with sole responsibility for oversight of an assisted dying framework. This removes questions or associations of unlawful or inappropriate behaviour and the body's focus on assisted dying means it could be comprised of people with specific and relevant expertise in this area. The body's functions could include independent review of assisted dying cases (retrospectively), systems-level monitoring of the assisted dying regime (including the ability to make recommendations for systemic reform), and appropriate data collection and reporting.

Role of conscience

As discussed in the core values section, there is a long-recognised ethical principle that a doctor may refuse to provide a lawful medical service that is contrary to his or her conscience. Yet refusing to provide assistance to die has potentially significant implications for an eligible patient, particularly if the objecting doctor has been responsible for the patient's ongoing care or is the only doctor who could provide treatment for the patient due to location (eg, in regional and remote areas).

The value of conscience supports doctors not being required to participate in assisted dying where doing so contradicts their conscience (although, as we noted above, for some doctors conscience points to being able to provide assisted dying for patients). However, other important values compete with conscience. The value of autonomy is not promoted if a doctor is permitted to deny an eligible request for assistance to die on the basis of his or her views. The same is true for the value of reducing suffering if a patient with intolerable suffering is denied access to a lawful medical service. Finally, the value of equality is implicated. Some eligible patients may be less able to physically seek assistance elsewhere than others who, for example, may be able to discharge themselves from one doctor's care to travel to another doctor. Other equality considerations can also arise including the more limited access to medical care and an alternative doctor that can arise from living in a regional or remote area.

In balancing these conflicting values, we consider that a legislative model should excuse a doctor from participation if that is inconsistent with their conscience. However, an objecting doctor should be obliged to transfer the patient's care (including advising of the request for assistance to die) to a doctor who is willing to assist, and the state should establish a transfer of care system so as to protect the conscience of objecting doctors while ensuring access for patients. Such a position would respect the value of conscience but not allow it to trump the other values outlined above which require that eligible patients be able to access a lawful medical service.

Conclusion

Whether or not the law in Australia should be reformed to permit assistance to die is hotly contested. All would agree that individuals should receive the highest possible medical care as they approach the end of their lives. And, for the most part, good quality medical care should enable seriously ill patients to experience good deaths. However, that is not always the case, and some individuals experience intolerable suffering at the end of their lives. This suffering causes trauma to the patients themselves and their families, and can lead to distress for their treating teams. Consensus will never be reached on how the law should respond to calls for reform. There will always be tensions between those who believe that a law that permits intentional killing is wrong, and those who believe that such a law can not only be justified but is necessary in a compassionate society.

In this chapter, we have sought to move this debate forward in two ways. We have first articulated a set of core values that we believe should underpin how assisted dying is regulated, and then proposed a legislative model that seeks to promote and balance these values in a principled way. This chapter is published at a critical time in our history. Legislators across the country are determining whether or not assisted dying laws should be introduced, and the nature of those laws. We offer the values and model articulated in this chapter for their consideration.

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International Perspectives on Reforming End-of-Life Law

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INTRODUCTION

This book has shed light on how and why reform of law that regulates the end of life occurs. Law reform in any area can be challenging, but this is particularly so in relation to such a sensitive and complex field. The book drew together ten case studies from six jurisdictions (the United Kingdom, the United States, Canada, Australia, Belgium and the Netherlands) considering different aspects of end-of-life law reform. Some case studies were framed as practical ‘how to’ guides, providing direct lessons about how to achieve law reform. This perspective is novel because very little has been written articulating a ‘roadmap’ for reform in this area. Downie and Scallion’s analysis of how medical assistance in dying became part of Canadian law federally and the lessons for law reformers is one case study that does this. Another is the Kitzingers’ account of how their research and advocacy led to removal of a supposed requirement to obtain court approval before withdrawing artificial nutrition and hydration from certain patients.

Other case studies took a more conceptual approach to their analysis of law reform. For example, Orentlicher’s analysis of end-of-life law reform in the United States argues that moves to allow assisted dying are consistent with already existing values in the end-of-life field. Taking a different tack, Lewis charts how a law reform proposal for prior judicial approval for assisted dying can simultaneously attract support from both opponents and proponents of law reform, and yet fail to meet key regulatory goals.

Many of the case studies in this book are about law reform in relation to assisted dying. And we note at this point that this chapter will use this generic terminology of

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* The authors acknowledge that within the authorial team there is a diversity of views about what constitutes optimal end-of-life law. This includes differences in opinion about the various assisted dying models in operation internationally (and about assisted dying generally). The authors would like to acknowledge the helpful research assistance of Emily Bartels.

assisted dying (as explained in Chapter 1) unless the context requires otherwise.[1] This focus on assisted dying is not surprising given the current hive of activity on this distinct issue in many parts of the globe. But there are also three case studies outside that field which consider the regulation of withholding and withdrawing life-sustaining treatment: the Kitzingers' examination of the requirement for court approval to withdraw artificial nutrition and hydration in certain cases; Pope's analysis of the passing and subsequent challenges to the Texas Advance Directives Act (resolving medical treatment disputes that arise at the end of life); and Jackson's discussion of how the best interests test for medical decision-making evolved over time. This wider perspective is important because the issues that arise for assisted dying will be relevant for law reform of other areas of end-of-life law and vice versa. Nevertheless, given the focus on assisted dying in this book, much of the discussion below will necessarily focus on reform in the context of that issue.

The purpose of this final chapter is to draw together the themes that emerge from an analysis of these ten case studies. Although it is true, as noted in the opening chapter, that 'all politics is local',[2] there are patterns that emerge about end-of-life law reform that transcend jurisdictional boundaries and the particular case study being considered. This chapter employs the comparative law method[3] to explore these themes, as we can better understand our own individual law reform process by seeing it through different eyes. A global/comparative perspective enables us to realise that what may seem local and parochial is part of a wider movement of law reform internationally. In doing so, we aim to shed light on how and why law reform occurs in the end-of-life field, and by doing so to contribute to reflections about law reform more generally.

CONCEPTUALISING LAW REFORM

Before considering reform in the context of end-of-life law, it is important to acknowledge two conceptual points about law reform. The first is that, as noted in the book's opening chapter, the term 'reform' implies that the change proposed or occurring is a positive advancement in law.[4] But the case studies, and the wider

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[1] As outlined in Chapter 1, assisted dying is referred to using a variety of terms which differ by jurisdiction and ideological outlook (e.g. 'voluntary assisted dying', 'medical aid in dying' and 'euthanasia'). While authors have tended to use local terminology in their chapters, for the purposes of this comparative chapter, we will use the generic term 'assisted dying', as defined in Chapter 1, unless context requires otherwise.

[2] This was a famous saying of the former Speaker of the United States House of Representatives, Tip O'Neill: Andrew Heywood, *Politics*, 2nd ed. (New York, NY: Palgrave Macmillan, 2002), 157.

[3] Mark Van Hoecke, 'Methodology of Comparative Legal Research' (2015) December *Law and Method* 1–35.

[4] William H. Hurlburt, *Law Reform Commissions in the United Kingdom, Australia and Canada* (Edmonton: Juriliber, 1986), ch. 1.

literature on end-of-life law and bioethics, show that legal changes in this area are contested.[5] What one considers to be progress, others consider bad lawmaking. This is particularly evident in relation to assisted dying laws. It will be clear from this chapter and the case studies as a whole, that most, if not all, of the authors regard many of the reforms in this book as positive developments. Indeed, many actively advocated for change in the reform process described. Further, the academic work of many contributing authors also supports the reforms outlined in this book. We acknowledge therefore that law reform as a concept discussed in this book is not a value-neutral one.

The second conceptual point relates to the agent (or agents) *undertaking* law reform. In other words, who initiates law reform, who manages the reform process, and who is responsible for making decisions about matters such as whether or not to reform and if so, what change to law should occur? Traditionally, responsibility for law, and therefore law reform, has been seen as residing with the State, because ultimately law can be changed only by the State acting through parliament or the judiciary. If seen through this top-down lens, law reform is a State-led process in which non-State groups and individuals participate. Victoria's wide and inclusive reform process led by the Government, which ultimately resulted in the passing of its assisted dying laws, provides an excellent case study of this.

However, even accepting such a State-oriented reference point (and some do not),[6] non-State actors such as interest groups, organisations and individuals often play a critical role in law reform. While decisions about whether or not to change the law and what changes to make ultimately rest with the State, others can initiate and lead reform processes. In other words, while law reform can occur top-down, it may also be driven bottom-up.

Some of the case studies in this book provide examples of this. The Kitzingers' case study describes how they, as academics but also family members, initiated and drove a reform process aiming to change the supposed need for mandatory court supervision of some medical decisions in relation to patients with cognitive impairments. Similarly, the case of *Carter* v. *Canada (Attorney General)* ('*Carter*')[7] in Canada depended on individual litigants (supported by legal counsel and advocacy organisations) to initiate a challenge to the validity of the law as it then was, ultimately

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[5] See for example Emily Jackson and John Keown, *Debating Euthanasia* (Oxford: Hart Publishing, 2011).

[6] Regulation theorists are increasingly arguing that regulation (of which law is a part) is becoming decentred, with non-State actors being pivotal in regulating or guiding behaviour in society: see, for example, Julia Black, 'Decentring Regulation: Understanding the Role of Regulation and Self-Regulation in a "Post-Regulatory" World' (2001) 45 *Current Legal Problems* 103–46 at 103–4; Julia Black, 'Critical Reflections on Regulation' (2002) 27 *Australian Journal of Legal Philosophy* 1–35 at 1–2. This is perhaps truer when talking about regulation other than law (e.g. policy or guidelines) given that law, narrowly construed, generally remains the province of the State.

[7] *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

resulting in a change to that law. Bottom-up reforms cannot occur without the State, at least when they require legal reform. As noted, the State controls formal changes to law. But they do remind us that there can be many agents of change in law reform.

LAW REFORM CAN OCCUR THROUGH DIFFERENT REGULATORY PATHS

The two main paths for end-of-life law reform, as noted above, are legislative change or judicial change through the courts.[8] In terms of legislative reform, this may occur by passing a new piece of legislation or amending existing legislation. Most commonly, this occurs through parliament as illustrated, for example, in the cases of the Belgian, Victorian, Texan and Québec legislation. In some jurisdictions, new legislation could also come into force via a citizen or voter referendum, as occurred in Oregon in relation to its assisted dying laws and some of the other US states that followed those reforms, such as Washington and Colorado. It is also possible to have a combination of both. Although not one of the case studies in this book, in 2019, the New Zealand Parliament passed assisted dying legislation, which became law only because it was then approved by the public at a referendum during the country's election at the end of 2020.[9]

End-of-life law can also change through judicial decision. One of the case studies which provides an example of this is *Carter*[10] where the Canadian Supreme Court held that the blanket criminal law prohibition on assisting a person to die violated the Canadian Charter of Rights and Freedoms.[11] The Supreme Court's ruling meant that the federal parliament could not prohibit assisted dying when the conditions set out in the decision were met, for example, the person had a grievous and irremediable medical condition. This then prompted the federal parliament to develop a legislative framework for assisted dying.[12]

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[8] For a wider discussion of the various paths to law reform for assisted dying, see Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16 *QUT Law Review* 84–112. Another path has been proposed in some US states. Because the practice of medicine is largely self-regulated, some have argued for reform through evolution in the standard of care: Kathryn Tucker, 'Aid in Dying: An End-of-Life Option Governed by Best Practices' (2012) 8 *Journal of Health and Biomedical Law* 9–26.

[9] End of Life Choice Act 2019 (NZ), s. 2; Electoral Commission of New Zealand, '2020 General Election and Referendums: Referendums Results', https://electionresults.govt.nz/electionresults_2020/referendums-results.html.

[10] *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

[11] Canada Act 1982 (UK), c. 11, sch. B, pt. 1, ss. 7, 15 ('Canadian Charter of Rights and Freedoms').

[12] Montana's case, *Baxter* v. *State*, 224 P 3d 1211 (Mont. 2009), is another example of assisted dying becoming lawful through judicial decision, although of note is that this case did not prompt a legislative response as in Canada. A further example of judicial initiation of reform is in Colombia where a decision of its Constitutional Court (Sentence C-239 (1997), Ref. Expedient D-1490 (Constitutional Court of the Republic of Colombia, 20 May 1997)) eventually prompted further regulation to permit access to assisted dying: see Penney Lewis, 'Legal Change on Assisted Dying', in S. Westwood (ed.), *Regulating the Ending of Life: Death Rights* (London: Routledge, 2021) (in press).

In contrast to cases such as *Carter*,[13] which adjudicate on statutes, changes to the common law through judicial decisions tend to be more incremental. This is illustrated in Jackson's chapter describing the evolution of the best interests test in England and Wales, following codification of factors relevant to a best interests assessment in the Mental Capacity Act 2005 (England and Wales).

Although not law, how actors behave at the end of life is also affected by policy and/or guidelines, which can be alternative paths to reform.[14] One of the case studies described challenges to the practice direction of the Court of Protection in England and Wales which stated that court approval was required for certain decisions to withdraw artificial nutrition and hydration. The culmination of that advocacy was a UK Supreme Court decision, *Re Y*[15] that concluded approval was not required as a matter of course. The abolition of the practice direction through a Court decision, brought about at least in part by advocacy, represents a significant example of law reform.

Another example, although not considered in this book, is the development of prosecutorial guidelines[16] which set out the factors that the Director of Public Prosecutions in England and Wales should take into account when deciding whether a person will be prosecuted for assisting another's suicide. Although they have not changed the law that governs assisted suicide, they have brought greater clarity and transparency to the question of whether a person is likely to face prosecution for assisting a suicide.

As is clear from the above discussion, the paths to law reform overlap. For example, judicial cases have prompted the enactment of legislation (*Carter*[17]), the production of guidelines (*R (Purdy)* v. *Director of Public Prosecutions*),[18] or the

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[13] *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

[14] This can give rise to questions about what counts as law, but scholars are increasingly looking beyond the primary sources of law to include other normative forces in wider regulatory analyses about what shapes behaviour. See, for example, Black, 'Decentring Regulation', 103–4; Black, 'Critical Reflections on Regulation', 1–2.

[15] *An NHS Trust v. Y* [2018] UKSC 46.

[16] Director of Public Prosecutions, 'Suicide: Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide', Crown Prosecution Service, October 2014, www.cps.gov.uk/legal-guidance/suicide-policy-prosecutors-respect-cases-encouraging-or-assisting-suicide. These guidelines were created after the House of Lords ruled that the Director of Public Prosecutions must create offence-specific prosecutorial guidelines for assisted suicide: *R (Purdy)* v. *Director of Public Prosecutions* [2010] 1 AC 345. Critiques of these guidelines include: Ben White and Jocelyn Downie, 'Prosecutorial Guidelines for Voluntary Euthanasia and Assisted Suicide: Autonomy, Public Confidence and High Quality Decision-Making' (2012) 36 *Melbourne University Law Review* 656–705; Jocelyn Downie and Ben White, 'Prosecutorial Discretion in Assisted Dying in Canada: A Proposal for Charging Guidelines' (2012) 6 *McGill Journal of Law and Health* 113–72. See also Penney Lewis, 'Informal Legal Change on Assisted Suicide: The Policy for Prosecutors' (2011) 31(1) *Legal Studies* 119–34.

[17] *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

[18] *R (Purdy) v. Director of Public Prosecutions* [2010] 1 AC 345.

abolition of a court's practice directions (*Re Y*).[19] In addition, guidelines and policies can shape how both cases and legislation are interpreted and operationalised.[20] The interaction between these sources of law (and 'soft' law of policies and guidelines[21]) suggests that law reform efforts are not focused only on a single legal instrument. This discussion also suggests that law reform is not a finite/discrete exercise with a definite end point. Although the law, once reformed, may stay that way, it also may change again as one reform may be overturned, qualified or explained by other developments that follow (more on this below).

The existence of different paths to law reform invites reflection about the relative strengths and weaknesses of legislation, case law and policy or guidelines in bringing about effective change. For example, there can be limitations in relying solely on case law to reform end-of-life law, particularly in relation to assisted dying. Unless a judicial decision prompts legislative or other regulatory reform, or a substantial body of case law emerges, it may be difficult to craft a comprehensive regulatory system through a handful of court judgements, which inevitably focus on the individual case before the court. If it is accepted that it is appropriate to have a detailed process for oversight and reporting of assisted dying, legislation provides a more appropriate vehicle to do that.[22]

Downie and Scallion, in contrasting the federal Canadian law with the Québec experience, also conclude in favour of reform initiated by the legislature rather than through the courts. They argue that the Québec legislative journey provided an opportunity for significant consultation and reflection in developing the law rather than having reform forced upon a parliament which then has to react, possibly within a tight time frame. When reform is initiated by a parliament, it has greater autonomy in designing its preferred legal framework, rather than having its parameters determined by the courts.[23] However, parliaments may judge that the public will be more accepting of change if they wait until they are required to act by the courts.

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[19] *An NHS Trust v. Y* [2018] UKSC 46. Other overlap can be seen in this case, as formal guidance documents from leading medical bodies were explicitly acknowledged by the Supreme Court as part of the relevant regulatory framework considered in its deliberations: at [77], [107].

[20] See, for example, Canadian Association of MAID Assessors and Providers, 'The Clinical Interpretation of "Reasonably Foreseeable"', January 2019, https://camapcanada.ca/wp-content/uploads/2019/01/cpg1-1.pdf.

[21] 'Soft law' refers to quasi-laws, such as rules, policies or guidelines, which are not enforceable in a legal sense, but influence both the interpretation of primary and delegated legislation and public behaviour. See, for example, Greg Weeks, *Soft Law and Public Authorities: Remedies and Reform* (Oxford: Hart Publishing, 2016), 13–17.

[22] Of course, not everyone accepts that such a process is appropriate: Tucker, 'Aid in Dying', 9–26.

[23] See also Lewis, 'Legal Change on Assisted Dying'.

LAW REFORM IS MORE LIKELY TO SUCCEED WITH 'GOOD PROCESS'

Many of the case studies highlighted the importance of a good process in securing law reform, particularly those that occurred through legislation. There are a range of features that are generally agreed upon as being part of a 'good process' when making law or public policy. They include: an extended period of time for consideration; engagement with available evidence about current practice and the need for reform; open public and professional dialogue about reform; and clear communication with the community about the nature of the proposed reform.[24]

Some of these are discussed further below in other sections but it is widely agreed that at the heart of a good law reform process is broad and inclusive consultation.[25] As Willmott and White note in relation to the Victorian assisted dying reforms, two key purposes of consultation are optimal design of the law and building support for the law by involving key stakeholders in the process.[26] Consistent with reforms in areas outside of end-of-life law,[27] wide consultation has been significant for successful reform in the case studies considered. As noted already, the extended Victorian assisted dying reform process was rated positively[28] and this was an integral factor which facilitated the eventual passage of the legislation. Consensus-building processes were also regarded as being pivotal in the Texas reforms and in Québec.[29]

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[24] These (and other) elements are outlined in the 'Wiltshire Test: Ten Criteria for a Public Policy Business Case': Matthew Lesh, 'Evidence Based Policy Research Project' (2018 Institute of Public Affairs) 5–6; John H. Howard, 'Public Policy Drift: Why Governments Must Replace "Policy on the Run" and "Policy by Fiat" with a "Business Case" Approach to Regain Public Confidence' (2012 Institute of Public Administration Australia) vii–viii. For other discussions of 'good process' in making law or public policy see Michael Hallsworth and Jill Rutter, 'Making Policy Better: Improving Whitehall's Core Business' (2011 Institute for Government) 14; Andrew Wyatt, 'Policy Cycle Models: Are We Throwing the Baby Out with the Bath Water?', in Gemma Carey, Kathy Landvogt and Jo Barraket (eds.), *Creating and Implementing Public Policy: Cross-Sectoral Debates* (New York, NY: Routledge, 2016), 41–57.

[25] See, for example, Peter M. North, 'Law Reform: Processes and Problems' (1985) 101 *Law Quarterly Review* 338–58. See also the extended discussions of the importance of consultation for law reform in a range of settings in Brian Opeskin and David Weisbrot (eds.), *The Promise of Law Reform* (Leichhardt: The Federation Press, 2005).

[26] See also Peter M. North, 'Law Reform: The Consultation Process' (1982) 6 *Trent Law Journal* 19–31.

[27] See, for example, successful law reform efforts following extensive consultation in areas of Australian succession law and anti-discrimination law in Sarah Moulds, 'Community Engagement in the Age of Modern Law Reform: Perspectives from Adelaide' (2017) 38 *Adelaide Law Review* 441–62; and criminal law in Eurydice Aroney and Penny Crofts, 'How Sex Worker Activism Influenced the Decriminalisation of Sex Work in NSW, Australia' (2019) 8 *International Journal of Crime, Justice and Social Democracy* 50–67.

[28] Lesh, 'Evidence Based Policy Research Project'.

[29] Also of note, in Jersey, is a more recent innovation in participation in law reform processes for assisted dying through the proposed use of citizen juries: Government of Jersey, 'Jersey Assisted Dying Citizens' Jury', www.gov.je/Caring/AssistedDying/Pages/CitizensJuryOnAssistedDying.aspx.

The opposite was noted in relation to the Canadian federal law case study: a failure to consult with experts contributed to the drafting of the legislation being problematic, and a resulting negative response from many.

Hillyard and Dombrink's study of the Oregon assisted dying law reform process also identified the significance of engaging with stakeholders across a range of fields and the value of building a broad coalition of diverse stakeholders in support of the law.[30] But it is not just in the top-down legislative setting that good process is important. The Kitzingers' case study also involved building a coalition of supporters interested in challenging the requirement for court approval. They included health and legal practitioners and academics, as well as families of patients subject to this requirement. Recognising that reform can also be generated from the bottom-up, the principles of wide and inclusive consultation with all key stakeholders apply here as well.

Who to consult and involve in the law reform process is critical. One key group noted in some of the case studies was the medical profession. Doctors are integrally involved in providing end-of-life care, and medical associations and groups also wield considerable lobbying power in policy-making.[31] The technical knowledge and expertise of the medical profession empowers it both to support change or block it. The role and participation of medical organisations in end-of-life law reform has differed depending on their attitude or involvement in different countries, and the social and political roles of its organisations. (Indeed, this diversity in medical opinion on assisted dying exists among doctors as *individuals*, with palliative care specialists – at least in some countries – expressing opposition to reform at a higher rate than other specialties, whose views have tended to be more mixed.[32])

At one end of the spectrum, the medical profession has traditionally been seen as a major barrier to assisted dying reform, often by framing assisted dying as incompatible with professional medical ethics. For example, this has been the case in the United Kingdom and Australia, where the major medical associations have generally opposed reform.[33] At the other end of the spectrum, assisted dying reform in Québec

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[30] Daniel Hillyard and John Dombrink, *Dying Right: The Death with Dignity Movement* (New York, NY: Routledge, 2001).

[31] Jenny M. Lewis, *Health Policy and Politics: Networks, Ideas and Power* (East Hawthorn, Vic: IP Communications, 2005); Jenny M. Lewis, 'Being Around and Knowing the Players: Networks of Influence in Health Policy' (2006) 62 *Social Science and Medicine* 2125–36.

[32] C. Seale, 'Legalisation of Euthanasia or Physician-Assisted Suicide: Survey of Doctors' Attitudes' (2009) 23 *Palliative Medicine* 205–12; Linda Sheahan, 'Exploring the Interface between "Physician-Assisted Death" and Palliative Care: Cross-Sectional Data from Australasian Palliative Care Specialists' (2016) 46 *Internal Medicine Journal* 443–51.

[33] BMA, 'The BMA's Position on Physician-Assisted Dying: The BMA's Policy Position on Voluntary Assisted Dying and How It Has Been Reached', *British Medical Association*, 28 February 2020, www.bma.org.uk/advice-and-support/ethics/end-of-life/the-bmas-position-on-physician-assisted-dying; AMA, 'Euthanasia and Physician Assisted Suicide', Position Statement from the Australian Medical Association (2016 AMA), https://ama.com.au/system/tdf/documents/AMA%20Position%20Statement%20on%20Euthanasia%20and%20Physician%20Assisted%20Suicide%202016.pdf?file=1&type=node&id=45402. See also Jodhi Rutherford,

emerged from and was driven by the medical regulator, le Collège des Médecins du Québec. In that province, the conceptualisation of assisted dying in certain circumstances as being an act of care located this issue within the medical domain and, therefore, it was seen to be the responsibility of the professional regulator to address it. The importance of some support for reform within the medical profession is also seen in the case study examining the extension of the Belgium assisted dying law to minors. Hillyard and Dombrink also consider that careful engagement with the medical profession about the Oregon assisted dying law led to the neutrality of key medical groups who had traditionally opposed changing the law.[34]

A related theme is the use of experts[35] in law reform. The case studies from Victoria (which took an approach that Western Australia largely followed[36]), Québec, Belgium and the Netherlands all reported the engagement of experts in law reform processes in various ways such as the establishment of expert panels to advise governments or formal hearings with experts to share their knowledge. Expert participation is likely to have dual functions: it helps improve proposed decision-making about what sort of law to enact, but also lends credibility to the reform process and its resulting law. The Ministerial Advisory Panel established in Victoria to develop the legislative framework is a good example of this, particularly given it comprised respected leaders in diverse fields.

Experts can also be pivotal in reform through judicial cases. The *Carter*[37] litigation drew heavily on experts providing social science evidence that assisted dying

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'The Role of the Medical Profession in Victorian Assisted Dying Law Reform' (2018) 26 *Journal of Law and Medicine* 246–64. Ball also notes that some consider the American Medical Association as the strongest secular opponent to assisted dying reform in that country: Howard Ball, *At Liberty to Die: The Battle for Death with Dignity in America* (New York, NY: New York University Press, 2012).

[34] Hillyard and Dombrink, *Dying Right*. See also Ball's discussion of the role of medical groups in the historical analysis of law reform in the US: Ball, *At Liberty to Die*.

[35] We note though that while law reform processes have typically engaged doctors and academics as experts, who is considered an 'expert' is contested and changing. For example, patients and their carers or family members have been recognised as experts regarding their own care: Ian Kramer, 'Patients as Experts' (2005) 12 *Nursing Management* 14–15; Kerstin Blomqvist, Eva Theander, Inger Mowide and Veronica Larsson, 'What Happens When You Involve Patients as Experts?: A Participatory Action Research Project at a Renal Failure Unit' (2010) 17 *Nursing Enquiry* 317–23. Family members have also been found to be active participants in assisted dying decision-making: Bernadette Roest, Margo Trappenburg and Carlo Leget, 'The Involvement of Family in the Dutch Practice of Euthanasia and Physician Assisted Suicide: A Systematic Mixed Studies Review' (2019) 20 *BMC Medical Ethics* 1–21; Marianne C. Snijdewind, Donald G. van Tol, Bregje D. Onwuteaka-Philipsen and Dick L. Willems, 'Complexities in Euthanasia or Physician-Assisted Suicide as Perceived by Dutch Physicians and Patients' Relatives' (2014) 48 *Journal of Pain and Symptom Management* 1125–34.

[36] Final Report from the Ministerial Expert Panel on Voluntary Assisted Dying (2019 Government of Western Australia, Department of Health).

[37] *Carter v. Canada (Attorney General)* [2012] BCSC 886, affirmed by *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

systems can be implemented safely (this is discussed further below).[38] Experts can also have an important role to play *after* a relevant law has been passed. The ongoing evaluation of the assisted dying law described in the Netherlands case study is an example of how experts' assessment of a law's operation can determine whether changes in law and practice are required. Another example of expert review following legislative enactment is the work of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. The Expert Panel reported on issues flagged in the federal legislation for further review: access by mature minors, advance requests and access solely for mental illness.[39]

A law reform process can generate credibility in other ways. A key finding from the Victorian case study was the significance of the government, rather than a single member of parliament in their individual capacity, leading the assisted dying reform process. Assisted dying is generally treated as a conscience issue, so each member of a parliament is allowed to vote according to their conscience rather than according to party lines.[40] For example, conscience voting occurred in the Belgian law extension to minors, in Québec, and in Victoria (and indeed in all Australian parliamentary votes on this topic[41]). But even with the choice that a conscience vote provides for individual parliamentarians, it is significant if the carriage of the reform, including advocacy in support of (or at least explaining the justification for) change, has rested with the government rather than an individual. This obviously has implications for the likelihood of success if only because of the differential level of resourcing available for government-led reform. However, the fact that a government is leading reform, rather than an individual parliamentarian, also lends

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[38] Jocelyn Downie, 'Social Science and Humanities Evidence in Charter Litigation: Lessons from *Carter* v *Canada* (Attorney General)' (2018) 22 *The International Journal of Evidence and Proof* 305–13. Downie and Scallion's chapter in this book also notes that this evidence was critical in the subsequent case of *Truchon* v. *Attorney General of Canada* [2019] QCCS 3792 (CanLII), challenging Canada's federal legislation.

[39] 'The State of Knowledge on Medical Assistance in Dying for Mature Minors', Report from the Expert Panel on Medical Assistance in Dying (2018 Council of Canadian Academies); 'The State of Knowledge on Advance Requests for Medical Assistance in Dying', Report from the Expert Panel on Medical Assistance in Dying (2018 Council of Canadian Academies); 'The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder Is the Sole Underlying Medical Condition', Report from the Expert Panel on Medical Assistance in Dying (2018 Council of Canadian Academies).

[40] Note, however, that despite a conscience vote being offered, this may not always result in a free vote as informal party pressure can be brought to bear: Lindy Willmott and Ben White, 'Private Thoughts of Public Representatives: Assisted Death, Voluntary Euthanasia and Politicians' (2003) 11 *Journal of Law and Medicine* 77–92; Lindy Willmott, Ben White, Christopher Stackpoole, Kelly Purser and Andrew McGee, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39 *University of New South Wales Law Journal* 1–46 at 13–14; Alison Plumb, 'The Future of Euthanasia Politics in the Australian State Parliaments' (2014) 29 *Australasian Parliamentary Review* 67–86.

[41] Willmott et al., '(Failed) Voluntary Euthanasia Law Reform in Australia', 13.

credibility to the process. This shifts assisted dying from a fringe reform effort to the mainstream and one to be taken seriously.

LAW REFORM OFTEN REQUIRES COMPROMISE

Law reform, regardless of the topic, often requires compromise.[42] The analogy sometimes given is choosing between half a loaf of bread (an imperfect reform that is the subject of compromise) or starving (insisting on what might be an optimal model which fails to become law). Reform in the end-of-life field is no exception, and indeed there may be a greater imperative for compromise given the strong and vested interests as reflected in the historical difficulties in passing assisted dying legislation. How much to compromise, or indeed whether to compromise at all, is a challenging question and case studies in this book illustrate the sorts of compromises that might be needed to effect change.

In Belgium, for example, to secure agreement to expand the assisted dying laws to include access to minors, more restrictive eligibility criteria and additional safeguards for this cohort were included. Indeed, the issue of access for minors was the subject of compromise in the original 2002 law, and was excluded at that time to secure the necessary political support for law reform. Similarly, the Texas Advance Directives Act only passed because of negotiation and compromise amongst key groups which led to a new agreed model.

Legislative compromise is often the result of the necessity to generate sufficient political support for a law to pass. Both of the examples given above involved the formation of unusual coalitions. In Belgium, the coalition was between both government and non-government parties. For the Texas reforms, the Texas Advance Directives Coalition brought together a diverse group of organisations that might ordinarily be expected to have very different views such as medical and health care associations and disability, right to life and elder rights organisations. The process of reaching consensus required explicit compromise about the precise terms of the law.

One (unsurprising) outcome of compromise is the likelihood of settling on a narrow or conservative legal model. It is easier to gain the necessary political and public support for law reform that is modest and incremental. This was the case in Oregon where an assisted dying model was advanced that permitted only physician-assisted dying (i.e. writing a prescription for medication which the patient themselves must take rather than a physician administering that medication).[43] Similarly, the Victorian Premier, Daniel Andrews, proclaimed the Victorian assisted dying

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[42] See, for example, North, 'Law Reform: Processes and Problems', 338–58; Laura Barnett, 'The Process of Law Reform: Conditions for Success' (2011) 39 *Federal Law Review* 161–93.

[43] Hillyard and Dombrink, *Dying Right*.

legislation to be the most conservative model in the world.[44] The proposed requirement for prior judicial approval for assisted dying in the United Kingdom further illustrates the conservative results of compromise. In discussing the 'consensus' that appears to have emerged, Lewis observes that even proponents of assisted dying have accepted this arguably impractical requirement in the interests of gathering sufficient political support. A final example may also be the decision of the Canadian government to pass its federal assisted dying law, but identify for further review the issues of access for mature minors, access solely for mental illness and advance requests for assisted dying.

A second outcome of compromise is that it can lead to a failure to achieve desired regulatory goals. Lewis's analysis of the proposal for prior judicial review before assisted dying can be accessed demonstrates a failure to meet suggested regulatory goals. For example, the time taken for such a process may have the practical effect of precluding access for a person who typically seeks assisted dying, namely a cancer patient with a limited time to live. This disconnect between the law and its regulatory goals can occur because the decision to accept a particular compromise is a tactical, rather than a principled one. A recent analysis of the Victorian assisted dying law has also concluded that in some respects it has failed to align with its own publicly identified regulatory goals.[45] The recent experience in Canada also reflects a failure to achieve the required regulatory outcome. There were discrepancies between the principles that had to guide law reform (here, constitutional rights that the Supreme Court found had been breached by the Canadian criminal law which prohibited all forms of assisted dying) and the actual law passed by the Canadian parliament in response to the *Carter*[46] decision.[47]

LAW REFORM IS INCREASINGLY DEPENDENT ON EVIDENCE

One noteworthy trend, which perhaps features more prominently in law reform in the end-of-life area than in other legal contexts, is the use of evidence. Historically, lawmaking has not engaged with evidence in the same way as in other fields.[48]

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[44] Premier Daniel Andrews, 'Voluntary Assisted Dying Model Established Ahead of Vote in Parliament', Office of the Premier of Victoria, 25 July 2017.

[45] Ben P. White, Katrine Del Villar, Eliana Close and Lindy Willmott, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43 *University of New South Wales Law Journal* 417–51. US states are also considering whether their traditional safeguards are too burdensome and are unduly restricting access: see, for example, H.B. 2419, 2020 Leg., 66th Sess. (Wash. 2020) (studying barriers to the use of the Washington Death with Dignity Act: Death with Dignity Act, Wash Rev Code § 70.245 (2008) (Washington)).

[46] *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

[47] The legislation was found to have breached the Canadian Charter of Rights and Freedoms (the very same rights that were at the heart of *Carter* v. *Canada (Attorney General)* [2015] 1 SCR 331) in *Truchon* v. *Attorney General of Canada* [2019] QCCS 3792 (CanLII)).

[48] Jeffrey J. Rachlinski, 'Evidence-Based Law' (2011) 96 *Cornell Law Review* 901–24.

While evidence-based medicine,[49] evidence-based health policy[50] and evidence-based business[51] have all become established approaches in those fields, evidence-based approaches are yet to fully gain traction in the discipline of law. But this is changing and there are increasing calls for evidence-based lawmaking,[52] including in relation to end-of-life law and particularly assisted dying, which lends itself to fact-based arguments.[53]

This trend towards greater use of evidence in lawmaking is evident in many of the case studies considered in this book. Social science evidence about how assisted dying regimes operated in countries where it is lawful was the subject of extensive consideration by the trial judges in the *Carter* and *Truchon* v. *Attorney General of Canada* ('*Truchon*') decisions.[54] This research was tendered to the court and some of the experts who produced this research were called to give evidence and subject to cross-examination.[55] The trial judge in *Carter* explicitly based some of her findings on the evidence that it was possible to design a safe and effective assisted dying system.[56] These findings were not disturbed on appeal. This same evidence was also considered and relied upon by the parliamentary committees in the Victorian (and later Western Australian) reform processes. Evidence about the Oregon regime was also regarded as influential in supporting reform in subsequent US states. For example, when deliberating about assisted dying reform in Washington, Ball notes the significance of considering a decade of experience under Oregon's laws.[57] Finally, empirical evidence about the incidence of assisted dying in a country *before* it is lawful has also been influential in law reform. Evidence that assisted dying was already happening in Belgium prior to the 2002

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[49] David L. Sackett, William M. C. Rosenberg, J. A. Muir Gray, R. Brian Haynes and W. Scott Richardson, 'Evidence Based Medicine: What It Is and What It Isn't' (1996) 312 *BMJ* 71–2.

[50] Katherine Baicker and Amitabh Chandra, 'Evidence-Based Health Policy' (2017) 377 *New England Journal of Medicine* 2413–15.

[51] Vishwanath V. Baba and Farimah Hakem Zadeh, 'Toward a Theory of Evidence Based Decision Making' (2012) 50 *Management Decision* 832–67.

[52] See, for example, Rachlinski, 'Evidence-Based Law'; Scott Burris, Laura Hitchcock, Jennifer Ibrahim, Matthew Penn and Tara Ramanathan, 'Policy Surveillance: A Vital Public Health Practice Comes of Age' (2016) 41 *Journal of Health Politics, Policy and Law* 1151–73.

[53] Ben P. White and Lindy Willmott, 'Evidence-Based Law-Making on Voluntary Assisted Dying' (2020) 44(4) *Australian Health Review* 544–546.

[54] *Carter* v. *Canada (Attorney General)* [2015] 1 SCR 331; *Truchon* v. *Attorney General of Canada* [2019] QCCS 3792 (CanLII); Downie, 'Social Science and Humanities Evidence in Charter Litigation', 305–13.

[55] See, for example, the complete list of experts called by the plaintiffs, the Attorney General (Canada) and the Attorney General (British Columbia): *Carter* v. *Canada (Attorney General)* [2012] BCSC 886 at [160]. Note also that this is a further example of experts being used as an important part of the reform process, as noted above.

[56] *Carter* v. *Canada (Attorney General)* [2012] BCSC 886, affirmed by *Carter* v. *Canada (Attorney General)* [2015] 1 SCR 331 at [3], [8].

[57] Ball, *At Liberty to Die*.

law[58] was a key factor for reform, with some arguing that regulation of this practice was needed.

One key outcome of the use of evidence in law reform debates is what has been referred to as a 'shrinking battlefield'.[59] Because there is evidence that assisted dying regimes can operate safely and effectively, arguments against reform which make claims about risks to the vulnerable should now be hard to sustain. This reduced ground to marshall arguments against assisted dying has shaped the nature of assisted dying debates and made reform more likely. This evidence can also change the views of some who, after engaging with the evidence, reduce their opposition to assisted dying reform, or indeed may be willing to support it.

It is not just in relation to assisted dying that evidence has been influential in bringing about reform. The Kitzingers' case study about withdrawing artificial nutrition and hydration reports on the systematic research undertaken by them and others to document the economic and personal costs of applying for court approval to withdraw treatment. This evidence was translated into easy to digest forms to assist with its wide dissemination to policy-makers and key stakeholders, ultimately supporting the case for change. This evidence was also placed before the UK Supreme Court in *Re Y*,[60] and informed professional guidance issued by the British Medical Association and the Royal College of Physicians. On the other hand, a perceived *lack* of evidence about the operation of the Texas Advance Directives Act (e.g. it is unknown the number and demographic characteristics of patients who have had the dispute resolution process invoked) was identified as contributing to the persistent challenges that have been mounted against it.

AN ENVIRONMENT CONDUCIVE TO LAW REFORM

Many of the case studies of successful reform also include discussions of failed attempts to change the law about assisted dying. Many of those reform efforts have been long-standing. In Australia, after earlier success with the Northern Territory legislation, there were approximately forty Bills aiming to change the law in Australia before the Victorian, and now Western Australian and Tasmanian, law changed.[61]

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[58] Luc Deliens, Freddy Mortier, Johan Bilsen, Marc Cosyns, Robert Vander Stichele, Johan Vanoverloop and Koen Ingels, 'End-of-Life Decisions in Medical Practice in Flanders, Belgium: A Nationwide Survey' (2000) 356 *The Lancet* 1806–11.

[59] Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42 *Australian Health Review* 616–20.

[60] *An NHS Trust v. Y* [2018] UKSC 46.

[61] Willmott et al., '(Failed) Voluntary Euthanasia Law Reform in Australia', 1–46; White and Willmott, 'Future of Assisted Dying Reform in Australia', 616–20. For a comprehensive analysis of the arguments raised by politicians in debates on these Bills, see Andrew McGee, Kelly Purser, Christopher Stackpoole, Ben White, Lindy Willmott and Juliet Davis, 'Informing the Euthanasia Debate: Perceptions of Australian Politicians' (2018) 41 *University of New South Wales Law Journal* 1368–417.

Lewis notes ten failed attempts at reform in the UK Parliament to date, and almost twenty years elapsed after the *Rodriguez* v. *British Columbia (Attorney General)*[62] case before the Canadian law was again challenged in *Carter*.[63] In Belgium, there had been ongoing discussion, even since the debates at the time the initial law passed in 2002, about whether assisted dying should extend to minors.

So, what factors contribute to an environment conducive to law reform? It has already been observed that a good process that includes engagement with experts and key stakeholders is more likely to lead to reform. But there can be other wider factors that may contribute to a favourable reform 'environment' such as the emergence of influential individuals or groups, legal changes outside the end-of-life law field, shifts in community sentiment and when the political parties represented in parliaments favour reform.

An important component in a reform environment is the leadership of one or more individuals in advancing the debate. There is a long history of the advocacy of individuals or a small group in bringing about social change and law reform more generally and that also appears to be true in the end-of-life field. The Victorian assisted dying case study names a number of key individuals whose leadership roles in politics, public advocacy and policy-making were influential in the assisted dying law passing.[64] In a different way, Gloria Taylor and Kay Carter's family as plaintiffs in the Canadian Charter of Rights and Freedoms challenges were pivotal to the law changing there. The same could be said for Jean Truchon and Nicole Gladu in the subsequent litigation in Québec. The Kitzingers themselves could also be included in this category as academic advocates and family members arguing for change. In some instances, the participation of a key group rather than an individual has been decisive in law reform efforts. The Québec assisted dying reform provides a good illustration of a key group, here its medical regulator, playing an important role in framing the eventual debate about reforming the law.

Another example, this time from the United States, was twenty-nine-year-old Brittany Maynard who moved to Oregon to access assisted dying for a brain cancer and whose advocacy is widely regarded as critical for the passage of assisted dying legislation in California. A key feature of Maynard's advocacy from a law reform perspective was the successful harnessing of the media.[65] In the weeks before her death, Maynard and her husband, Dan Diaz, partnered with the advocacy group

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[62] *Rodriguez v. British Columbia (Attorney General)* [1993] 3 SCR 519.

[63] *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

[64] These key figures included: former Chief Minister of the Northern Territory, Marshall Perron; Premier of Victoria, Daniel Andrews; former Minister for Health, Jill Hennessy MP; media personality, Andrew Denton; neurosurgeon and former federal President of the Australian Medical Association, Professor Brian Owler; and retired urologist and activist, Dr Rodney Syme.

[65] Kimberly Lauffer and Sean Baker, 'U.S. Media Coverage of Brittany Maynard's Choice to Die: How Ideology and Framing Converged' (2019) 12 *Atlantic Journal of Communication* 1–14.

Compassion and Choices, to publicise her story.[66] The video interview they created immediately garnered considerable public and media attention globally.[67] She recorded a second video which was tendered as evidence to the California legislature ahead of the Senate committee vote on the State's assisted dying law.[68] These examples of individual or organisational advocacy are linked to the conceptual point made at the outset of this chapter that reform can occur both from the top-down and from the bottom-up. However, regardless of where a reform process sits within this spectrum, it is clear that key individuals and organisations can have decisive roles as instigators and/or drivers of reform.

An environment for law reform may also develop because of a change in a different, although related, legal context. For example, the *Carter*[69] challenge was made possible because of changes in Charter jurisprudence. These occurred in non-assisted dying contexts, but were capable of being applied to the blanket criminal law prohibition against assisted dying. That new legal environment was pivotal to the success of the *Carter*[70] challenge.

Other changes may be more incremental, so that the window for reform is not flung open at once but slowly pushed further and further ajar. The gradual accumulation of empirical evidence that assisted dying regimes can operate safely (mentioned above) is one such example. Perhaps another is the gradual shift of community sentiment in support of reform, as occurred in Oregon. Clark examined the right to die movement in the United States and why the use of citizen-initiated ballot measures had been an effective vehicle of law reform (she considers the initial failure to pass laws in Washington and California, followed by success in Oregon[71]).

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[66] 'Brittany Maynard', Compassion and Choices, 2020, https://compassionandchoices.org/stories/brittany-maynard. See also Barbara Coombs Lee and David Grube, 'Medical Aid in Dying: The Cornerstone of Patient-Centered Care' (2017) 41 *Generations: Journal of the American Society on Aging* 39–41.

[67] At the time of her death, Maynard's video was reported to have over nine million views on YouTube: BBC, 'Right-to-Die Advocate Brittany Maynard Ends Life', *BBC News*, 3 November 2014, www.bbc.com/news/world-us-canada-29876277. An exclusive story of Maynard's death on the *People* magazine website had the largest audience any Time Inc. brand publication had ever had for a single story, according to internal figures: Michael Sebastian, 'Brittany Maynard Story Leads to Record Digital Traffic for People', *Ad Age*, 6 November 2014, https://adage.com/article/media/brittany-maynard-story-sets-digital-traffic-record-people/295738.

[68] Eliana Dockterman, 'Watch Brittany Maynard's Video in Support of Right-to-Die Legislation', *Time*, 25 March 2015, https://time.com/3759208/brittany-maynard-right-to-die-video-california/.

[69] *Carter v. Canada (Attorney General)* [2015] 1 SCR 331.

[70] Ibid.

[71] Nina Clark, *The Politics of Physician Assisted Suicide* (New York, NY: Routledge, 1997). See also Thaddeus M. Pope, 'Legal History of Medical Aid in Dying: Physician Assisted Death in U.S. Courts and Legislatures' (2018) 48 *New Mexico Law Review* 267–301. Early assisted dying reform in Washington, California and Oregon involved a citizen-initiated ballot process in which a petition signed by registered voters could lead to a public vote on proposed legislation if sufficient support was achieved. In California, a 1988 attempt failed to achieve sufficient support to place legislation authorising both self-administration and practititioner administration assisted dying on the ballot. Further attempts restricted to legislation permitting

She concludes that a failure of the traditional policy machinery of government to engage substantively with the issue combined with a sense that 'time had come' for assisted dying meant that these initiatives were a logical outlet for this desire for change.[72]

A final, and perhaps obvious, example is the political environment in which end-of-life reform is considered. For example, the composition of a parliament will have a significant impact on the likelihood of a law being passed and the content of any such law. Particularly critical here is the political philosophy of the governing party or parties. Historically, socially progressive parties are more likely to undertake and support reform than conservative or religiously aligned parties.[73] Of course, reform may be required of governments, regardless of their political philosophy, to comply with constitutionally entrenched human rights, as occurred in Canada. But generally speaking, changes are more likely to occur with progressive governments, as recently occurred in Victoria. This was also the case in the Netherlands where the assisted dying legislation was enacted while the coalition government was comprised of liberals and social democrats and did not include the Christian Democratic Party.[74]

The foregoing discussion reveals some themes that transcend individual case studies. However, the factors that will ultimately lead to reform in any one jurisdiction at any particular time are idiosyncratic. The impact of particular individuals, the position and involvement of key groups and the composition of parliaments will vary in each jurisdiction. To this extent, as mentioned earlier, all politics is local. The triggers for change and how the window for reform arises will vary significantly from place to place. That said, being attentive to external factors which can make an

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self-administration in Washington, in 1991, and California, in 1992, failed at the ballot stage. Oregon enacted its assisted dying legislation successfully using the ballot process in 1994 after remodelling its campaign and inclusions based on the previous failed attempts. Washington also passed legislation modelled on the Oregon Act through a successful ballot initiative in 2008. Colorado passed nearly identical legislation through a ballot initiative in 2016.

[72] Clark, *The Politics of Physician Assisted Suicide*. It is significant to note that those early pre-1994 ballot initiatives were for both self-administration and practititioner administration assisted dying. All subsequent bills in the United States have been limited to legislation permitting only self-administration: Pope, 'Legal History of Medical Aid in Dying', 267–301.

[73] Although not always. For example, the Northern Territory assisted dying legislation was passed when a conservative government was in power: Willmott et al., '(Failed) Voluntary Euthanasia Law Reform in Australia', 13.

[74] John Griffiths, Heleen Weyers and Maurice Adams, *Euthanasia and Law in Europe: With Special Reference to the Netherlands and Belgium* (Portland, OR: Hart Publishing, 2008), 29–50; Heleen Weyers, 'Euthanasia: The Process of Legal Change in the Netherlands: The Making of the "Requirements of Careful Practice"', in A. Klijn, F. Mortier, M. Trappenburg and M. Otlowski (eds.), *Regulating Physician-Negotiated Death* (The Hague: Elsevier, 2001), 11–27; Francis Pakes, 'Under Siege: The Global Fate of Euthanasia and Assisted-Suicide Legislation' (2005) 13 *European Journal of Crime and Justice* 119–35; Francis Pakes, 'Tolerance and Pragmatism in the Netherlands: Euthanasia, Coffeeshops and Prostitution in the "Purple Years", 1994–2002' (2003) 5 *International Journal of Police Science and Management* 217–28.

environment ripe for reform may be strategic for those seeking to bring about change, or they may even wish to take steps to try and create such an environment.

The other global observation about environment is that reform generally only occurs after persistent agitation for change. Reform on any topic rarely happens quickly and this seems particularly so in the end-of-life field. All of the case studies described, in various ways, were the result of a long process which finally culminated in reform.

CRITICAL EVALUATION OF LAW REFORM AND PROPOSED LAW REFORM IS IMPORTANT

The case studies show that critical evaluation of proposed laws and indeed laws which have been enacted is important. The reason for evaluating proposed reforms is self-evident. The utility of a law and its likelihood of achieving proposed policy goals are important to consider when deciding whether or not the law, as proposed, should pass. Lewis's evaluation of prior judicial approval for assisted dying is a good example of this. As mentioned above, the quality of a law and its alignment with regulatory goals can sometimes be a casualty of compromise.[75] Given the difficulty of passing a law, and the difficulty of changing even a flawed law, careful evaluation of proposals is critical. We consider this should occur both in relation to the proposed law's stated policy goals[76] but also in relation to the proposal's alignment with wider values or ethical principles.[77]

But it is not just evaluation *prior* to a law coming into force that is important. The Netherlands has made a key contribution to assisted dying law reform internationally through the ongoing and rigorous government-funded evaluation of the operation of its law, providing a crucial evidence base for other jurisdictions to assess.[78] These reviews are undertaken by independent academics and their outcomes are publicly available. This transparency has not only supported law reform in other jurisdictions, but has also facilitated frank discussions about the efficacy of the Dutch law within

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[75] White et al., 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?', 417–51.

[76] Ibid.

[77] For an example of an articulation of the values that should guide assisted dying reform, see Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model for Reform', in K. A. Petersen and I. R. Freckelton (eds.), *Tensions and Traumas in Health Law* (Sydney, NSW: The Federation Press, 2017), 479–510. For an example of this approach in relation to unilateral medical decisions about withholding and withdrawing potentially life-sustaining treatment, see Jocelyn Downie, Lindy Willmott and Ben White, 'Cutting the Gordian Knot of Futility: A Case for Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment' (2014) 26 *New Zealand Universities Law Review* 24–59; Jocelyn Downie, Lindy Willmott and Ben White, 'Next Up: A Proposal for Values-Based Law Reform on Unilateral Withholding and Withdrawal of Potentially Life-Sustaining Treatment' (2017) 54 *Alberta Law Review* 803–29.

[78] Bregje Onwuteaka-Philipsen, Lindy Willmott and Ben P White, 'Regulating Voluntary Assisted Dying in Australia: Some Insights from the Netherlands' (2019) 211 *Medical Journal of Australia* 438–39.e1.

that jurisdiction. The Dutch case study in this book reports on the most recent (third) evaluation and its implications for the existing law. It reviews the law and its operation against the law's identified policy goals, providing opportunities for reflection on possible changes to the law and its application in practice. The evaluation also includes a study of public opinion to determine the degree and nature of support for the law. Given the debates about the operation of all assisted dying laws, including whether they should be narrowed or widened, that will continue after their enactment, a systematic method of evaluation should be encouraged. As already noted, the failure to do this in relation to the Texas Advance Directives Act has made it vulnerable to challenge for failing to operate fairly and effectively.

LAW REFORM EFFORTS ARE ONGOING

It is apparent from the book as a whole and this chapter in particular that law reform at the end of life is an ongoing exercise. This is especially evident in relation to law regulating assisted dying. Even if such a law is passed, there are likely to be calls from all sides for ongoing consideration of that law. For some individuals or groups, the law will not go far enough and they may advocate widening the law or considering categories of cases not currently covered. Other groups or individuals may continue their efforts to either narrow the law or repeal it entirely.

There have been sustained efforts to repeal or amend many of the end-of-life laws discussed in this book (and beyond). The enactment of a law might serve as a catalyst for efforts to change or repeal the law by judicial, legislative and/or policy means.[79] The Texas Advance Directives Act case study is an excellent case in point. The law passed after significant compromise, but since then there have been attempts (some successful) to narrow the scope of its application (e.g. to exclude artificial nutrition and hydration) as well as attempts to overturn the entire law on the ground that it is unconstitutional. The Belgian law extending assisted dying to minors was also the subject of an unsuccessful constitutional challenge,[80] as was the Oregon assisted dying law (challenged in numerous cases[81]). Another example is the Northern Territory assisted dying law, which was also unsuccessfully challenged on constitutional grounds,[82] but was ultimately overturned by the federal Australian government after only a brief period of operation.

This book has included two of the very few major changes internationally to the scope of assisted dying laws. The first is the Belgian extension of their law to include

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[79] Ball, *At Liberty to Die*. One of Ball's key contributions to law reform literature is to document the battles that continue after assisted dying laws are passed.

[80] Judgement 153/2015, Constitutional Court of Belgium (29 October 2015) (English translation).

[81] See, for example, Ball, *At Liberty to Die*. Assisted dying laws in California, New Jersey, Oregon, and Vermont were subjected to judicial challenges. Assisted dying laws in Montana and Washington, DC were subject to legislative challenges.

[82] *Wake and Gondarra* v. *Northern Territory and Asche* (1996) 5 NTLR 170.

access for minors in limited circumstances. Although controversial internationally at the time of passing, this case study has shown that this change was the product of debate and consideration over an extended period of time, that the law was subject to parliamentary and other scrutiny, and in practice has represented a very modest change of law with only four minors having used the law since its passing in 2014. The second is the *Truchon*[83] case, which struck down the Québec requirement that a patient be 'at the end of life' and the federal requirement that 'natural death has become reasonably foreseeable' on the grounds that they violated the Canadian Charter of Rights and Freedoms. In this instance, it could be argued that rather than extending the scope of law in Canada, this case simply reflects the position that was required by Canada's constitutional law.

The Dutch system of official and regular evaluations of their assisted dying law reflects government recognition that review of the law and its operation should be ongoing. As noted above, that evaluation includes whether the existing law is working as intended, as well as the views of the general public about the current scope of the law and whether it should be extended to other groups of people who do not currently have access to assisted dying.

One lesson for those interested in law reform – particularly in a field that is as important and emotionally charged as end-of-life law – is that it is an open-ended process, rather than a one-off event. Even if a law is enacted, we should expect ongoing discussion about its operation, its scope and whether it should be retained, amended or repealed. Reform is a journey and not a destination, and those active in the field need to adopt a long-term approach and be prepared for these ongoing debates. The Dutch approach also counsels a willingness to evaluate end-of-life law and to be open to reforms that such evaluation may signal.

DESIGN OF LAW IS CHALLENGING

Before turning to the future of law reform in this area, a final point to note is the challenge of designing law to govern end-of-life decision-making. We have mentioned that sometimes the design of a law can be complicated by a decision to compromise. This can result in inconsistency within the law, a failure to align with regulatory objectives and suboptimal lawmaking generally.

But even where compromise does not occur, designing law to govern the complex interface between law and medicine in the setting of end-of-life decision-making is difficult, at both a policy and a practical level.[84] One example in the assisted dying context is whether to adopt a model that permits or requires administration of the

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[83] *Truchon* v. *Attorney General of Canada* [2019] QCCS 3792 (CanLII).

[84] Ben White, Lindy Willmott and Eliana Close, 'Victoria's Voluntary Assisted Dying Law: Clinical Implementation as the Next Challenge' (2019) 210 *Medical Journal of Australia* 207–9.e1.

assisted dying medication by a doctor (or health professional), one that requires the person to take that medication themselves, or one that permits both, in some or all circumstances. These are matters about which people and policy-makers can have different views, depending on the values or principles they prioritise as most important.

Even if higher-level principles can be agreed upon, expressing them in concrete legislative form can be challenging. Long-standing regulatory challenges when designing law include the problems of rule indeterminacy and interpretation.[85] Orentlicher commented that the US model of assisted dying reflects a preference for 'bright-line' policy choices, which is manifested, for example, in the inclusion of a six-month anticipated time period until death in their laws. This can be contrasted with the more open-ended and subjective approaches to assessing time to death that have been used in Canada, such as natural death being reasonably foreseeable (federal) or a patient being at the end of life (Québec). Putting aside recent changes to the Canadian law, the point here is that both bright-line and more subjective approaches bring challenges. The US model is arguably arbitrary in selecting a specified time frame,[86] whereas the Canadian and Québec approaches proved difficult to interpret and apply consistently. There is not scope here to critique these various approaches, but it is sufficient to observe the inherent challenges in drafting a law which is certain but does not unjustly exclude access to assisted dying for some people.

Another challenge is that it cannot always be predicted how a law will work in practice. The consensus that supported the Texas reforms was based in part on assumptions that did not eventuate, namely that hospital transfers would be readily available for patients. The Canadian federal law failed to anticipate situations such as people voluntarily stopping eating and/or drinking to become eligible for assisted dying, or ceasing pain medication to maintain decision-making capacity in order to provide informed consent immediately prior to receiving assistance in dying. There are also examples of these unforeseen consequences outside the case studies. One from the Victorian law is the much-discussed prohibition on health professionals

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[85] Karen Yeung, 'Regulating Assisted Dying' (2012) 23 *King's Law Journal* 163–79.

[86] In the Australian context, charges of arbitrariness in terms of criteria about expected time until death have been made in Willmott and White, 'Assisted Dying in Australia', 503–4 and White et al., 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?', 417–51. Prognostication about time until death is notoriously difficult: Joanne Lynn, Frank E. Harrel Jr., Felicia Cohn, Mary Beth Harrell, Neal Dawson and Albert W. Wu, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35 *Duquesne Law Review* 311–36; Eric Chevlen, 'The Limits of Prognostication' (1996) 35 *Duquesne Law Review* 337–54; James Downar, Russell Goldman, Ruxandra Pinto, Marina Englesakis and Neill K. J. Adhikari, 'The "Surprise Question" for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-Analysis' (2017) 189 *Canadian Medical Association Journal* E484–93; Paul Glare, Christian Sinclair, Michael Downing, Patrick Stone, Marco Maltoni and Antonio Vigano, 'Predicting Survival in Patients with Advanced Disease' (2008) 44 *European Journal of Cancer* 1146–56 at 1147.

raising the topic of assisted dying with their patients.[87] Although designed to ensure the patient's decision was voluntary and not a result of influence from health professionals, in practice it has led to confusion about what health professionals can and cannot say (as well as the wider question of whether this prohibition is consistent with the assisted dying law's policy goals.)[88] As has been suggested above, for example in contrasting the Québec legislation with the federal Canadian law reform, a good consultation process may assist with addressing some of these challenges. However, it is not always possible to foresee the various possible issues that can arise with a law once implemented.

LIMITS OF A CASE STUDY APPROACH: WHAT IS MISSING?

This chapter has undertaken a comparative law analysis of ten case studies of reform in six countries. The breadth of this analysis has helped provide new insights about law reform that would otherwise not emerge. Although ten case studies is regarded as a large sample in comparative law terms, such an approach necessarily has some limitations. One is that not all cases of end-of-life law reform can be examined.[89] Another is that the majority of the case studies focus on assisted dying. While this reflects important recent trends in assisted dying reform internationally, this has implications for the applicability of the analysis to end-of-life law reform more broadly.

The case studies also generally consider reforms or proposed reforms that are relatively recent, including new developments rather than original law reforms in jurisdictions that legalised assisted dying some time ago, such as Belgium and the Netherlands. There is literature considering reform from earlier eras,[90] and that has informed the present analysis. But that experience is now dated and occurred in a different environment, for example, before there was a body of reliable social

[87] *Voluntary Assisted Dying Act 2017* (Vic), s. 8. See also: Lindy Willmott, Ben White, Danielle Ko, James Downar and Luc Deliens, 'Restricting Conversations about Voluntary Assisted Dying: Implications for Clinical Practice' (2020) 10 *BMJ Supportive and Palliative Care* 105–110; Carolyn Johnston and James Cameron, 'Discussing Voluntary Assisted Dying' (2018) 26 *Journal of Law and Medicine* 454–63; Bryanna Moore, Courtney Hempton and Evie Kendal, 'Victoria's Voluntary Assisted Dying Act: Navigating the Section 8 Gag Clause' (2020) 212 *Medical Journal of Australia* 67–8.e1; White et al., 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?', 417–51.

[88] Willmott et al., 'Restricting Conversations about Voluntary Assisted Dying', 105–10; Johnston and Cameron, 'Discussing Voluntary Assisted Dying', 454–63; Moore, Hempton and Kendal, 'Victoria's Voluntary Assisted Dying Act', 67–8.e1; White et al., 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?', 417–51.

[89] For example, a case study about reform of the law governing palliative care was not selected by any of the contributing authors for inclusion in this book. Further, the need to select a feasible number of case studies also meant that not all significant cases of end-of-life law reform could be included.

[90] See, for example, Ball, *At Liberty to Die*; Clark, *The Politics of Physician Assisted Suicide*; Hillyard and Dombrink, *Dying Right*; Pope, 'Legal History of Medical Aid in Dying', 267–301.

science evidence about how assisted dying regimes can function in practice. Accordingly, the case studies in this collection represent a deliberate choice to provide an analysis of modern efforts to undertake end-of-life law reform.

A final limitation is that the case studies in this book predominantly consider instances when reform did occur. This prevents an effective comparison between case studies of successful reform and those where reform was unsuccessful, although some insight into this comes from jurisdictions where the law changed after a history of many failed attempts. This focus on cases of successful reform may also prioritise particular perspectives because, by definition, reform that is successful means that barriers and opponents to change were not sufficient to prevent the law from changing. As a result, the focus of these case studies was more often on the reasons why the law changed – that is, the facilitators of reform and the individuals or groups who were influential in fostering change – rather than on the reasons why reform was challenging. This is perhaps particularly so for those case studies examining why reform had happened after many failed attempts; the 'how to guides' necessarily focus more on the facilitators of reform than the barriers to it.

One implication of this is that the case studies include only modest discussion of opposition from certain groups. For example, some literature about assisted dying law reform identifies churches, particularly the Catholic Church, and other religious organisations as having long-standing opposition to assisted dying.[91] Yet these groups received limited consideration in the preceding chapters.[92] The opposition of medical associations and bodies in some jurisdictions to assisted dying reform was also given modest attention. As noted, the limited engagement in this book with these potentially opposing groups may be due to the book's focus on successful cases of law reform. But it may also reflect the declining influence on the formation of

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[91] Taylor E. Purvis, 'Debating Death: Religion, Politics, and the Oregon Death with Dignity Act' (2012) 85 *Yale Journal of Biology and Medicine* 271–84; Ball, *At Liberty to Die*; Steven Kettell, 'How, When, and Why Do Religious Actors Use Public Reason? The Case of Assisted Dying in Britain' (2019) 12 *Politics and Religion* 385–408; Eli D. Stutsman, 'Political Strategy and Legal Change', in Timothy E. Quill and Margaret P. Battin (eds.), *Physician-Assisted Dying: The Case for Palliative Care and Patient Choice* (Baltimore: Johns Hopkins University Press, 2004), 259.

[92] For example, Raus, Deliens and Chambaere note the opposition of churches, particularly the Belgian Catholic Church, to the extension of assisted dying to minors. Van der Heide, Legemaate, Delden and Onwuteaka-Philipsen note that the absence of the Christian Democratic political party from the coalition government was a key factor in the passage of assisted dying legislation in the Netherlands. Willmott and White note that leaders of religious and faith-based organisations actively provided evidence to the Parliamentary Inquiry that preceded assisted dying legislation in Victoria. Lewis notes that groups calling for prospective judicial approval of assisted dying legislation in Canada and the United Kingdom include those opposed to reform on religious grounds. Orentlicher also notes that the Catholic Church has been vocal in ethical debate surrounding assisted dying and the withdrawal of life-sustaining treatment. Pope acknowledges that the Texas Advance Directives Act was enacted in part due to the support of a broad coalition of stakeholders, including the Christian group, Texas Right to Life, while the loss of this consensus resulted in attempts to dismantle the legislation.

public policy of these and other groups who oppose assisted dying reform.[93] This is an empirical question not resolved in this book but is one which warrants future research.

FUTURE OF END-OF-LIFE LAW REFORM

Reforming end-of-life law is a challenging exercise. In the opening chapter, we identified five features that made reform in this area even more difficult than law reform generally. Law reform at the end of life involves issues of obvious gravity and significance that concern every individual in society; it requires deliberation on complex ethical issues and engages sincerely held values about which reasonable people can differ; there is a large and complex body of empirical evidence to grapple with and interpret; it requires legal mastery to draft new end-of-life laws or coherently amend existing complex laws; and finally, aligning oneself with a particular position on assisted dying can be politically dangerous.

These ten case studies across six jurisdictions provide global lessons about how law reform can occur, despite these challenges. One clear theme that emerged is that law reform in this field is hard. However, a review of the current landscape reveals an environment that is increasingly more conducive to reform. Internationally, at least in relation to assisted dying, there is a growing momentum for change.[94] First, there has been a slow but steady trend towards enacting assisted dying laws internationally, which itself can create an environment for further reform.[95] This has been supported by the body of social science evidence and its use in debates, creating a ‘shrinking battlefield’ which can limit opponents’ arguments that previously had traction.[96] This evidence can also change the minds of individuals and organisations who may have opposed assisted dying.

Societal attitudes and values that support reform also appear to be evolving. Patient autonomy, including in relation to end-of-life choices, is increasingly becoming an important social norm that is driving changes to the law. Orentlicher has argued that these values already underpinned existing laws about withholding and withdrawing life-sustaining treatment in the United States, and are now being reflected in the passage of limited assisted dying laws in a growing number of states. While individual rights have historically been a feature of the US legal system, this trend is emerging more generally in the Western countries included in this book. For example, in the Netherlands and Belgium, where arguably the assisted dying law initially developed primarily as a compassionate

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[93] See, for example, the discussion of the declining influence of the Catholic Church on public policy in Purvis, ‘Debating Death’, 271–84; Kettell, ‘How, When, and Why Do Religious Actors Use Public Reason?’, 385–408.

[94] White and Willmott, ‘Future of Assisted Dying Reform in Australia’, 616–20.

[95] Ibid.

[96] Ibid.

response to suffering, there appears to be growing recognition of patient autonomy as an important justification for their laws.[97] We also see greater recognition of patient views, albeit in a more modest way, in Jackson's analysis of how the best interests test has evolved in England and Wales.

As a result, we anticipate that assisted dying law reform, and other end-of-life law reform, is likely to continue. The rate of change to date has been slow but these factors are likely to align to bring about ongoing change in the law, and perhaps at a faster rate than in the past. The future reform attempts that will be successful are likely to be those that have some or all of the features outlined earlier in this chapter.

The subtitle of this book, 'Politics, Persuasion and Persistence', captures the essence of many of the issues considered in this chapter. Reform is most likely to succeed if careful attention is paid to the politics of reform. This, of course, encompasses the political or parliamentary process, which is often a critical component in reform. But the politics of reform also should involve a robust law reform process that includes broad and inclusive consultation involving experts, key stakeholders and the wider community.

Persuasion is linked to the politics of reform but also refers to the types of arguments that should be mounted. A key component is the importance of evidence. Persuading lawmakers about the importance of reliable evidence and explaining what it means in a particular context has been significant in effecting legal change, and will continue to be so. Persuasion should also focus on arguments at a principled level. Proposing reforms that are internally sound, consistent and align with the identified regulatory goals is important and essential to effective advocacy.

Finally, persistence is an essential part of law reform. All of the case studies of reform resulted from long-standing efforts over an extended period of time. Sometimes this required waiting for the right reform environment to emerge, and at other times it was possible to advocate to create that environment. In all cases, however, there were no overnight successes.

We conclude by briefly noting the implications that this review has for law reform generally. When thinking about reform in the end-of-life field, we have naturally drawn on wider law reform debates and scholarship. As noted in the opening chapter, we acknowledge that this book sits within a long-standing tradition of discussion about how and why law reform occurs. The factors that support reform

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[97] Pauline S. C. Kouwenhoven, Ghislaine J. M. W. van Thiel, Agnes van der Heide, Judith A. C. Rietjens and Johannes J. M. van Delden, 'Developments in Euthanasia Practice in the Netherlands: Balancing Professional Responsibility and the Patient's Autonomy' (2019) 25 *European Journal of General Practice* 44–8; H. A. M. J. ten Have, 'Euthanasia: Moral Paradoxes' (2001) 15 *Palliative Medicine* 505–11; Joachim Cohen, Isabelle Marcoux, Johan Bilsen, Patrick Deboosere, Gerrit van der Wal and Luc Deliens, 'Trends in Acceptance of Euthanasia Among the General Public in 12 European Countries (1981–1999)' (2006) 16 *European Journal of Public Health* 663–9.

to occur in other socially progressive settings such as same-sex marriage,[98] abortion,[99] non-therapeutic sterilisation[100] or access to IVF[101] are also relevant here.

Indeed, many of the contributors to this book have been involved in law reform processes on a range of topics and in a range of roles, including as a parliamentarian, law reform commissioners, experts before courts and parliaments, litigants in public interest cases and members of pro bono legal teams advancing those cases. In the same way that this book benefitted from insights from the wider law reform field, we hope too that reform in the end-of-life area may help shed light on and advance thinking about law reform generally. End-of-life law reform may therefore be seen as a case study of how change can occur. The authors hope that the findings of this book may be useful for law reformers striving in other controversial fields to change the law.

[98] See, for example, Celia Kitzinger and Susan Wilkinson, 'Social Advocacy for Equal Marriage: The Politics of "Rights" and the Psychology of "Mental Health"' (2004) 4 *Analyses of Social Issues and Public Policy* 173–94; Rosemary Auchmuty, 'Same-Sex Marriage Revived: Feminist Critique and Legal Strategy' (2004) 14 *Feminism and Psychology* 101–26; Jamie Gardiner, 'Same-Sex Marriage: A Worldwide Trend?' (2010) 28 *Law in Context* 92–107.

[99] See, for example, Jenny Morgan, 'Abortion Law Reform: The Importance of Democratic Change' (2012) 35 *University of New South Wales Law Journal* 142–74; Mary Ziegler, 'The Framing of a Right to Choose: *Roe* v. *Wade* and the Changing Debate on Abortion Law' (2009) 27 *Law and History Review* 281–330; Joanna N. Erdman, 'The Politics of Global Abortion Rights' (2016) 22 *The Brown Journal of World Affairs* 39–57; Emily Jackson, 'Abortion', in *Regulating Reproduction Law, Technology and Autonomy* (Oxford: Hart Publishing, 2001), ch. 3, 71–111.

[100] See, for example, Penney Lewis, 'Legal Change on Contraceptive Sterilisation' (2011) 32 *Journal of Legal History* 295–317; Emily Jackson, 'Birth Control', in *Regulating Reproduction Law, Technology and Autonomy* (Oxford: Hart Publishing, 2001), ch. 2, 11–69.

[101] Emily Jackson, 'Reproductive Technologies', in *Regulating Reproduction Law, Technology and Autonomy* (Oxford: Hart Publishing, 2001), ch. 5, 161–259; Anna Smajdor, 'The Changing Face of IVF Regulation' (2008) 3 *Expert Review of Obstetrics and Gynecology* 433–6; Kirsty Horsey, 'Revisiting the Regulation of Human Fertilisation and Embryology', in Kirsty Horsey (ed.), *Revisiting the Regulation of Human Fertilisation and Embryology* (New York, NY: Routledge, 2015), 1–11.

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Perspective

Evidence-based law making on voluntary assisted dying

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Abstract. Voluntary assisted dying is a major social policy issue with significant implications for the health system, health and medical professionals and the wider community. Voluntary assisted dying is now lawful in Victoria in limited circumstances, and other states are likely to follow Victoria and legalise the practice. In the same way that we expect the making of health policy and the provision of health care to be evidence based, so too should we should expect evidence-based law making from our parliamentarians on this important topic.

What is known about the topic? The importance of evidence when making health policy and providing evidence-based medical care is well accepted. Australian states are actively considering laws about voluntary assisted dying.
What does this paper add? This paper argues that evidence-based law making by parliamentarians is needed as they deliberate proposed voluntary assisted dying laws. There has been limited recognition of the value of evidence-based approaches in the discipline of law.
What are the implications for practitioners? A failure by parliaments to adequately consider evidence can lead to suboptimal law making. When this occurs about important health issues, such as voluntary assisted dying, it leads to problematic regulatory frameworks for patients, health professionals and health systems.

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Introduction

Voluntary assisted dying (VAD) is a major social policy issue with significant implications for the health system, health and medical professionals and the wider community. VAD is now lawful in Victoria in limited circumstances, and other states are likely to follow Victoria and legalise VAD.[1] The Western Australian parliament is currently debating a VAD bill tabled in August, and Queensland and South Australia are holding parliamentary inquiries; a bill is also expected to be presented to the Tasmanian parliament within the next year. In the same way that we expect the making of health policy[2] and the provision of health care[3] to be evidence based, so too should we expect evidence-based law making from our parliamentarians.

There are diverse views on VAD across the community. Although public opinion broadly favours reform,[4] individuals, advocacy groups and organisations on both sides of the debate continue to advance conflicting viewpoints. Of interest is the recent activity by health and medical organisations releasing a spectrum of position statements. Although the Australian Medical Association[5] is against changes to the law, the Royal Australasian College of Physicians[6] and the Royal Australian College of General Practitioners[7] have both chosen not to oppose reform. Significantly, the recent Palliative Care Australia Position Statement ‘neither advocates for, nor argues against’ legalisation of VAD.[8] All four organisations specifically endorse that the decision about whether VAD laws should be passed is an issue for government and society. In contrast with the medical organisations, the Australian Nursing and Midwifery Federation supports law reform for a limited cohort of people.[9]

This breadth of community and organisational interest in VAD is illustrated by the thousands of submissions the Victorian, Western Australian, Queensland and South Australian parliamentary committees collectively received. Parliamentarians in Victoria and Western Australia have also reported being heavily lobbied when they were actively debating their laws. How then should parliaments weigh the diverse and often conflicting arguments about whether VAD laws should be passed?

Sometimes viewpoints will differ because of different positions about the ethics of VAD. These are matters on which people can reasonably disagree. For some, VAD is ethically wrong because it involves the intentional ending of life. Others consider VAD is ethically permissible as an appropriate response to a competent request to relieve suffering. Law making on complex social policy inevitably and appropriately involves weighing competing ethical considerations.[10]

However, some differences in views about VAD are based on claims about facts: whether or not something is happening in practice. Examples are whether vulnerable cohorts are more likely to seek VAD or whether VAD adversely affects palliative care. These are factual claims, and the extent to which they are true or not depends on evidence. There is not scope here to engage in these debates, although we note that two Australian parliamentary

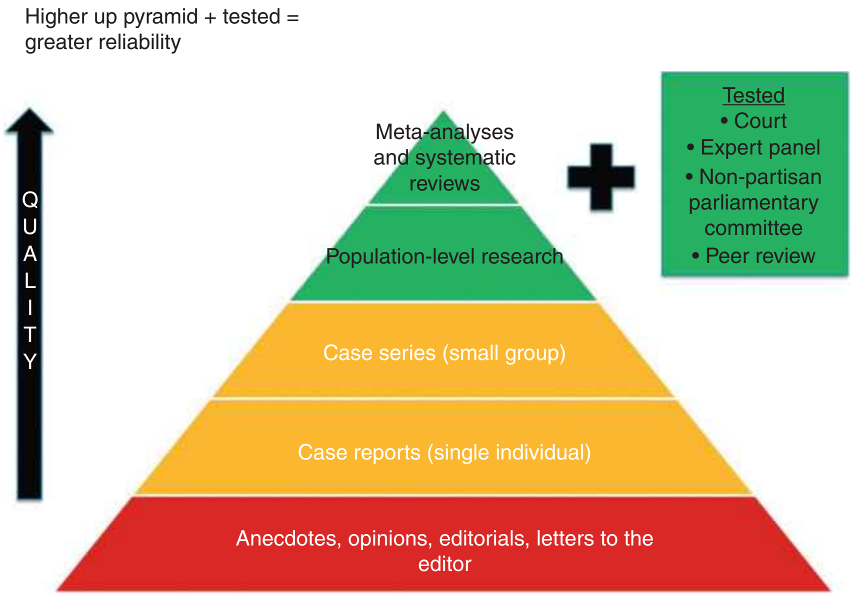

Fig. 1. Reliability of evidence pyramid for law making about voluntary assisted dying. Modified with permission from Downie.[16]

committees to date have undertaken evaluations of available evidence about VAD.[11,12] Rather, the point here is to distinguish views about the ethics of VAD from views based on facts about VAD. We do acknowledge there can be overlap: for example, claims about facts are not necessarily value free. Nevertheless, we contend this distinction remains important because claims about facts are capable of being evaluated against evidence.

The use of evidence in health and medicine is vexed and there are debates about a range of issues, including the effects of values and research design, and challenges of translating evidence into practice.[2,13] Nevertheless, the important role of evidence in making health policy and in providing evidence-based medical treatment to patients is well accepted. Evidence-based approaches are increasingly gaining traction in other fields, such as business.[10] We should also expect law makers to make their decisions based on reliable evidence. Unfortunately, Law's utilisation of evidence has lagged behind other disciplines.[10] There is also relatively little literature on the concept of evidence-based law making. Although some may conceptualise law as a subset of health policy, even if this is true there are very distinctive facets of law making that warrant careful and separate consideration of the role of evidence in parliamentary debate. For example, the legislative process, by definition, occurs in the public domain and there is an opportunity for scrutiny of such decision making that is often not present in health policy making.

One challenge for evidence-based law making is that established models from medicine for evaluating evidence in different settings[14,15] are not readily applicable to law making. (This is also a known problem in health policy.[13]) To assist with the process of assessing evidence, Downie proposed an approach specifically designed for the context of law-making about VAD (see Fig. 1).[16] This model incorporates the traditional notion of ascending reliability up a pyramid, but is adapted to reflect those types of evidence likely to be used in these debates. For example, randomised control trials are omitted. In addition, Downie's model includes external testing of that evidence not only through the usual peer review, but also by common law and policy processes such as evaluation by a court or parliamentary committee.[16]

Using this approach, the Dutch[17] and Belgian[18] research about rates of VAD over time would be regarded as reliable evidence. These are population-level studies and, through publication in top international medical journals, have been subject to rigorous peer review. Other significant evidence includes annual reports published by health departments about patients' and doctors' participation in VAD each year. The best examples are reports of data mandated to be collected under the *Oregon Death with Dignity Act 1994* (and this approach is replicated in other parts of the US). Although not in peer-reviewed journals, these reports provide insight into how VAD systems as a whole function by collecting all reported cases of VAD over an extended period; now 21 years in the case of Oregon.[19]

At the other end of the spectrum are anecdotes in media reports about a particular case or cases of VAD. These are at the bottom of the pyramid and have not been externally tested, and so are not reliable evidence. The positions against and for VAD reform of the Australian Medical Association and the Australian Nursing and Midwifery Federation respectively are also worth considering. We regard them as statements based on values, rather than purporting to be factual claims about VAD of the type discussed above. However, to the extent they may be advanced by others as a form of evidence, we consider them to be 'opinion', which is also at the bottom of the pyramid.

Parliamentarians, and indeed the wider discipline of Law, must follow the evidence-based approach increasingly expected in other fields. We should be clear though that we are not suggesting law making become just a technical exercise of implementing evidence; some limits on using evidence were noted above. Further, we acknowledge that it is appropriate for values to play a role in what is ultimately a political exercise,[10] although those values should be disclosed by parliamentarians. Nevertheless, we call for evidence-based law making and consider this especially important for complex social issues such as VAD, where proponents of various positions make broad and often conflicting factual claims. Decisions about our laws must reflect the state of available evidence, so these claims must be rigorously evaluated. Accordingly, we call on parliaments to engage in evidence-based law making that includes careful deliberation informed by reliable evidence.

Competing interests

Ben White and Lindy Willmott have been engaged by the Victorian Government to design and provide the legislatively mandated training for doctors involved in VAD. Lindy Willmott is also a member of the board of Palliative Care Australia, but this article only represents her views. Ben White is an Associate Editor for *Australian Health Review*.

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Assisted dying and evidence-based law-making: a critical analysis of an article's role in New Zealand's referendum

Ben P White, Lindy Willmott, Jocelyn Downie, Andrew Geddis, Colin Gavaghan

ABSTRACT

AIM: To critically analyse the reliability of an article which claims to be evidence that the End of Life Choice Act 2019 provides a "potential hotspot for family, community and social discord that may not be easily remedied" should the legislation receive public support in New Zealand's September 2020 referendum.

METHODS: The subject article was reviewed multiple times by all authors and critiqued against three criteria: a reliability pyramid developed to weigh evidence about assisted dying; principles that guide the conduct of social science research; and the use of reliable and current social science literature to support factual claims.

RESULTS: The study being analysed involved a single interview and so is located at the second bottom row of the reliability pyramid. Its research design is also unable to support the broad findings that are asserted. Other flaws in method included findings being extended beyond the data, and failure to state appropriate limitations in the research method. Further, claims are made that are unsupported by the weight of reliable social science literature.

CONCLUSION: The subject article is methodologically and factually flawed so is unreliable as evidence. It should not be considered in the assisted dying debates preceding the forthcoming referendum.

Assisted dying (AD) is a significant social policy issue, so reliable evidence to inform law-making is critical.[1] Society expects health policy[2] and healthcare[3] to be evidence-based. This expectation should extend to law-making.[1]

In September 2020, New Zealanders will participate in a binding referendum to determine whether the End of Life Choice Act 2019 (EOLCA)—legislation permitting AD already passed by Parliament—will come into force.[4] A recent article published in the *New Zealand Medical Journal* by Winnington and MacLeod (WM article)[5] raised concerns about the potential impact of this law. Further, the WM article proposed that the "evidence from this study must be factored into the New Zealand debate before the referendum on the [EOLCA]" (p21).

This article responds to the suggestion that the WM article be evidence in this debate. Our goal is to undertake a critical analysis of the evidence it purports to contribute, to determine its reliability and therefore probative value. We conclude that a combination of the nature of the study, flaws in its research design, its use of data to draw conclusions, a failure to outline limitations and inadequate engagement with social science literature make the WM article unreliable. It should not be considered as evidence in deliberations about the EOLCA.

Methods

Criteria to assess reliability

We applied three criteria to assess reliability. The first is a pyramid of evidence developed by one of the authors (JD). This pyramid draws on existing models for assessing evidence and graphically depicts how reliability increases as it ascends the pyramid, but is adapted for the evidence most commonly used when making law about AD and the sort of external review that can occur (Figure 1). Reliability is assessed both by determining the level of the pyramid at which particular evidence sits, and by considering whether it has been externally tested and the nature of that testing—whether by peer review or review by courts, non-partisan parliamentary committees or expert panels.

The second criterion is the principles that guide the conduct of social science research. We are conscious of different approaches in quantitative and qualitative research[6] but there is broad acceptance across different research traditions of the following principles: study design (including data collection and analysis) that is appropriate to research aims; rigorous use of selected research methods; and fair presentation of results including only conclusions sustained by data and acknowledging appropriate limitations.

The third criterion for reliability was whether factual claims made in the WM article were defensible in light of available social science literature. We inquired whether factual claims were based on literature that was reliable (informed by some of the above considerations), up to date and fairly represented the field's state of knowledge.

Review process

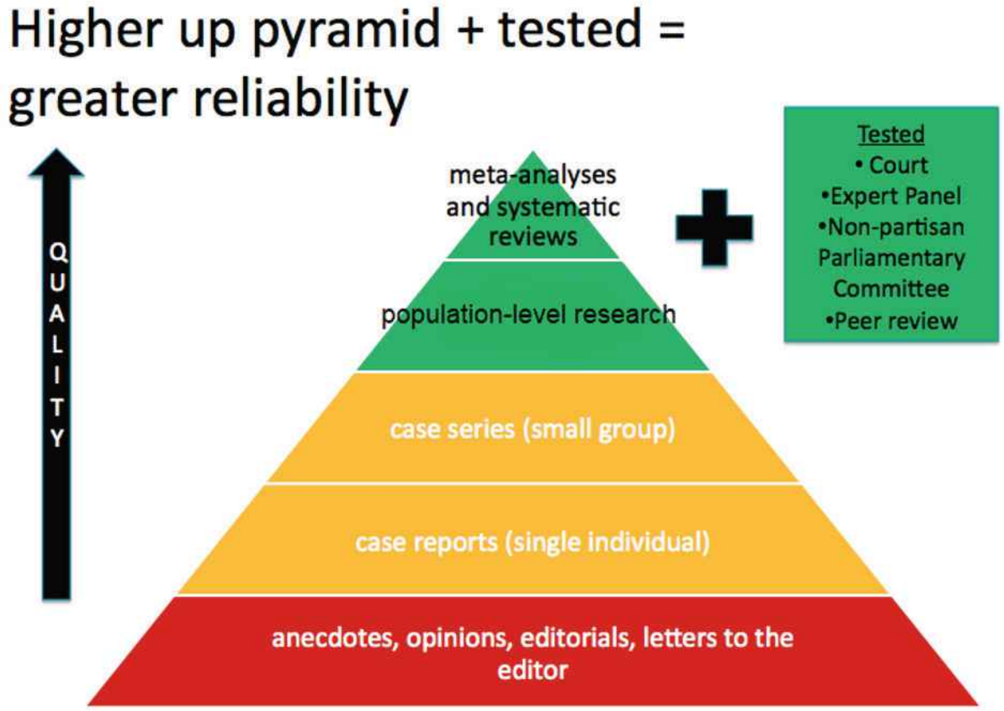
Two authors (BW and LW) reviewed the WM article multiple times and compiled a list of possible failures to meet the reliability criteria. These were grouped according to issue type and written up. These critiques were reviewed by other authors with an invitation to add new areas, revise or remove existing ones. All authors endorse the critical analysis below.

Results

Summary of Winnington and MacLeod article

The stated aim of the WM article was to consider "the possibility of consequences … for families left behind, communities and society as a whole" should New Zealand legalise AD (p18). To address this aim, a

Figure 1: Adapted reliability pyramid of evidence for assisted dying.



single semi-structured interview was undertaken with a person who had experience with AD in a country where AD is lawful. The interviewee's perspective was from being married to a sibling of the person who chose AD. Thematic analysis of this interview identified three key themes: potential expectations that people would seek AD when unwell and possibly facing a life-threatening illness; stigma for individuals using AD and their families; and the potential for AD legislation to produce contagion (not defined in the article but we understand refers to the notion that AD may activate others to seek AD who would not otherwise do so) (p18).

The article calls for further research including "to investigate whether a contagion effect of AD is possible (or even probable)" (p22).

Criterion 1: reliability pyramid

As research based on a single case study, this study falls into the second bottom row of the pyramid (Figure 1). On this basis alone, the reliability of such evidence is limited. In addition, some conclusions or claims are not based on the data or go beyond what the data could support (see examples below), and would fall to the bottom row: anecdotes and opinion.

Although the nature of the study means it is of limited reliability, some external testing adds reliability; the article is published in the peer-reviewed *New Zealand Medical Journal*.

Criterion 2: reliability in terms of principles of social science research

Study design not appropriate for aims

The article's aim was to consider "the possibility of consequences … for families left behind, communities and society as a whole" should New Zealand legalise AD (p18). In terms of study design, a single interview is not capable of meeting this ambitious aim, even with the qualifier "possibility". This is particularly so in relation to consequences for the wider communities and society as a whole. Such a method might shed light on family experiences, albeit in a very limited way with only one interview, but it cannot reliably inform about broader community perspectives.

Results extended beyond what data reasonably supports

The WM article's analysis identified three key themes (abstract, p18):

- "the potential for assisted dying becoming an expectation for others to pursue when unwell and possibly facing a life-threatening illness;"
- "the notion of stigma being associated with the individual using assisted dying legislation and the family left behind;" and
- "that there may be the potential for such legislation to produce a contagion effect."

We accept the interviewee discussed these three issues. But a threshold concern is whether all themes are supported by the data. It is possible that an interview with a member of an extended family with an experience of AD could, with relevant limitations articulated, produce findings about stigma **within a family**.

However, it is not justifiable to present the other themes as results from these data. Both relate to wider, societal-level trends rather than individual experience. The experience of one person could not, from a scientific perspective, be reliable evidence of wider community views or experiences. Determining the existence of these phenomena would require quite different research methods such as community surveys or, in the case of the contagion argument, quantitative studies about use of AD.

A second concern is how these results are extended and transformed into substantive potential problems for society. In other words, an issue is raised in the data and unjustifiably elevated to a level beyond which can be safely done from the data. We provide three examples.

Example 1: Fracturing society. The WM article expresses "concern that the legislation for AD in New Zealand has potential to fracture family and community structures" (p21). This statement is followed by the interviewee suggesting that "fractured families" make it more likely, without "support of their family", to seek AD (p21). The first problem is that there is no evidence in the quote that the interviewee was basing his comment on experience within his family (as opposed to speculation about what might happen). The second problem is that the authors' claim—that AD legislation could fracture family and community structures—is different from the interviewee's point, namely that those without family support (ie, in already fractured families) may be more likely to seek AD. Yet, the segue is made from one to the other. The third problem is the shift from families (as stated by the interviewee), to the "potential to fracture family and **community structures**" (emphasis added) (p21), and then to the even broader claim of "potential of fracturing of **our New Zealand communities and broader social settings**" (emphasis added) (p21). This progression involves a significant shift from the data (a family perspective) to the wider community level.

Example 2: AD contagion. The article itself noted that the interviewee only "hinted" (p21) at this issue. This was based on the interviewee having known "three extended family members use the [AD] legislation over a short period of time" as well as AD being chosen by two of his father's friends. However, nothing about contagion can be drawn from his quotes—there is no evidence that the three extended family members or two friends of his father who had AD knew each other or knew that each other had had AD. Furthermore, the interviewee worries that AD may be "infectious" (p21) but does not link this to the experience of his extended family member receiving AD (essential for the case study method). It could just be a pre-existing fear unrelated to the case study.

Even more concerning is that this discussion of contagion, which comprised only three paragraphs in the Results section, was transformed into a substantive concern. The shift during the article is noteworthy: from the interviewee hinting at the issue, to the conclusion calling for further research to investigate "whether a contagion effect of AD is **possible**", and then "(or even **probable**)" (emphasis added) (p22).

Example 3: "Slippery slopes". The WM article claims the data support slippery-slope arguments. Because of this claim's significance, two key sentences are extracted in full here: "In conducting this study, it was anticipated that social consequences of AD legislation may be present in terms of the slippery-slope discourse. However, it was unexpected to obtain data that painted a distinct picture of how the slippery-slope effect was unfolding in a country where AD was legal" (p21, endnotes omitted). The interviewee noted a view that there may be an expectation on people to use AD, and we understand this to be the sense in which the term slippery slope is used. (We note, however, that this is not what the "slippery-slope effect" in the "slippery-slope discourse" generally means—even in the literature the authors reference for this claim).

Claims that a "distinct picture" (p21) of this occurring (an expectation that people use AD) are unsustainable. We note the many empirical studies which rebut the common slippery-slope claim that the vulnerable are more likely to seek AD.[7–10] These studies include large meta-analyses or population-level studies (and so are at or towards the top of the reliability pyramid). They have been peer reviewed, and many have also been the subject of further external testing by courts,[11] expert panels[12–14] and non-partisan parliamentary committees.[15,16] When this sort of research is placed beside the WM article, it is not reasonable to consider this single interview as reliable evidence of the "slippery-slope effect" (p21).

Appropriate statements of limitations of research

The WM article does not have a sufficiently robust statement of limitations. It acknowledges that it is based on a single interview, and that this interview was conducted in a country other than New Zealand (where AD is legal). However, the implications of this latter point are not identified, namely that findings from this single interview are not generalisable to other countries with different healthcare, social welfare, and legal systems and AD models. To illustrate, it is unclear if AD in the case study would have been available under the EOLCA, as no mention is made of an eligible terminal illness (indeed, the description at p19 makes it highly unlikely). The WM article also fails to note that a person's pre-existing views about AD may affect their assessment of their experience. But perhaps the most significant limitation omitted was to make clear that views expressed in a single interview cannot support claims about wider societal effects such as community expectations to die and AD contagion. Indeed, instead of noting such limitations, these data from a single interview were explicitly used to ground such claims.

‘Generation’ of evidence through discussion of issues on which no data is reported

Finally, conclusions were drawn where there were **no** data to support such findings. While consideration of related issues may occur in an article, particularly in Background or Discussion sections, a study’s results and conclusions must be grounded in data.

The WM article at times identifies a concern about AD raised in literature (often without mentioning conflicting literature: see below). It then discusses that issue as a concern of substance, but this occurs without supporting data from the interview. One example is the claim that AD will be shaped by financial drivers. The article notes a potential consequence of AD legislation that it “reduces our future existence to being considered only through the practical lens relating to the cost of care and reduces our life to having a dollar value” (p21). This is revisited in the Conclusion: “… this case study offers insight into some elements associated with slippage [reference to slippery slope in sentence preceding] in terms of family members being expected to die when their care becomes too difficult or expensive” (p22). This significant (and very controversial) issue was not present in the data reported so its inclusion in the article’s Conclusion is not justifiable.

Criterion 3: Reliability evidenced by factual claims being defensible in light of literature

Authors must ensure that factual claims are defensible having regard to the weight of reliable literature and the field’s current state of knowledge. Some claims in the WM article cannot be defended in this way. We are not able to comprehensively catalogue all such concerns here. However, we provide one example of a claim that is not defensible and is also presented in a misleading way. The relevant passage appears in Background: “Despite the potential for those using AD legislation to be judged or stigmatised, there is further concern that AD may produce a contagion effect.[13–15] Jones and Paton observed that unlike some studies that perceived AD as providing a suicide-inhibiting effect, their results suggested that any inhibitory mechanisms were counteracted by ‘equal or larger opposite effects’[16–18]” (p19, WM endnotes in Figure 2).

A preliminary point is why, when the article claims to focus on *AD* contagion (ie, cases of AD leading to more AD cases), it shifts to engage with literature on the different issue of *suicide* contagion (ie, legalising AD leading to an increased suicide rate). Further, its suggestion that suicide contagion is a credible concern (later leveraged in potential concerns about AD contagion) is not supported by the literature, nor does the article engage with the current state of knowledge.

For instance, there is a later article by Lowe and Downie[17] which critically analyses the primary source relied upon for suicide contagion (Jones and Paton), but this was not considered or even acknowledged in the WM article. Lowe and Downie identify significant errors in the Jones and Paton methodology and concerns about how the results were presented, and urge caution in relation to its findings.[17] While not all literature can be cited, it is concerning that an article which has been the subject of a detailed critical analysis is presented without qualification. Also missing was the report from a major review of the state of evidence in relation to various aspects of AD undertaken by the Council of Canadian Academies (comprised of experts both in favour of AD and opposed). It concluded, including after considering the two papers above: “There is no evidence of any association between the legal status of assisted dying in a country and its suicide rate”.[18] In short, there is no reliable evidence that suicide contagion will occur if AD is legalised.

A further concern is that the WM article references (Figure 2) are misleading, creating the perception that six references support the suicide contagion proposition in some way. In fact, only one study purports to consider suicide contagion (Jones and Paton: reference 16, although as noted above, Lowe and Downie argue it does not address this concept and should not be relied upon[17]). References 13 and 14 address potential stigma of AD (presumably a reference for the first half of the sentence), while reference 17 is Posner's book, which includes a claim that AD may reduce rates of suicide (contrary to suicide contagion). Reference 18 appears to be to Hansard (not a study but rather a statement in parliament) although incomplete citation details mean we cannot locate what the parliamentarian said. Reference 15 refers to suicide contagion (incorrectly according to Lowe and Downie[17]) but is not an independent study, rather just a commentary on the Jones and Paton article.

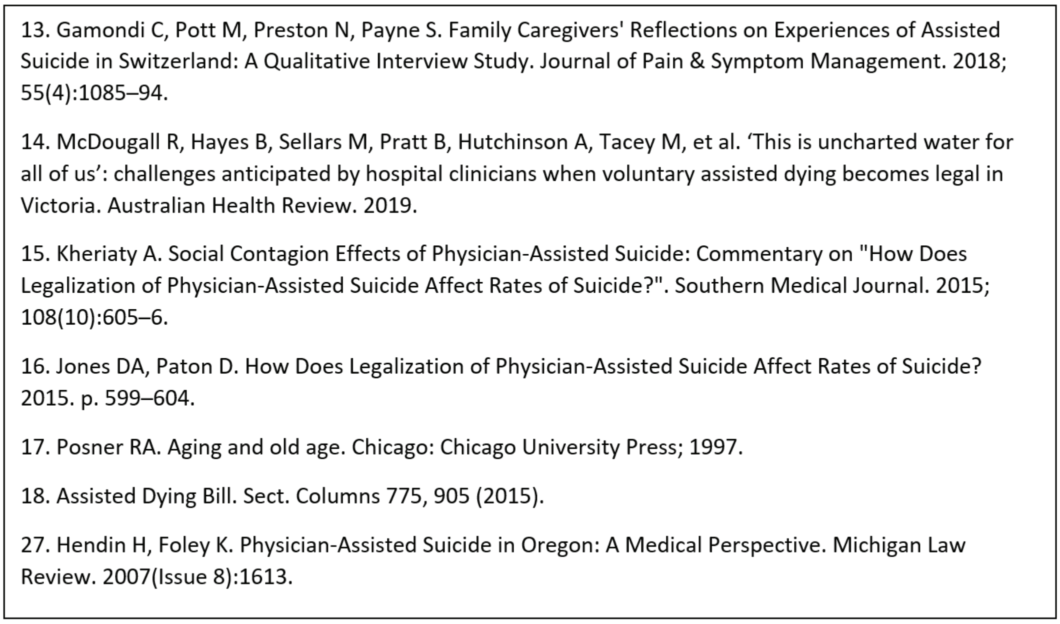
There are other concerns about engagement with literature that could be raised. One is using literature which draws on anecdotal evidence (at the bottom of the reliability pyramid): both the Kheriaty (reference 15) and Hendin and Foley (reference 27) articles are relied upon by the WM article but they are in turn merely reporting on single cases they read about in newspaper reports. Another is not engaging with the large body of social science literature (and findings of expert panels, non-partisan parliamentary committees and courts) about "slippery slopes" (discussed above), and also being unclear about what is meant by this concept. However, as mentioned, there is not scope to include these more detailed analyses here.

Discussion

The New Zealand public will shortly decide whether AD should become lawful. Evidence-based law-making, including through a referendum, is critical, especially for significant social policy reform such as AD. This requires critical review of evidence proffered to inform public debates and public decision-making about AD.

The WM article proposed it be considered as evidence in the deliberations about AD in New Zealand. Our analysis has concluded, however, that the article is not reliable evidence and should not form part of these deliberations. It is based on a single interview with a person (the brother-in-law of a person who accessed AD) from an unidentified country where AD is legal (not New Zealand). This methodology is not capable of supporting the article's significant claims, in particular about potential expectations that people when unwell and facing a life-threatening illness should use AD and the potential of AD contagion. In addition, the WM article presents assertions beyond what its very limited data can sustain and

Figure 2: Selected references as cited by Winnington and MacLeod article.



13. Gamondi C, Pott M, Preston N, Payne S. Family Caregivers' Reflections on Experiences of Assisted Suicide in Switzerland: A Qualitative Interview Study. Journal of Pain & Symptom Management. 2018; 55(4):1085–94.

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17. Posner RA. Aging and old age. Chicago: Chicago University Press; 1997.

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27. Hendin H, Foley K. Physician-Assisted Suicide in Oregon: A Medical Perspective. Michigan Law Review. 2007(Issue 8):1613.

indeed, makes claims for which there is no data in support. Further, the study fails to appropriately limit the scope of its findings; indeed, it makes claims beyond what is justified. Finally, its reliability can also be questioned as not all of its factual claims can be supported by the social science literature.

We conclude by repeating our call for evidence-making law-making on the critical social policy issue of AD.[1]

Competing interests:

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COMPARATIVE AND CRITICAL ANALYSIS OF KEY ELIGIBILITY CRITERIA FOR VOLUNTARY ASSISTED DYING UNDER FIVE LEGAL FRAMEWORKS

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Eligibility criteria determine a crucial question for all voluntary assisted dying frameworks: who can access assistance to die? This article undertakes a critical and comparative analysis of these criteria across five legal frameworks: existing laws in Victoria, Western Australia, Oregon and Canada, along with a model Bill for reform. Key aspects of these criteria analysed are capacity requirements; the nature of the medical condition that will qualify; and any required suffering. There are many similarities between the five models but there are also important

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We disclose that Ben White and Lindy Willmott were engaged by both the Victorian and Western Australian governments to design and provide the legislatively mandated training for doctors involved in voluntary assisted dying. Jayne Hewitt was the project manager for the Victorian training project and Rebecca Meehan, Laura Ley Greaves and Eliana Close were employed on the project. Eliana Close and Katrine Del Villar were also employed on the Western Australian training project. James Cameron was a Senior Legal Policy Officer at the Department of Health and Human Services (Victoria) and developed and implemented the *Voluntary Assisted Dying Act 2017* (Vic). Jocelyn Downie was a member of the Royal Society of Canada Expert Panel on End-of-Life Decision-Making, a member of the plaintiffs' legal team in *Carter v Canada (Attorney General)* [2015] 1 SCR 331, a member of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and a member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. Rebecca Meehan is an employee of Queensland Parliament, but this article only represents her views. Ben White is a recipient of an Australian Research Council Future Fellowship (project number FT190100410: Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying) funded by the Australian government. The authors gratefully acknowledge the research assistance of Emily Bartels.

differences which can have a significant impact on who can access voluntary assisted dying and when. Further, seemingly straightforward criteria can become complex in practice. The article concludes with the implications of this analysis for designing voluntary assisted dying regulation. Those implications include challenges of designing certain yet fair legislation and the need to evaluate voluntary assisted dying frameworks holistically to properly understand their operation.

I INTRODUCTION

Internationally, voluntary assisted dying ('VAD') is permitted in an increasing number of jurisdictions. In Europe, VAD is legal in certain circumstances in the Netherlands,[1] Belgium[2] and Luxembourg.[3] Further, in Switzerland,[4] and more recently in Germany,[5] assisting a person to self-administer lethal medication in certain circumstances has been decriminalised. In the United States of America ('US'), there are now ten states and one district where VAD is lawful, with ten having legalised the practice by passing legislation[6] and one through judicial decision.[7] VAD is also permitted in Canada[8] and Colombia.[9]

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[1] *Wet Toetsing Levensbeëindiging op Verzoek en Hulp Bij Zelfdoding 2001* [Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001] (The Netherlands).

[2] *Loi Relative à L'euthanasie 2002* [Act on Euthanasia 2002] (Belgium).

[3] *Legislation Reglementant les Soins Palliatifs ainsi que L'euthanasie et L'assistance au Suicide 2009* [Legislation Regulating Palliative Care and Euthanasia and Assisted Suicide 2009] (Luxembourg).

[4] *Schweizerisches Strafgesetzbuch 1937* [Swiss Criminal Code 1937] (Switzerland) art 115: 'Any person who for selfish motives incites or assists another to commit or attempt to commit suicide is, if that other person thereafter commits or attempts to commit suicide, liable to a custodial sentence not exceeding five years or to a monetary penalty'.

[5] Bundesverfassungsgericht [German Constitutional Court], 2 BvR 2347/15,ECLI:DE:BVerfG:2020:rs20200226.2bvr234715, 26 February 2020 reported in (2020) BverfG1.

[6] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.897 (1994) ('*Oregon Act*'); *Death with Dignity Act*, Wash Rev Code §§ 70.245.010–70.245.903 (2008); *Patient Choice and Control at End of Life Act*, Vt Stat Ann §§ 5281–93 (2013); *End of Life Option Act*, Cal Health and Safety Code §§ 443–443.22 (West 2015); *Death with Dignity Act of 2016*, DC Code §§ 7-661.01–7-661.16 (2017) (District of Columbia); *Colorado End-of-Life Options Act*, Colo Rev Stat §§ 25-48-101–25-48-123 (2017); *Our Care, Our Choice Act*, Haw Rev Stat §§ 327L-1–327L-25 (2018); *Medical Aid in Dying for the Terminally Ill Act*, NJ Stat Ann §§ 26:16-1–26:16-20 (West 2021); *Maine Death with Dignity Act*, 22 Me Rev Stat Ann § 2140 (2019); *Elizabeth Whitefield End-of-Life Options Act*, NM Stat § 3 (2021).

[7] *Baxter v Montana*, 224 P 3d 1211 (Mont, 2009). Pope argues that VAD is also lawful in North Carolina through a 'standard of care' approach. There is no legislation, regulation or court case that permits VAD, but VAD is not prohibited under current law. See Thaddeus Pope, 'Medical Aid in Dying: Key Variations Among U.S. State Laws' (2020) 14(1) *Journal of Health and Life Sciences Law* 25, 35.

[8] Across Canada through the *Criminal Code*, RSC 1985, c C-46, ss 241.1–241.4 ('Canadian *Criminal Code*') and in Quebec also through the *Act Respecting End-of-Life Care*, RSQ 2014, c S-32.0001. The criteria in these laws are similar but not identical. However, because the federal law applies across the whole of Canada, this article focuses on the eligibility criteria contained in the Canadian *Criminal Code*.

[9] A court decision in Colombia permitted VAD in 1997: *Sentence C-239/97*, Republic of Colombia Constitutional Court, Ref Expedient D-1490, 20 May 1997, which was followed by government regulations to facilitate the practice in 2015: Ministry of Health and Social Protection, *Protocolo para la Aplicación del Procedimiento de Eutanasia en Colombia* [Protocol for the Application of the Procedure of

Australia too has seen law reform in this area. In November 2017, the *Voluntary Assisted Dying Act 2017* (Vic) (‘*Victorian Act*’) was passed. It came into force on 19 June 2019, permitting VAD in Australia for the first time in 20 years.[10] This was followed in December 2019 by the enactment of the *Voluntary Assisted Dying Act 2019* (WA) (‘*WA Act*’), after an extensive parliamentary debate which followed reviews by a Parliamentary Committee[11] and a Ministerial Expert Panel.[12] These laws may herald a shift in political thinking, because despite a long history of unsuccessful attempts of reform,[13] it appears that the climate in Australia may now be more conducive to change.[14] As this article was being finalised for publication, Tasmania passed VAD legislation,[15] there is a Bill before the South Australian[16] and Queensland[17] Parliaments, and a Bill is also proposed in 2021 in New South Wales.[18]

A key policy question for Australian and international legislators when designing such laws is who should be permitted to access VAD. The primary means by which access is regulated is through eligibility criteria. Although generally only a small part of the legislation in terms of the number of provisions, eligibility criteria play a significant role in determining the breadth of VAD laws. Broad eligibility criteria exclude very few individuals from VAD, whereas narrow and tightly constrained criteria can significantly limit access.

This article is the first in a two-part series[19] that critically analyses the scope and operation of eligibility criteria in five VAD legal frameworks. In particular, the articles consider these two questions: for what medical conditions, and at what stage in the trajectory of those conditions, would a person be eligible to access VAD? While eligibility criteria commonly contain provisions unrelated to a person’s health state, such as residency and age requirements, the most contentious

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Euthanasia in Colombia] (Report, 2015) <https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/DE/CA/Protocolo-aplicacion-procedimiento-eutanasia-colombia.pdf>.

[10] VAD was briefly permitted in the Northern Territory by the *Rights of the Terminally Ill Act 1995* (NT) but this legislation was overturned later by the *Euthanasia Laws Act 1997* (Cth).

[11] Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice* (Report No 1, 23 August 2018).

[12] Ministerial Expert Panel on Voluntary Assisted Dying, Department of Health (WA), *Final Report* (Report, June 27 2019) (‘*MEP Report*’).

[13] For a detailed discussion of the history of attempts at law reform in Australia, see Lindy Willmott et al, ‘(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics’ (2016) 39(1) *University of New South Wales Law Journal* 1. See also updated data in Ben White and Lindy Willmott, ‘Future of Assisted Dying Reform in Australia’ (2018) 42(6) *Australian Health Review* 616 (‘Future of Assisted Dying Reform’).

[14] White and Willmott, ‘Future of Assisted Dying Reform’ (n 13) 618–19.

[15] *End-of-Life Choices (Voluntary Assisted Dying) Act 2021* (Tas). This will take effect in October 2022, after a prescribed implementation period: s 2.

[16] Voluntary Assisted Dying Bill 2020 (SA).

[17] Voluntary Assisted Dying Bill 2021 (Qld).

[18] Michael Koziol, ‘Fresh Bid to Legalise Assisted Dying Set to Test NSW Government’, *Sydney Morning Herald* (online, 13 December 2020) <https://www.smh.com.au/politics/nsw/fresh-bid-to-legalise-assisted-dying-set-to-test-nsw-government-20201209-p56m2t.html>.

[19] The second article is Ben P White et al, ‘Who is Eligible for VAD? Nine Medical Conditions Assessed Against Five Legal Frameworks’ (2022) 45(1) *University of New South Wales Law Journal* (forthcoming) (‘Who is Eligible for VAD?’).

discussion when debating eligibility under VAD laws has been in relation to when, and with what medical conditions, a person could seek access to VAD.[20]

This first article undertakes a critical analysis of the eligibility criteria outlined in five selected models of VAD, with a particular focus on those criteria that are relevant to a person's health state. Key aspects of those criteria are: the nature of the medical condition or illness a person must have, and the requirement to retain decision-making capacity when seeking VAD. The criteria in three Australian models have been chosen for review: the *Victorian Act*, the *WA Act*, and a model Voluntary Assisted Dying Bill 2019 ('Model Bill')[21] recommended by the Queensland Parliamentary Inquiry considering VAD as the proposed basis for reform.[22] The Victorian legislation has served as a basis for both the *WA Act* and the Model Bill, although both incorporate important differences.

Additionally, the review includes two other important common law comparators.[23] The first is Oregon's *Death with Dignity Act 1994* ('*Oregon Act*').[24] It is the original legislation in the US and has largely been copied by other states in that country. It was also cited as an important departure point when designing the Victorian model.[25] The second law considered is Canada's federal law about VAD (called 'MAiD': medical assistance in dying), which is contained in its *Criminal Code* ('Canadian *Criminal Code*').[26] Shared legal heritage means Canada is a

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[20] For example, in Victoria, the debate on the eligibility criteria ranged over people with neurological disease, an insulin dependent diabetic who decides to stop taking insulin, renal disease, terminal cancer, people with disabilities, loneliness, incontinence, autism and mental illness: Victoria, *Parliamentary Debates*, Legislative Council, 21 November 2017, 6216–24, 6232–9. In Western Australia, the debate on the eligibility clause was briefer, but canvassed a person with gangrene who refuses amputation and a diabetic who refuses insulin (Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9199–201), as well as people with autism and mental illnesses such as schizophrenia, anorexia and depression (Western Australia, *Parliamentary Debates*, Legislative Council, 22 October 2019, 7978–9 (Rick Mazza)).

[21] Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1 ('Model Bill').

[22] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020) 105, 'Recommendation 1' ('*Queensland Parliamentary Report*').

[23] We note that the New Zealand Parliament passed its *End of Life Choice Act 2019* (NZ) in late 2019 (which would only take effect if approved by a public referendum, as subsequently occurred in late 2020). However, this occurred only after this analysis in this article was finalised and accordingly, we will not consider this Act further. Also not included are the European models and Colombia. This is because these jurisdictions are culturally more distinct from Australia than other common law countries, and their laws operate within quite different legal systems.

[24] *Oregon Act*, Or Rev Stat §§ 127.800–127.995 (1994).

[25] For example, in relation to the eligibility criteria: preference for self-administration at a time of the person's choosing without a medical practitioner needing to be present; a prescribed waiting period before VAD can be accessed; review and reporting: Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report, 9 June 2016) 217–18, 228 ('*LSIC Report*'). There are also numerous references to similarities between the *Oregon Act* and the proposed Victorian law in the Ministerial Advisory Panel on Voluntary Assisted Dying, Department of Health and Human Services (Vic), *Final Report* (Report, 31 July 2017) ('*MAP Report*'). See examples just in relation to the eligibility criteria: at 53, 55, 56, 63, 69.

[26] Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.1–241.4. The Canadian law has undergone various iterations (including through amendments made through Bill C-14, *An Act to Amend the Criminal Code*

natural comparator for Australia when considering law reform.[27] Canada's MAiD law has been considered, and Canadian experts consulted, in Australian reviews of VAD,[28] for example, in respect of its terminology requiring the person's medical condition to be 'incurable',[29] and in relation to the requirement of unbearable or intolerable suffering.[30]

After critically analysing each of the varying approaches to eligibility, this article undertakes a comparative analysis of the five jurisdictions to identify important areas of similarity and difference. Although this work establishes the foundation for the consideration of medical conditions that follows in the second article, this legal analysis is significant in its own right and has implications for designing VAD regulation, which are identified in Part IV.

The second article then applies this analysis to evaluate whether different medical conditions would be eligible for VAD under the five regimes. These conditions are: cancer (specifically colorectal cancer), motor neurone disease, chronic obstructive pulmonary disease, chronic kidney disease, dementia (specifically Alzheimer's disease), anorexia, spinal cord injury, Huntington's disease and frailty. This diverse group of conditions was chosen with a view to illustrate how the various eligibility criteria would apply in a range of settings. Regard was had to considerations such as those conditions most likely to be relied upon to access VAD, common causes of death in Australia, and conditions in the literature that have sparked controversy about access to VAD.

The analysis in the second article demonstrates how changes in the framing of eligibility criteria can have an impact on who is included or excluded from accessing VAD, and at what point this access may be possible in their illness trajectory. This has implications for law reform, for example, when certain conditions may be seen by the public as important in the case for allowing VAD, but people with those conditions would not be eligible for VAD under the law as drafted. Another conclusion from this research is that concrete thinking is needed when designing VAD laws. While criteria can be considered in the abstract, it is this practical exercise of ascertaining where eligibility criteria will draw lines that is critical. While these decisions have been made for Victoria and Western Australia as their Acts have passed, there is scope to inform the remaining Australian jurisdictions (and indeed other countries) considering VAD reform.

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and to Make Related Amendments to Other Acts (Medical Assistance in Dying), 1st Sess, 42nd Parl, 2016 ('Bill C-14') and Bill C-7, *An Act to Amend the Criminal Code (Medical Assistance in Dying)*, 1st Sess, 43rd Parl, 2020 ('Bill C-7')).

[27] White and Willmott, 'Future of Assisted Dying Reform' (n 13) 618; Stephen Kirchner, Sean Speer and Jason Clemens, 'Policy Reforms in Australia and What They Mean for Canada' (Research Paper, Fraser Institute, 3 December 2013) <https://ssrn.com/abstract=2392622>. See also, particularly in relation to reform of the common law by reference to United Kingdom and Canadian examples: *Cook v Cook* (1986) 162 CLR 376, 390 (Mason, Wilson, Deane and Dawson JJ); James Allsop, 'Some Reflections on the Sources of Our Law' (2014) 11(4) *Judicial Review* 365, 371–2.

[28] The Ministerial Expert Panel in Western Australia met with four Canadian experts and one from Oregon in drafting the VAD legislation: *MEP Report* (n 12) 126. Note that Quebec was also considered in Victoria's *MAP Report*: see above n 25.

[29] See, eg, *MEP Report* (n 12) 33–4 (although they did not adopt this criterion).

[30] See *LSIC Report* (n 25) 217.

We conclude this introduction with two practical matters. The first is about the scope of analysis of the eligibility criteria. The focus of this two-part series is on the contentious issue of the impact that a person's medical condition has on their eligibility to access VAD. Accordingly, the analysis which follows emphasises criteria such as whether a condition is incurable or likely to cause death, and gives less consideration to other criteria, such as age and residency requirements.

The second practical matter is about terminology. In general, the terminology in relation to VAD used in the *Victorian Act* (and subsequently mirrored in the Model Bill and the *WA Act*) will be adopted. VAD therefore includes both 'self-administration' (where the person takes the prescribed medication themselves, sometimes called physician-assisted suicide or dying) and 'practitioner administration' (where the person is administered the medication by a doctor, or nurse practitioner in Western Australia or Canada, sometimes called voluntary euthanasia). However, when considering Canadian law, the specific defined term used in that law (MAiD) will be used. The article will also refer to a person's 'medical condition'. This is meant in a broad sense, whether that condition is caused by disease, illness, disability, or injury, although we note some VAD laws specifically address these latter concepts.

II ELIGIBILITY CRITERIA OF FIVE MODELS

A Introduction

This section outlines the eligibility criteria in the five VAD models: three Australian models in chronological order (the *Victorian Act*, the Model Bill and the *WA Act*) and then the *Oregon Act* and the Canadian *Criminal Code*. As noted above, while all eligibility criteria are noted for completeness, this article focuses on analysing those criteria particularly relevant to determining which medical conditions may provide access to VAD. A final point to note is that the Canadian eligibility criteria have been subject to extensive discussion, including academic commentary specifically aimed at interpreting these criteria, as well as some judicial and now legislative consideration, and this is reflected in the extended treatment of this jurisdiction's law below. By contrast, the Australian models are very new and have been subject to very limited critical analysis to date, and so are addressed more succinctly.

B *Voluntary Assisted Dying Act 2017* (Vic)

The *Victorian Act* came into force on 19 June 2019 after a planned 18-month implementation period and permits access to VAD after a rigorous process that requires at least three requests from an eligible patient and at least two assessments by qualified and trained medical practitioners. VAD is intended usually to be self-administered, as practitioner administration is permitted only when a person is physically incapable of taking or digesting the medication themselves.[31] The Victorian law was described by the Victorian government at the time of introduction to Parliament as the safest and most conservative VAD model in the world.[32]

Part of this claim is based on the Act's eligibility criteria. Section 9(1) of the *Victorian Act* outlines the primary eligibility criteria and states that '[f]or a person to be eligible for access to voluntary assisted dying':

> (a) the person must be aged 18 years or more; and
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> (b) the person must–
>
> (i) be an Australian citizen or permanent resident; and
>
> (ii) be ordinarily resident in Victoria; and
>
> (iii) at the time of making a first request, have been ordinarily resident in Victoria for at least 12 months; and
>
> (c) the person must have decision-making capacity in relation to voluntary assisted dying; and
>
> (d) the person must be diagnosed with a disease, illness or medical condition that–
>
> (i) is incurable; and
>
> (ii) is advanced, progressive and will cause death; and
>
> (iii) is expected to cause death within weeks or months, not exceeding 6 months [or 12 months if the disease, illness or medical condition is neurodegenerative];[33] and
>
> (iv) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.

Section 9 continues and clarifies that disability and mental illness alone are not grounds to access VAD.[34] However, the mere fact of a disability or a mental illness will not preclude a person from accessing VAD if the eligibility criteria are met.[35]

1 Decision-Making Capacity

Subsection 9(1)(c) requires the person to have decision-making capacity in relation to VAD and this is assessed at multiple points during the process.[36] If VAD is provided by practitioner administration, capacity is also specifically assessed at that final point in time. For self-administration, capacity is assessed at each stage during the request and assessment process but not at the time of ingestion, as this is done later at a time of the person's choosing and without a practitioner necessarily being present.

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[31] *Voluntary Assisted Dying Act 2017* (Vic) ss 46, 48 ('*Victorian Act*').

[32] Daniel Andrews, 'Voluntary Assisted Dying Model Established Ahead of Vote in Parliament' (Media Release, Premier of Victoria, 25 July 2017) 1 <https://www.premier.vic.gov.au/voluntary-assisted-dying-model-established-ahead-of-vote-in-parliament> ('Andrews Media Release').

[33] The words in square brackets have been inserted based on *Victorian Act 2017* (Vic) s 9(4).

[34] Ibid ss 9(2)–(3).

[35] *MAP Report* (n 25). See 'Ministerial Advisory Panel Recommendation 5' in respect of mental illness: at 80–2. See also 'Ministerial Advisory Panel Recommendation 6' in respect of disability: at 83–5.

[36] *Victorian Act 2017* (Vic) ss 16, 25, 36, 47, 48, 64.

A person has decision-making capacity if they meet four requirements. The person must be able to understand the relevant information, retain that information, use or weigh the information as part of a decision-making process, and communicate their decision.[37] There is a presumption that an adult has decision-making capacity, and to displace that presumption, it must be demonstrated they do not meet one of the four requirements.[38] Under the legislation, a person is unable to make a request for VAD in advance of losing decision-making capacity by means of an advance directive.[39]

The decision-making capacity assessment only requires doctors to assess whether the person meets the four requirements, not whether they consider the person's decision to be wise.[40] The limited basis on which a doctor may determine a person does not have decision-making capacity is further explained in the Guidance for Health Practitioners produced by the Victorian Department of Health and Human Services.[41] As that document makes clear, the presence of depression or other mental illness does not necessarily mean a person lacks decision-making capacity. What is being assessed is whether the person meets the four requirements listed and mental illness does not necessarily prevent this.

Consistent with other Victorian legislation,[42] the *Victorian Act* also recognises decision-making capacity is decision specific, that information may be tailored to meet a person's particular needs, and that people may be supported to make decisions. The Act adopts an inclusive approach to assessing decision-making capacity, recognising that people may understand or communicate things in different ways and that this does not necessarily mean they cannot make decisions for themselves.[43] The Act also recognises a person may have decision-making capacity if they are able to make a decision through the use of practicable supports.[44] These provisions recognise people using non-standard forms of communication or receiving some form of support should not be excluded from accessing VAD on this basis.

2 Disease, Illness or Medical Condition that Is Incurable

Subsection 9(1)(d)(i) of the *Victorian Act* requires the relevant disease to be 'incurable'. The Explanatory Memorandum explains that this assessment is based on the individual's circumstances and comorbidities, but whether a disease is 'incurable' is a question of 'whether there is a clinically indicated treatment that

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[37] Ibid s 4.

[38] Ibid s 4(2).

[39] *Medical Treatment Planning and Decisions Act 2016* (Vic) s 8A as inserted by *Victorian Act 2017* (Vic) s 140.

[40] Ibid s 4(4)(c).

[41] Department of Health and Human Services (Vic), 'Voluntary Assisted Dying: Guidance for Health Practitioners' (Clinical Guideline, 4 July 2019) 34 <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying/coordinating-consulting-medical-practitioner-information> ('Guidance for Health Practitioners').

[42] See, eg, *Medical Treatment Planning and Decisions Act 2016* (Vic) s 4; *Powers of Attorney Act 2014* (Vic) s 4.

[43] *Victorian Act 2017* (Vic) s 4(3).

[44] Ibid s 4(4)(d).

will cure the disease'.[45] During the parliamentary debate, Minister Jennings further clarified this by stating that '[t]his is an objective test based on available medical treatments'.[46]

The Explanatory Memorandum also recognises that '[t]here is a difference between *managing* the symptoms of a disease, illness or medical condition and *curing* it, which requires the complete eradication of the disease, illness or medical condition'.[47] For example, renal dialysis manages kidney disease, but it does not cure the disease. The fact that a person refuses treatment for a curable disease does not make it incurable (although refusing treatment may allow the condition to progress to the point that it becomes incurable). This suggests the assessment of whether a disease is incurable is a medical assessment based on available treatments and that a person will not be eligible if they are refusing treatment for an otherwise curable condition.

3 Disease, Illness or Medical Condition that Is Advanced and Progressive

It is not sufficient that a disease is incurable; it must also be advanced and progressive.[48] These criteria mean the person's condition must be deteriorating and this deterioration must be at an advanced stage.

Neither the term 'advanced' nor the term 'progressive' is defined. The Department of Health and Human Services' Guidance for Health Practitioners suggests a condition will be progressive if 'the patient is experiencing an active deterioration'.[49] Applying the ordinary meaning of the term 'advanced' suggests the condition must have significantly progressed along its expected trajectory. When applied in conjunction with the term 'progressive', it must be expected the person will continue to decline along this trajectory. This would prevent access by people in the earlier stages of a terminal condition. The extent to which a condition is advanced and progressive may also cause confusion, as both criteria are ultimately a question of degree and one may ask how far advanced a condition needs to be or what constitutes progression. In practice, the effect of these criteria and any potential confusion are likely to be limited. This is because of the further requirement that death must be expected within 6 months (or 12 months for a neurodegenerative condition). In order to meet these timeframes, it is likely the person's condition would be advanced and progressive, which gives context to what is meant by these terms.

4 Disease, Illness or Medical Condition that Will Cause Death and Is Expected to Cause Death Within 6 or 12 Months

The relevant condition must be one that will cause death. The necessary connection between the condition and the ultimate cause of death has not been explained in either parliamentary debates or subsequent health policies. For many

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[45] Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3 cl 9.

[46] Victoria, *Parliamentary Debates*, Legislative Council, 21 November 2017, 6218 (Gavin Jennings).

[47] Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3 cl 9 (emphasis added).

[48] *Victorian Act 2017* (Vic) s 9(d)(ii).

[49] 'Guidance for Health Practitioners' (n 41) 37.

conditions, death may be the result of organ failure that is a predictable but not necessary outcome of the condition. For example, a metastatic cancer may hinder the functioning of the digestive system, which may result in malnourishment and dehydration that causes death. It is suggested that the requirement that a condition will cause death will be fulfilled if the condition causes a chain of events that will result in death.

Under subsection 9(1)(d)(iii) of the *Victorian Act*, the medical condition must be expected to cause death within 6 months, except in the case of neurodegenerative conditions where the relevant time is 12 months. The assessment of this criterion is complex because 'most prognostication tools have been developed to assist in identifying patients' needs and to plan care and support, not for determining a timescale for death'.[50] The words 'expected to' in this criterion appear to recognise prognosis is not an exact science and cannot be as definitive as some of the other eligibility criteria.

While the requirement for the condition to be 'incurable' must be based on an objective assessment of clinically indicated treatments, an assessment of whether the disease will cause death and will do so within the requisite timeframe must consider the individual and the treatments acceptable to them. The Explanatory Memorandum explains that, in assessing the timeframe within which a person is expected to die, a medical practitioner must consider the 'individual's own particular circumstances, including their condition, their comorbidities, and the available treatments that they are prepared to accept, noting the right to refuse medical treatment'.[51] This recognises that conditions progress in different ways in different people. It also recognises that if a person has an incurable condition but there are treatments that could slow the progress of that disease, they should not be required to undergo all such treatments prior to accessing VAD. For example, a person who chooses not to undergo further chemotherapy for quality of life reasons may still be eligible for VAD even if that treatment may temporarily prolong their life.

5 Disease, Illness or Medical Condition Is Causing Suffering

The final criterion in subsection 9(1)(d)(iv) of the *Victorian Act* is that the condition must be causing suffering that cannot be relieved in a manner deemed tolerable by the person. The use of the term 'suffering' recognises that a condition may cause more than physical pain to a person, and that existential distress or other forms of suffering caused by the condition may also be sufficient.[52] This assessment has two parts. First, the person's suffering must be caused by their condition. Second, the suffering must not be able to be relieved in a manner deemed tolerable by the person. Whether suffering can be relieved is a 'subjective' assessment, assessed by the person.[53]

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[50] Ibid 38.

[51] Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3 cl 9.

[52] Guidance for Health Practitioners (n 41) 39.

[53] Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3 cl 9; see also Victoria, *Parliamentary Debates*, Legislative Assembly, 21 September 2017, 2949 (Jill Hennessy).

C Model Voluntary Assisted Dying Bill 2019

The Model Bill was written by two of the authors and publicly released in April 2019 as a submission to the Queensland Parliament's inquiry into aged care, end of life and palliative care, and voluntary assisted dying.[54] The final report from that inquiry recommended that the Queensland government use the Bill 'as the basis for a legislative scheme for voluntary assisted dying'.[55] The goal of the Model Bill was to state preferred policy positions on VAD and represent those positions in the concrete form of a draft Bill that could be considered by jurisdictions undertaking reform. Although initially submitted to a Queensland law reform exercise, the Model Bill was written not only for that State and was proposed for consideration by other Australian States too.

The Model Bill is based on a series of values that had been articulated earlier as appropriate to guide design of a VAD law.[56] The values articulated as relevant were: life; autonomy; freedom of conscience; equality; rule of law; protecting the vulnerable; and reducing human suffering. In addition, influenced by the Victorian Ministerial Advisory Panel,[57] added to this list was the concept of safe and high quality care.[58]

The Model Bill also drew heavily on the *Victorian Act*, recognising that the Act had already been subject to intense scrutiny when debated and passed by an Australian Parliament. (The *WA Act* was not released at the time and so could not be considered.) Accordingly, the Bill adopted or adapted the drafting of the *Victorian Act* where the Model Bill's policy position was the same or similar. However, the application of these values did lead to some key differences between the *Victorian Act* and the Model Bill.[59] One key difference is that the Model Bill proposes that people be given a choice between self-administration and practitioner administration, and that VAD be medically supervised.[60] There are also some differences in relation to eligibility criteria.

Clause 9 of the Model Bill contains the eligibility criteria for access to VAD:

(a) the person must be aged 18 years or more; and

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[54] The Model Bill (n 21) was first published as a submission at <https://eprints.qut.edu.au/128753/> in April 2019 and was subsequently published as Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.

[55] *Queensland Parliamentary Report* (n 22) 105, 'Recommendation 1'. The Model Bill (n 21) was also referred to in the Western Australian reform process: *MEP Report* (n 12) 78. The Model Bill is currently being considered by the Queensland Law Reform Commission as part of its role in developing proposed VAD legislation: Queensland Law Reform Commission, *Queensland's Laws Relating to Voluntary Assisted Dying* (Terms of Reference, 21 May 2020) <https://www.qlrc.qld.gov.au/__data/assets/pdf_file/0004/651379/vad-tor.pdf>.

[56] These values are set out in Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 479, 488–99 ('Assisted Dying in Australia').

[57] *MAP Report* (n 25) 11, 22, 46. See also Ben P White et al, 'Does the *Voluntary Assisted Dying Act 2017* (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417 ('Does the *VAD Act* (Vic) Reflect Its Stated Policy Goals?').

[58] See Explanatory Notes: White and Willmott, 'Model Bill' (n 21) 6.

[59] Ibid 7–14 ('Explanatory Notes').

[60] Ibid 19–20 cl 6.

(b) the person must –
    (i) be an Australian citizen or permanent resident; and
    (ii) be ordinarily resident in [State]; and
(c) the person must have decision-making capacity in relation to voluntary assisted dying; and
(d) the person's decision to access voluntary assisted dying must be –
    (i) enduring;
    (ii) made voluntarily and without coercion; and
(e) the person must be diagnosed with a medical condition that –
    (i) is incurable; and
    (ii) is advanced, progressive and will cause death; and
    (iii) is causing intolerable and enduring suffering.

Clause 10 then clarifies certain aspects of the eligibility criteria. One clarification is that whether a person's medical condition will cause death is to be 'determined by reference to available medical treatment that is acceptable to the person'.[61] This is consistent with the Victorian position above but is made explicit in the Bill. The other clarifications relate to the nature of suffering required and stipulate that suffering:[62]

- is to be subjectively determined (again consistent with the *Victorian Act* but explicitly stated in the Bill);
- includes suffering caused by treatment for the medical condition; and
- includes physical, psychological and existential suffering (again explicit in the Bill but consistent with the Victorian approach).

Because of the Model Bill's similarity with the *Victorian Act*, the focus of the discussion here will be on the ways in which the Model Bill is different on the issue of eligibility. It is anticipated that, given the intentional use of the same or similar wording as in the *Victorian Act*, the analysis outlined above would also be generally applicable to the Model Bill.

The most significant difference in relation to eligibility is that the Bill does not include the Victorian requirement that death is expected within a specified timeframe. It was considered that a specified time limit is arbitrary.[63] Further, while a secondary consideration, not imposing a time limit avoids a registered medical practitioner having to engage in the difficult task of determining prognosis and timing of death.[64] In this way, the Model Bill is wider than the *Victorian Act* in that it does not limit access to VAD to a window of temporal proximity to death. However, despite the absence of a time limit, the Model Bill's other requirements

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[61] Ibid 21 cl 10(1).

[62] Ibid 21 cl 10(2).

[63] Ibid 8 ('Explanatory Notes'); Willmott and White, 'Assisted Dying in Australia' (n 56) 503.

[64] White and Willmott, 'Model Bill' (n 21) 9 ('Explanatory Notes'); Willmott and White, 'Assisted Dying in Australia' (n 56) 503–4.

cumulatively operate to restrict eligibility to persons suffering with an advanced, progressive and incurable medical condition that will cause death.

The Model Bill also differs from the *Victorian Act* in relation to suffering. It requires 'intolerable and enduring suffering', which is arguably higher than the level of suffering required under the Victorian legislation.

Another difference relevant to the medical conditions that may be eligible for access to VAD is the definition of decision-making capacity. Clauses 7(1) and (2) of the Model Bill define capacity in terms that correspond to the Victorian definition in sections 4(1) and (2) of that Act. However, the Model Bill does not include the extended explanation of capacity contained in the *Victorian Act* as noted above, for example, in relation to supported decision-making. The Model Bill's requirement that VAD be medically supervised also has implications for capacity in that immediately prior to VAD being provided, whether by self-administration or practitioner administration, the registered medical practitioner must ensure the person requesting VAD still has capacity.[65]

There are two final differences which are noted for completeness but are unlikely to impact on whether or not a person's medical condition will satisfy the eligibility requirements. One is that the Model Bill includes, as part of its eligibility criteria, a requirement that the person's decision to access VAD is enduring and made voluntarily and without coercion. While the *Victorian Act* does require assessment of these factors at various points during the request and assessment process,[66] this is not part of its formal eligibility criteria. In practice, this may not be significant given this aspect of decision-making is assessed under both systems. The other difference is residency. Under the Model Bill, only one of Victoria's residency requirements is included: namely, being a resident of the State. There is no 12-month residency limit prior to a first request being made for VAD.

D *Voluntary Assisted Dying Act 2019* (WA)

Following extensive consultation over a two-year period, the Voluntary Assisted Dying Bill 2019 (WA) was introduced into the Western Australian Parliament in August 2019 and after lengthy debate was passed in December 2019.[67] The *WA Act* broadly follows the approach of the *Victorian Act*. Some departures from the *Victorian Act* were designed to accommodate differences in the geography and demography of Western Australia.[68] Other departures reflect different policy positions. One notable example is that although the *WA Act* retains self-administration as the default approach, in some circumstances, practitioner

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[65] White and Willmott, 'Model Bill' (n 21) 31–3 pt 4 div 2.

[66] *Victorian Act 2017* (Vic) ss 20(1)(c), 29(1)(c), 34(2)(a)(i).

[67] Between August 2017–18, a Joint Select Committee inquired into end-of-life choices for Western Australians. The Committee recommended the introduction of voluntary assisted dying legislation, and in support of this recommendation the government appointed a Ministerial Expert Panel to consult and develop a legislative framework for WA. The Panel's report was tabled in Parliament on 27 June 2019: see *MEP Report* (n 12).

[68] Western Australia, *Parliamentary Debates*, Legislative Assembly, 7 August 2019, 5136 (Roger Cook, Minister for Health). The most significant of these was to allow for the use of telehealth in certain circumstances.

administration can be chosen by a person, in consultation with their medical practitioner. This can occur where the medical practitioner advises the person that self-administration would be inappropriate having regard to the person's ability to self-administer, the person's concerns about it, and the most suitable method of VAD for the patient.[69]

The differences between the *Victorian Act* and the *WA Act* in terms of eligibility criteria are more subtle. Subsection 16(1) of the *WA Act* contains the eligibility criteria that must be met for access to VAD:

a) the person has reached 18 years of age;

b) the person –
   (i) is an Australian citizen or permanent resident; and
   (ii) at the time of making a first request, has been ordinarily resident in Western Australia for a period of at least 12 months;

c) the person is diagnosed with at least 1 disease, illness or medical condition that –
   (i) is advanced, progressive and will cause death; and
   (ii) will, on the balance of probabilities, cause death within a period of 6 months or, in the case of a disease, illness or medical condition that is neurodegenerative, within a period of 12 months; and
   (iii) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable;

d) the person has decision-making capacity in relation to voluntary assisted dying;

e) the person is acting voluntarily and without coercion; and

f) the person's request for access to voluntary assisted dying is enduring.

As in Victoria, the *WA Act* states that disability and mental illness alone are not grounds to access VAD.[70] However, also like in Victoria, extrinsic material confirms that provided the eligibility criteria are met, the presence of a disability or a mental illness in itself will not preclude a person from accessing VAD.[71]

Because the eligibility criteria in the *WA Act* are so similar to those in the *Victorian Act*, the remaining discussion will focus on key areas of difference, and where appropriate, comparisons with the Model Bill.[72] A key difference between the *WA Act* and both the *Victorian Act* and Model Bill is that in Western Australia there is no requirement for an eligible condition to be 'incurable'. In Victoria, whether or not a disease, illness or condition is incurable is viewed as an objective test based on available medical treatments.[73] This explanation was provided in the context of

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[69] *Voluntary Assisted Dying Act 2019* (WA) s 56(2) ('*WA Act*').

[70] Ibid s 16(2).

[71] Explanatory Memorandum, Voluntary Assisted Dying Bill 2019 (WA) 6 cl 15.

[72] One minor difference noted but not considered further is that the *WA Act*, like the *Victorian Act*, requires a person to be ordinarily resident in the State for at least 12 months before the first request for VAD, but it does not repeat the (superfluous) requirement in the *Victorian Act* to also be ordinarily resident in the State: *WA Act 2019* (WA) s 16(1)(b); *Victorian Act 2017* (Vic) s 9(1)(b).

[73] Victoria, *Parliamentary Debates*, Legislative Council, 21 November 2017, 6218 (Gavin Jennings).

discussion about the ability of medical practitioners to accurately prognosticate about how long a person may have to live.[74] The presence of an incurable illness that was advanced and progressive would strongly indicate that the end of life was near. In considering a legislative framework for Western Australia, the Ministerial Expert Panel ('MEP') did not specifically engage with the concept of an incurable disease,[75] but instead explored whether a person should have a 'terminal' condition in order to be eligible to access VAD.[76] They formed the view that including a criterion that an illness or disease is 'advanced, progressive and will cause death' clearly 'emphasise[s] the terminal nature of the illness or disease'.[77] Consequently, further qualification of the type of illness, disease or condition was not seen as being required, and the *WA Act* does not refer to an 'incurable' condition. In debate on the Bill, the government indicated that they considered the term 'incurable' just reiterated existing criteria.[78] The Premier, Mark McGowan also observed that including a criterion of 'incurable' might require a person to undergo treatment they wish to refuse, or exhaust all treatment options,[79] potentially including experimental treatment in 'some far-flung place around the world'.[80] This would 'cut across the fundamental principle of patient autonomy'.[81]

In contrast, providing a timeframe within which a person is expected to die was seen as an important safeguard in the legislative framework.[82] The Model Bill does not require medical practitioners to engage with the challenging problem of estimating when a person might die, in part, because any suggested timeframe would be arbitrary. While substantially reflecting the *Victorian Act*, the *WA Act* seeks to address the prognostic challenge of estimating when a person might die by requiring the assessment of life expectancy on the balance of probabilities.[83] That is, a medical practitioner must be satisfied that it is more likely than not[84] that the person will die within 6 months (or 12 months in the case of a person with a neurodegenerative condition).[85] In determining if a disease, illness or condition is likely to cause the death of a person, the medical practitioner can take account of the person's individual circumstances, their comorbidities and their treatment

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[74] Ibid.

[75] Although the MEP did refer to the fact that Canada's and Luxembourg's laws require an incurable condition: *MEP Report* (n 12) 33.

[76] Ibid 33–4.

[77] Ibid 34.

[78] Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson). See also Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Mark McGowan).

[79] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Mark McGowan). See also Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson).

[80] Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson).

[81] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6603 (Roger Cook).

[82] *MEP Report* (n 12) 36–40.

[83] *WA Act 2019* (WA) s 16(1)(c)(ii).

[84] See generally John Dyson Heydon, *Cross on Evidence* (LexisNexis Butterworths, 12th ed, 2020) 387–9.

[85] *WA Act 2019* (WA) s 16(1)(c)(ii).

choices,[86] making it more than a pure mathematical exercise in probabilities. Traditionally, the 'balance of probabilities' has been reserved for tribunals trying to determine particular facts from competing or contradictory claims.[87] Parliamentary debate sheds little light on this terminology, other than to observe that 'the test is easily understood and has case law to support it',[88] and is commonly used and well understood by medical practitioners.[89] The MEP originally recommended the use of the phrase 'reasonably foreseeable', and did not mention 'balance of probabilities'.[90] However, legal officers within the government felt that 'reasonably foreseeable' was not clear enough, and that 'balance of probabilities' provided the 'greatest clarity' and 'most utility'.[91] How it does so, and how or if it differs from 'expected' or 'reasonably foreseeable', was not explained. It was confirmed, however, in parliamentary debates that this new wording was not intended to import a lower standard than is contained in the *Victorian Act*.[92]

The *WA Act*, like the *Victorian Act* and the Model Bill, requires a person seeking access to VAD to have decision-making capacity in relation to VAD and requires capacity to be assessed at several points throughout the process. Like Victoria, the final assessment of capacity occurs at the point of practitioner administration, or for self-administration, at the conclusion of the request and assessment process (but not at the time of later ingestion). The *WA Act*, however, defines decision-making capacity in slightly different terms from the *Victorian Act*,[93] presumably to promote consistency with other Western Australian legislation defining decision-making capacity.[94] However, the similarity in approach means that its effect is likely to be the same. The *WA Act*, like the Model Bill, also does not have the extended explanation of capacity found in the *Victorian Act*.

For completeness, it is noted that the *WA Act* mirrors the Model Bill in including a requirement that the person's decision to access VAD must be enduring, made voluntarily and without coercion as part of the eligibility criteria.[95] Although different from the *Victorian Act*, as suggested above, the practical effect of this difference is likely to be insignificant.

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[86] Explanatory Memorandum, Voluntary Assisted Dying Bill 2019 (WA) 5 cl 15.

[87] James Allsop et al, 'Are You Sure?' (2019) 47(2) *Australian Bar Review* 122, 124.

[88] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6582 (Mark McGowan), 6606 (Roger Cook).

[89] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6606 (Roger Cook); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9196 (Stephen Dawson).

[90] *MEP Report* (n 12) 36–9.

[91] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6606–7 (Roger Cook); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9196 (Stephen Dawson).

[92] Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9196 (Stephen Dawson).

[93] *WA Act 2019* (WA) s 6.

[94] See, eg, *Mental Health Act 2014* (WA) s 15.

[95] *WA Act 2019* (WA) ss 16(1)(e), (f).

E *Death with Dignity Act* (Oregon)

The *Oregon Act*[96] was passed through a ballot initiative process. At the November 1994 election, Oregon's citizens voted directly to approve the law by 51 to 49 percent.[97] However, a series of constitutional challenges delayed the implementation of the law by three years,[98] until the injunction against the operation of the law was lifted on 27 October 1997.[99] In November 1997, Oregonians rejected a direct ballot designed to repeal the *Oregon Act*, by a margin of 60 to 40 percent.[100] The law has been operational since that time.[101]

The *Oregon Act*, on which legislation in other US states is based,[102] has a rigorous assessment process that has been described as 'so carefully crafted, so narrowly drawn, and so laden with procedural safeguards that it may well demand more energy and fortitude to comply with it than some terminally ill people are likely to have'.[103] The model of VAD in Oregon is restricted to a doctor prescribing medication which the patient self-administers. There is no provision for practitioner administration.

The *Oregon Act* provides that to be eligible to request assistance to die a person must be:[104]

> An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die …

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[96] *Oregon Act*, Or Rev Stat §§ 127.800–127.995 (1994).

[97] Patrick M Curran Jr, 'Regulating Death: Oregon's *Death with Dignity Act* and the Legalization of Physician-Assisted Suicide' (1998) 86(3) *Georgetown Law Journal* 725, 728.

[98] It was argued that the legislation violated a number of constitutional rights, including due process and equal protection rights under the Fourteenth Amendment; the free exercise of religion and freedom of association rights under the First Amendment; and statutory rights under the *Americans with Disabilities Act of 1990*, 42 USC §§ 12101–213; section 504 of the *Rehabilitation Act of 1973*, 29 USC §§ 701–96l; and the *Religious Freedom Restoration Act of 1993*, 42 USC §§ 2000bb–bb4. The District Court of Oregon found the Act violated the equal protection clause, and issued injunctions preventing the law commencing: *Lee v Oregon*, 869 F Supp 1491 (D Or, 1994) (issuing preliminary injunction); *Lee v Oregon*, 891 F Supp 1429 (D Or, 1995) (equal protection opinion); *Lee v Oregon*, 891 F Supp 1439 (D Or, 1995) (issuing permanent injunction). On appeal, the Ninth Circuit Court held that the plaintiffs lacked standing: *Lee v Oregon*, 107 F 3d 1382 (9th Cir, 1997), and the Supreme Court refused leave to appeal: *Lee v Harcleroad*, 522 US 927 (1997). For discussion of these cases, see Brian Boyle, 'The Oregon *Death with Dignity Act*: A Successful Model or a Legal Anomaly Vulnerable to Attack' (2004) 40(5) *Houston Law Review* 1387, 1393–5.

[99] Curran (n 97) 729; Boyle (n 98) 1391.

[100] Curran (n 97) 729; Raphael Cohen-Almagor and Monica G Hartman, 'The Oregon *Death with Dignity Act*: Review and Proposals for Improvement' (2001) 27(2) *Journal of Legislation* 269, 274.

[101] The law has been subject to, and survived, later litigation not directly challenging the statute itself, but alleging that a medical practitioner who prescribed drugs for assisted dying was not prescribing for a 'legitimate medical purpose' within the meaning of the federal *Controlled Substances Act*, 21 USC §§ 821–32, and consequently risked having his or her registration revoked: *Oregon v Ashcroft*, 192 F Supp 2d 1077 (D Or, 2002); *Oregon v Ashcroft*, 368 F 3d 1118 (9th Cir, 2004); *Gonzales v Oregon*, 546 US 243 (2006). For discussion of these cases, see Boyle (n 98) 1396–9.

[102] See above n 6 for the legislation in other US states.

[103] Alan Meisel, Kathy L Cerminara and Thaddeus M Pope, *The Right to Die: The Law of End-of-Life Decisionmaking* (Wolters Kluwer, 3rd ed, 2016) 12–91 §12.06[A][1].

[104] *Oregon Act*, Or Rev Stat § 127.805(1) (1994).

Age or disability is specifically noted as being insufficient, of itself, to qualify for assistance to die.[105] Each of the Act's eligibility criteria, aside from being an adult and residence, will be considered separately below.

1 Capacity

To make a request for VAD a person must be 'capable', which is defined as having 'the ability to make and communicate health care decisions to health care providers'.[106] Communication can be made through persons familiar with the patient's manner of communicating if necessary. Capacity must be assessed by the patient's attending physician and consulting physician in every case before VAD is authorised,[107] and may additionally be evaluated by a psychiatrist or psychologist if there is concern that the person might be 'suffering from a psychiatric or psychological disorder or depression causing impaired judgment'.[108] The *Oregon Act* does not allow a person to request VAD in an advance directive.[109] While the person must have decision-making capacity at the time of the request and assessment process, capacity does not need to be assessed again at the point a person ingests the medication.[110]

2 Terminal Disease

A person must be 'suffering from a terminal disease'[111] to be eligible to receive assistance to die in Oregon. 'Terminal disease' is defined to mean 'an incurable and irreversible disease that has been medically confirmed and will, within reasonable medical judgment, produce death within six months'.[112] This means that a person with a chronic illness, such as Parkinson's disease or multiple sclerosis, which is incurable but will not of itself result in death, is not eligible under the legislation.[113]

'Medically confirmed' means that the diagnosis of a terminal disease is determined by two doctors: the attending physician and the consulting physician. The 'attending physician' is the doctor who has primary responsibility for the care of the patient and treatment of the terminal disease.[114] The attending physician

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[105] Ibid § 127.805(2).

[106] Ibid § 127.800(3).

[107] Ibid §§ 127.815(1)(a), 127.820.

[108] Ibid § 127.825. These words were added by amendments in 1999: Meisel, Cerminara and Pope (n 103) 12–92.4 §12.06[A][1]. The Act specifically prohibits access to VAD for this cohort being evaluated until it is determined that 'the patient is not suffering from a psychiatric or psychological disorder or depression causing impaired judgment': *Oregon Act*, Or Rev Stat § 127.825 (1994). As to the role of depression in impairing decision-making, see Linda Ganzini, 'Legalised Physician-Assisted Death in Oregon' (2016) 16(1) *QUT Law Review* 76, 81–3.

[109] See Ganzini (n 108) 77.

[110] Note that Ganzini (n 108) raises concern about the possibility that a person may have lost capacity by that stage: at 81.

[111] *Oregon Act*, Or Rev Stat § 127.805(1) (1994).

[112] Ibid § 127.800(12).

[113] This distinction is made by IG Finlay and R George, 'Legal Physician-Assisted Suicide in Oregon and The Netherlands: Evidence Concerning the Impact on Patients in Vulnerable Groups' (2011) 37(3) *Journal of Medical Ethics* 171, 173.

[114] *Oregon Act*, Or Rev Stat § 127.800(2) (1994).

makes the initial diagnosis that the disease is terminal. This medical opinion is then confirmed by a consulting physician, after examining the patient and the patient's relevant medical records.[115]

Neither 'incurable' nor 'irreversible' is defined, so it is unclear whether the statute would include a person who refused available medical treatment which has a chance of curing or reversing the process of disease, thus rendering an otherwise non-fatal condition terminal.[116] Oregon's *Guidebook for Health Care Professionals* suggests that '[d]oubts concerning the patient's diagnosis, prognosis, and volition should be resolved against provision of medication'.[117] That is, where the doctor is uncertain whether or not the patient qualifies as terminally ill, they should refuse a request for VAD. However, this guidance does not directly address the issue of treatment refusal. In practice, the application of 'incurable and irreversible' may vary according to the condition from which the person is suffering. For example, an Oregon doctor stated that he declined a request for VAD from a diabetic patient who was refusing insulin treatment, but he would accept a request from a person with treatable lymphoma who was refusing chemotherapy.[118] The application of the statutory criteria may also vary according to the views of the assessing doctor, as other doctors have stated they would not accept a request from a person refusing lymphoma treatment.[119]

3 Suffering

There is no separate requirement under the *Oregon Act* that a person be in pain, or experiencing any suffering.[120] In this sense, the phrase 'suffering from a terminal illness' means having or experiencing such an illness.

4 Voluntary

To be eligible for VAD, a person must have 'voluntarily expressed his or her wish to die'.[121] The criteria for voluntariness are not defined in the *Oregon Act*, or in rules or regulations made under the Act.[122] However, witnesses are required to

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[115] Ibid § 127.800(8).

[116] The Oregon Health Authority (unhelpfully) states that: 'The Act does not specify whether or not all treatment options must be exhausted prior to a prescription being written': Oregon Health Authority, 'Public Health's Role: Oregon's *Death with Dignity Act*', (Web Page) <https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ohdrole.aspx>.

[117] Kelly Hagan, 'Liability and Negligence' in Patrick Dunn and Bonnie Reagan (eds), *The Oregon Death with Dignity Act: A Guidebook for Health Care Professionals*, (Centre for Ethics in Health Care, Oregon Health and Science University, 2007) ch 15, Guideline 15.10 <https://www.wsha.org/wp-content/uploads/Death-with-Dignity_Death-with-dignity-guidebook.pdf>.

[118] Anita Hannig, 'Author(iz)ing Death: Medical Aid-in-Dying and the Morality of Suicide' (2019) 34(1) *Cultural Anthropology* 53, 70.

[119] Ibid.

[120] See Herbert Hendin and Kathleen Foley, 'Physician-Assisted Suicide in Oregon: A Medical Perspective' (2008) 106(8) *Michigan Law Review* 1613, 1615.

[121] *Oregon Act*, Or Rev Stat § 127.805(1) (1994).

[122] James L Werth Jr and Howard Wineberg, 'A Critical Analysis of Criticisms of the Oregon *Death With Dignity Act*' (2004) 29(1) *Death Studies* 1, 20; Michaela Estelle Okninski, 'Commentary on Undue

sign, as part of a person's request for assisted dying, that the person 'appears to be … not under duress, fraud or undue influence'.[123] It has been suggested that acting voluntarily involves excluding external influences such as duress, fraud or undue influence.[124]

F Canadian *Criminal Code*

In February 2015, in *Carter v Canada (Attorney General)* ('*Carter*'),[125] the Supreme Court of Canada struck down the *Criminal Code* prohibition on voluntary euthanasia and assisted suicide, ruling it was contrary to the Canadian *Charter of Rights and Freedoms* ('*Charter*'):

> The appropriate remedy is therefore a declaration that s. 241(*b*) and s. 14 of the *Criminal Code* are void insofar as they prohibit physician-assisted death for a competent adult person who (1) clearly consents to the termination of life; and (2) has a grievous and irremediable medical condition (including an illness, disease or disability) that causes enduring suffering that is intolerable to the individual in the circumstances of his or her condition. 'Irremediable', it should be added, does not require the patient to undertake treatments that are not acceptable to the individual.[126]

In response to this decision, albeit after 16 months,[127] the Canadian Parliament passed *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)* in June 2016 ('Bill C-14').[128] This legislation permits 'medical assistance in dying' (MAiD), after a person seeking

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Influence Provisions under Oregon's *Death with Dignity Act* and California's *End of Life Option Act*' (2017) 25(1) *Journal of Law and Medicine* 77, 80. Clinical criteria to assess voluntariness have been proposed in David Orentlicher, Thaddeus Mason Pope and Ben A Rich, 'Clinical Criteria for Physician Aid in Dying' (2016) 19(3) *Journal of Palliative Medicine* 259.

[123] *Oregon Act*, Or Rev Stat § 127.897 (1994).

[124] For this interpretation, see Okninski (n 122) 80. A witness' ability to attest to voluntariness has been questioned by Hendin, Foley and White who note that there is no requirement that the witnesses be independent of the person, or even that they know the person: Herbert Hendin, Kathleen Foley and Margot White, 'Physician-Assisted Suicide: Reflections on Oregon's First Case' (1998) 14(3) *Issues in Law and Medicine* 243, 254–5. Note also that Okninski has suggested that the *Oregon Act* does not provide sufficient protection against external factors which may overbear a person's will, because doctors are not required to report refusals of requests on the ground of concerns about voluntariness. This allows doctor shopping until a person or their relative finds a doctor willing to certify that a request for assistance to die is voluntary. Okninski cited anecdotal evidence of the Kate Cheney case, in which two doctors and a psychiatrist refused Ms Cheney's request because of concerns of undue influence or coercion by her daughter, before a doctor was found who was willing to write a prescription for lethal medication: Okninski (n 122) 82–3, citing Kathleen Foley and Herbert Hendin, 'Physician-Assisted Suicide in Oregon: A Medical Perspective' (2008) 24(2) *Issues in Law and Medicine* 121, 131–2. We note, however, that the source of information about Kate Cheney for the Foley and Hendin paper is a 1999 newspaper article.

[125] *Carter v Canada (Attorney General)* [2015] 1 SCR 331 ('*Carter*'). For commentary on this case, see Jocelyn Downie, 'Permitting Voluntary Euthanasia and Assisted Suicide: Law Reform Pathways for Common Law Jurisdictions' (2016) 16(1) *QUT Law Review* 84, 96–8.

[126] *Carter* [2015] 1 SCR 331, 390 [127] (emphasis in original).

[127] The Court suspended the declaration of invalidity for 12 months to allow the Canadian government to develop a legislative response to the judgment: *Carter* [2015] 1 SCR 331, 396 [147]. The suspension was then extended by a further four months due to a period of legislative inactivity because of an election: *Carter v Canada (Attorney General)* [2016] 1 SCR 13.

[128] Bill C-14, 1st Sess, 42nd Parl, 2016, amending the Canadian *Criminal Code*, RSC 1985, c C-46, ss 14, 226, 241. Although note that provincial legislation permitting VAD was first enacted in Quebec which commenced operation in December 2015: *Act Respecting End-of-Life Care*, RSQ c S-32.0001.

access for this assistance has been found to be eligible through a rigorous assessment process. MAiD includes both practitioner administration and self-administration, although, to date, self-administration has been very rarely used.[129]

For a person to be eligible for MAiD, Bill C-14 required that:

241.2(1)

(a) they are eligible – or, but for any applicable minimum period of residence or waiting period, would be eligible – for health services funded by a government in Canada;

(b) they are at least 18 years of age and capable of making decisions with respect to their health;

(c) they have a grievous and irremediable medical condition;

(d) they have made a voluntary request for medical assistance in dying that, in particular, was not made as a result of external pressure; and

(e) they give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care.

Bill C-14 stated that a person has a grievous and irremediable medical condition if:

(a) they have a serious and incurable illness, disease or disability;

(b) they are in an advanced state of irreversible decline in capability;

(c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable; and

(d) their natural death has become reasonably foreseeable, taking into account all of their medical circumstances, without a prognosis necessarily having been made as to the specific length of time that they have remaining.[130]

Aspects of Bill C-14 were controversial from the outset, in particular the requirement that to amount to a grievous and irremediable medical condition a person's natural death must be 'reasonably foreseeable'.[131] Critics argued that this criterion violated the *Charter*, was too uncertain and was not an accurate reflection of the Supreme Court's reasoning in *Carter*.[132] On 11 September 2019, in

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[129] Christopher Harty et al, 'Oral Medical Assistance in Dying (MAiD): Informing Practice to Enhance Utilization in Canada' (2019) 66(9) *Canadian Journal of Anaesthesia* 1106.

[130] Bill C-14, 1st Sess, 42nd Parl, 2016, s 3, inserting Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2).

[131] 'Reasonably foreseeable' is not defined in the legislation. It is widely accepted that 'reasonably foreseeable' is not limited to situations in which: death is solely caused by the grievous and irremediable condition; death is imminent; the patient has a fatal condition; the patient is terminally ill; or the patient has an expected remaining lifespan of six months (as in Oregon, for example). See *AB v Canada (Attorney General)* (2017) 138 OR (3d) 139; Jocelyn Downie and Jennifer A Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation* (IRPP Report, 1 March 2018) <https://irpp.org/research-studies/interpreting-canadas-medical-assistance-in-dying-maid-legislation> ('IRPP Report').

[132] See, eg, Jocelyn Downie and Kate Scallion, 'Foreseeably Unclear: The Meaning of the 'Reasonably Foreseeable' Criterion for Access to Medical Assistance in Dying in Canada' (2018) 41(1) *Dalhousie Law Journal* 23; James Downar and Louise Hugo Francescutti, 'Medical Assistance in Dying: Time for Physicians to Step up to Protect Themselves and Patients' (2017) 189(25) *Canadian Medical Association Journal* E849. The primary source of uncertainty over 'reasonably foreseeable' death is how close to death

Truchon v Procureur Général du Canada ('*Truchon*'),[133] Baudouin J of the Quebec Superior Court accepted aspects of these arguments, and ruled that the 'reasonably foreseeable' eligibility criterion was constitutionally invalid.[134] In response to the *Truchon* decision, on 17 March 2021, *An Act to Amend the Criminal Code (Medical Assistance in Dying)* ('Bill C-7') was passed and came into force.[135] Bill C-7 makes three changes to the law that are of particular relevance to this article:

1. It repeals the eligibility criterion in section 241.2(2)(d) that a person's natural death must be reasonably foreseeable;[136]
2. It explicitly stipulates that (until 17 March 2023) for the purposes of determining whether someone has a serious and incurable illness, disease, or disability, mental illness is not considered an illness, disease, or disability;[137] and
3. It permits two forms of requests for MAiD made in advance of loss of decision-making capacity (a 'final consent waiver' and 'advance consent' explained in detail below).[138]

1 Decision-Making Capacity

The first eligibility criterion, in section 214.2(1)(a) of the Canadian *Criminal Code*, which we will not consider in detail, is that a person must be eligible for health services in Canada. The second criterion, in section 241.2(1)(b), is that a person accessing MAiD must be capable of making decisions with respect to their health. Two independent health practitioners must be of the opinion that this criterion and the other eligibility requirements are satisfied.[139] The capacity

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a person must be to satisfy this requirement. On a narrow interpretation, a temporal link to death is required and that period of time must not be too remote, even though the medical or nurse practitioner does not have to estimate a specific length of time. On a broader interpretation, this criterion would be satisfied if *either* death is predicted in a period of time that is not too remote *or* there is a predictable cause of death. This latter interpretation is supported by, for example, College of Physicians and Surgeons of Nova Scotia, 'Professional Standard Regarding Medical Assistance in Dying' (Professional Standard, 14 December 2018) <https://cpsns.ns.ca/wp-content/uploads/2018/12/ProfessionalStandard_MedicalAssistanceInDying_Dec2018.pdf>. In contrast, when introducing Bill C-7 Justice Minister David Lametti appeared to endorse a narrower standard, although his office later clarified via email that the definition had not changed: Joan Bryden, 'Lametti Sows Uncertainty over Meaning of Foreseeable Death in Assisted-Dying Bill', *National Newswatch* (online, 3 March 2020) <https://www.nationalnewswatch.com/2020/03/03/lametti-sows-uncertainty-over-meaning-of-foreseeable-death-in-assisted-dying-bill-2/#.Xl8BMkBuLvV>.

[133] (2019) 158 WCB (2d) 246.

[134] Baudouin J suspended her declaration of invalidity for six months, giving the government until 11 March 2020 to amend the legislation (should it wish to do so). The government obtained four extensions of this deadline and had until 26 March 2021 to pass Bill C-7. See Joan Bryden 'Feds Get Another Month to Reform Assisted-Dying Law as Bill Stalls in the Commons' *CBC News* (online, 25 February 2021) <https://www.cbc.ca/news/politics/assisted-death-maid-1.5928316>; *Truchon v Procureur Général du Canada* (2021) 171 WCB (2d) 65.

[135] Bill C-7, 1st Sess, 43rd Parl, 2020 came into force on 17 March 2021 <https://parl.ca/DocumentViewer/en/43-2/bill/C-7/royal-assent>.

[136] Ibid s 1(1), repealing Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(d).

[137] Bill C-7, 1st Sess, 43rd Parl, 2020, s 1(2), inserting Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2.1).

[138] Bill C-7, 1st Sess, 43rd Parl, 2020, s 1(7), inserting Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(3.2) ('final consent – waiver'), (3.5) ('advance consent – self-administration').

[139] Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(3)(a), (e), (f).

requirement is phrased more broadly in the Canadian *Criminal Code* than in the Australian models, which state that the person must have decision-making capacity for VAD specifically. In practice, however, capacity assessments are similar in Canada because it is understood that capacity in the health care context (and MAiD is understood to be a form of health care) is decision specific.

The test for capacity is framed somewhat differently depending on the Canadian province or territory, but all provincial/territorial statutes centre on understanding the proposed treatment and appreciating the consequences of the decision.[140] Several provinces state that a person is capable of making a treatment decision if they: 1) understand the information that is relevant to making the decision; and 2) appreciate the reasonably foreseeable consequences of both choosing the treatment and not choosing the treatment.[141] Other jurisdictions adopt additional,[142] or slightly different criteria.[143]

Canada is unique amongst the jurisdictions considered in this article in permitting two limited forms of advance request for MAiD, through the 'final consent waiver' and 'advance consent – self-administration'. The default position in Canada is that a person must have capacity when making the request for MAiD and later when giving express consent immediately before it is provided.[144] However, this latter requirement can be waived for persons in two circumstances. First, for individuals whose natural death is reasonably foreseeable who have lost capacity after they have been found eligible for MAiD ('final consent waiver').[145] The final consent waiver is only valid if the person satisfies all eligibility criteria and safeguards in the legislation, and they have entered into a written agreement with a doctor or nurse practitioner to provide MAiD on a specified day.[146] The doctor or nurse practitioner must also have informed the person about the risk of losing capacity prior to the day specified.[147] If the person loses capacity, MAiD can be provided on or before the specified day. Despite this final consent waiver, the doctor or nurse practitioner must not administer the substance if the person resists or refuses by words, sounds or gestures.[148] Second, for persons (whether natural

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[140] See, eg, *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 1(d); *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 7; *Health Care Directives and Substitute Health Care Decision Makers Act*, SS 2015, c H-0.002, s 2(1); *Health Care Directives Act*, CCSM 1993, c H27, s 2; *Health Care Consent Act*, SO 1996, c 2, sch A s 4.

[141] *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 1(d); *Health Care Directives Act*, CCSM 1993, c H27, s 2; *Health Care Consent Act*, SO 1996, c 2, sch A s 4.

[142] The Saskatchewan legislation adopts the two criteria used in Ontario, Alberta and Manitoba, and also requires that a person must be able to communicate a decision about the proposed treatment: *Health Care Directives and Substitute Health Care Decision Makers Act*, SS 2015, c H-0.002, s 2(1).

[143] In British Columbia, the *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 7 requires the health care provider to assess whether the adult demonstrates that they understand information about the proposed treatment.

[144] Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(1)(b), (e), (3)(a), (h), (3.1)(a), (k).

[145] Ibid s 241.2(3.2).

[146] Ibid s 241.2(3.2)(a)(i), (ii).

[147] Ibid s 241.2(3.2)(a)(iii).

[148] Ibid s 241.2(3.2)(c). Note also that section 241.2(3.3) clarifies that 'involuntary words, sounds or gestures made in response to contact do not constitute a demonstration of refusal or resistance for the purposes of paragraph (3.2)(c)'.

death is reasonably foreseeable or not) who enter into a written arrangement with their provider for MAiD to be provided should self-administration fail. In such circumstances, if the person has lost capacity, the practitioner was present at the time of self-administration, and the person has not died within the specified period, the provider-administered MAiD is permitted.[149]

2 Grievous and Irremediable Medical Condition

The most complex aspect of the eligibility criteria for MAiD is the requirement that the person have a grievous and irremediable medical condition. Section 241.2(2) of the Canadian *Criminal Code* states that a person will have a grievous and irremediable medical condition if:[150]

(a) they have a serious and incurable illness, disease or disability;

(b) they are in an advanced state of irreversible decline in capability; and

(c) that illness, disease or disability or that state of decline causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable.

(a) Serious and Incurable Illness, Disease or Disability

The first requirement for a 'grievous and irremediable medical condition' is that the person must have a serious and incurable illness, disease or disability.[151] A key issue is whether the medical condition must be incurable by any means, or whether it is limited to means that are acceptable to the patient.[152] Parliament did not define 'incurable' in the Canadian *Criminal Code*, nor did the government define it in its glossary to Bill C-14, and there is no case law on point. One interpretation is that 'incurable' should be viewed from an objective perspective because the government did not reference treatments acceptable to the person in the legislation,

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[149] Ibid s 241.2(3.5).

[150] Ibid s 241.2(2).

[151] Ibid s 241.2(2)(a).

[152] Note that this aspect of the Canadian *Criminal Code* is one of the grounds for a 2016 constitutional challenge launched by Julia Lamb and the British Columbia Civil Liberties Association shortly after Bill C-14 was passed ('*Lamb*'). For background on the case see the interim ruling: *Lamb and British Columbia Civil Liberties Association v Canada (Attorney General)* (2017) 5 BCLR (6th) 175. See also Julia Lamb and British Columbia Civil Liberties Association, 'Notice of Civil Claim', Notice of Civil Claim in *Lamb and British Columbia Civil Liberties Association v Canada (Attorney General)*, Supreme Court of British Columbia, No S-165851, 27 June 2016 <http://eol.law.dal.ca/wp-content/uploads/2016/07/Lamb-v-Canada.pdf> ('*Lamb* Claim'). This litigation is now adjourned indefinitely. Lamb and the British Columbia Civil Liberties Association argued, in part, that the legislation is overbroad and violates the *Canada Act 1982* (UK) c 11, sch B pt I ('*Charter*') for those individuals who have a grievous and irremediable medical condition that is curable, but only by treatment options unacceptable to the patient. Note that the Attorney General in its Response to Civil Claim argued that the law does not infringe the *Charter* (or alternatively, if it does is a reasonable limit under section 1), but does not directly address the issue of treatments that are acceptable to the person: 'Response to Civil Claim', Response to Civil Claim in *Lamb and British Columbia Civil Liberties Association v Canada (Attorney General)*, Supreme Court of British Columbia, No S-165851, 27 July 2016 <https://bccla.org/wp-content/uploads/2016/08/2016-07-27-Response-to-Civil-Claim.pdf>.

as it did in relation to the criterion of suffering.[153] The other interpretation, now widely accepted by MAiD assessors and providers' lawyers based on *Carter*, and statements made in Parliament, is that incurable should be interpreted by reference to treatment that is acceptable to the person.[154]

Section 241.2(2.1) of the Canadian *Criminal Code* stipulates that a mental illness is not considered to be an illness, disease or disability under section 241.2(2)(a). This exclusion will be automatically repealed on 17 March 2023 by operation of a 'sunset clause' included in Bill C-7.[155]

(b) Advanced State of Irreversible Decline in Capability

A second requirement for a 'grievous and irremediable medical condition' is that the person must be 'in an advanced state of irreversible decline in capability'.[156] Again, there are no court decisions that consider the criterion,[157] and there are several aspects that are potentially unclear:[158] does the decline relate to cognitive as well as physical function; does it relate to stabilised as well as ongoing declines in capability? The latter uncertainty is significant, for example, to individuals who have had a precipitous decline in capability (such as from a previous traumatic injury) but who have stabilised. Downie and Chandler argue that such a person would satisfy the criterion,[159] although we note that this interpretation is somewhat broader than the wording in the glossary that accompanied Bill C-14. The glossary

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[153] In other words, if the government had intended for 'incurable' to mean only by means that a person found acceptable, the government would have specified this in the provision itself: see discussion in IRPP Report (n 131) 16–19.

[154] Ibid. Downie and Chandler take the view that this criterion should be interpreted as 'in the professional opinion of the medical or nurse practitioner, the person cannot be cured by means acceptable to that person': at 17. In other words, a medical practitioner has concluded that there are no clinical options that would satisfy the individual's assessment of what is acceptable to them. Downie and Chandler raise a number of grounds for this including that such an approach is consistent with the position taken by the Supreme Court in *Carter*, and reflects the position taken by the Canadian Minister of Health and Senior Counsel for the Department of Justice when C-14 was before the Parliament: IRPP Report (n 131)18. The Minister of Health and Senior Counsel for the Department of Justice both stated when appearing before the Senate that 'incurable' should be interpreted as meaning by any means acceptable to the patient: Canada, *Parliamentary Debates*, Senate, 1 June 2016, 766 (Dr Jane Philpott) <https://sencanada.ca/Content/SEN/Chamber/421/Debates/pdf/041db_2016-06-01-e.pdf>; Evidence to Standing Senate Committee on Legal and Constitutional Affairs, Parliament of Canada, Ottawa, 6 June 2016, (Carole Morency, Joanne Klineberg) <www.parl.gc.ca/content/sen/committee/421/LCJC/52666-E.HTM>.

[155] Bill C-7, 1st Sess, 43rd Parl, 2020, s 6 specifies that the exclusion of mental illness as a sole underlying condition will be automatically repealed two years after Bill C-7 received royal assent, ie on 17 March 2023. This grace period is intended to enable the government of Canada to commission an independent expert panel review of safeguards, protocols and guidance for MAiD and mental illness, and to allow the federal government and provincial and territorial governments enough time to develop these: Government of Canada, 'About Mental Illness and MAiD', *Medical Assistance in Dying* (Web Page, 30 June 2021) <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>.

[156] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

[157] Note that one of the arguments in *Lamb* (now adjourned indefinitely) was that the applicant is precluded from MAiD because she was not in an advanced state of irreversible decline, which she argued infringes her section 7 *Charter* right to life, liberty, and security of the person: *Lamb* Claim, Supreme Court of British Columbia, No S-165851, 27 June 2016.

[158] See IRPP Report (n 131) 23–6.

[159] Ibid.

states that a person must be '*in* an irreversible decline towards death', which could suggest that the decline needs to be ongoing.[160] There is also uncertainty around the standard against which the decline is judged. Downie and Chandler argue that assessment should be relative to the individual's prior capability rather than some objective standard.[161]

(c) Intolerable Suffering

The third requirement of 'grievous and irremediable medical condition' is that *either* the illness, disease, disability *or* state of decline must be causing enduring physical or psychological suffering that is intolerable to the person.[162] The legislation frames this as a subjective inquiry; the provision refers to suffering that cannot be relieved under conditions the person considers acceptable.

3 Voluntary Request

Like the Model Bill and the *WA Act*, the Canadian *Criminal Code* includes a voluntary request as an eligibility criterion for MAiD. Section 241.2(1)(d) specifically notes that the request must not be made as a result of external pressure. A number of safeguards listed in sections 241.2(3) and 241.2(3.1) are designed to promote and ensure the voluntariness of the request.[163]

4 Informed Consent

The final eligibility criterion is that the person must 'give informed consent to receive medical assistance in dying after having been informed of the means that are available to relieve their suffering, including palliative care' and, for persons whose natural death has not become reasonably foreseeable, have been 'informed of the means available to relieve their suffering, including, where appropriate, counselling services, mental health and disability support services, community services and palliative care'.[164] The legislation also requires that a person's request for MAiD must occur after they were informed by a medical or nurse practitioner that they have a grievous and irremediable medical condition.[165]

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[160] 'Glossary', *Department of Justice* (Web Page, 7 July 2021) <https://www.justice.gc.ca/eng/cj-jp/ad-am/glos.html#archived> (emphasis added).

[161] IRPP Report (n 131) 23–6.

[162] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c).

[163] The medical or nurse practitioner ('MAiD provider') must ensure the request is made in writing, signed and dated, and witnessed by one independent witness: ibid ss 241.2(3)(c), (3.1)(c). The MAiD provider must also inform the person they may withdraw their request at any time and in any manner: at ss 241.2(3)(d), (3.1)(d); and must give the person an opportunity to withdraw the request immediately before providing MAiD: at s 241(3.1)(k); except where the requirements for a final consent waiver or advance consent have been met under sections 241.2(3.2) or (3.5) respectively.

[164] Ibid ss 241.2(1)(e), (3.1)(g).

[165] Ibid s 241.2(3.1)(b)(ii).

The Canadian *Criminal Code* requirement for informed consent intersects with provincial and territorial health care consent legislation[166] and the common law.[167] For example, for an adult to provide consent, British Columbia legislation imposes obligations on the health care provider to give the adult specified information including information about the person's condition, the nature of the proposed health care, the associated risks and benefits and alternative courses of health care. The health care provider must also give the adult an opportunity to ask questions and receive answers about the proposed health care.[168]

The common law has established that a health care provider seeking informed consent 'generally, should answer any specific questions posed by the patient as to the risks involved and should, without being questioned, disclose to him the nature of the proposed operation, its gravity, any material risks and any special or unusual risks attendant upon the performance of the operation'.[169]

Across Canada, the various laws taken together require the individual requesting MAiD to have any questions they ask answered by their health care provider and to be informed: that they have a grievous and irremediable medical condition; of the nature of MAiD; of material, special or unusual risks, and potential benefits of MAiD and other available treatment options (including no treatment); and of available means to relieve suffering, including palliative care.

III COMPARATIVE ANALYSIS OF KEY ELIGIBILITY CRITERIA RELATING TO A PERSON'S MEDICAL CONDITION

The purpose of this part is to undertake a comparative analysis of the eligibility criteria relevant to a person's medical condition and their access to VAD across the five models outlined above. The key criteria in this analysis are outlined below in Table 1, and the comparative issues that can have a significant impact on a person's access to VAD are explored below.

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[166] Consent to health care is a matter of provincial/territorial jurisdiction. See, eg, *Adult Guardianship and Trusteeship Act*, SA 2008, c A-4.2, s 1(d); *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 6; *Health Care Directives and Substitute Health Care Decision Makers Act*, SS 2015, c H-0.002, s 2(1); *Health Care Directives Act*, CCSM 1993, c H27, s 2; *Health Care Consent Act*, SO 1996, c 2, sch A s 4.

[167] *Reibl v Hughes* [1980] 2 SCR 880. See College of Physicians and Surgeons of Alberta, 'Informed Consent for Adults' (Advice to the Profession, August 2019) <http://www.cpsa.ca/wp-content/uploads/2016/02/AP_Informed-Consent-for-Adults.pdf>; College of Physicians and Surgeons of Alberta, 'Informed Consent' (Standards of Practice, June 2016) <http://www.cpsa.ca/standardspractice/informed-consent/>. See also Louise Bélanger-Hardy, 'Informed Choice in Medical Care' in Joanna N Erdman, Vanessa Gruben and Erin Nelson (eds), *Canadian Health Law and Policy* (LexisNexis, 5th ed, 2017) 329.

[168] *Health Care (Consent) and Care Facility (Admission) Act*, RSBC 1996, c 181, s 6.

[169] *Hopp v Lepp* [1980] 2 SCR 192, 210.

Table 1 Comparative Table of Key Criteria Relevant to Medical Conditions and Eligibility for Access to VAD[170]

Capacity					
	Victoria	**Model Bill**	**Western Australia**	**Oregon**	**Canada**
Nature of capacity[171]	decision-making capacity in relation to voluntary assisted dying	decision-making capacity in relation to voluntary assisted dying	decision-making capacity in relation to voluntary assisted dying	capable	capable of making decisions with respect to their health
Nature of medical condition[172]					
	Victoria	**Model Bill**	**Western Australia**	**Oregon**	**Canada**
Prospect of cure	incurable	incurable	–	terminal disease, that is incurable and irreversible	incurable
Stage and nature of condition	advanced and progressive	advanced and progressive	advanced and progressive	–	serious; advanced state of irreversible decline in capability
Prospect and timing of death	will cause death and this is expected within weeks or months, not exceeding 6 months or 12 months for neuro-degenerative conditions	will cause death	will on balance of probabilities cause death within 6 months or 12 months for neuro-degenerative conditions	will, within reasonable medical judgment, produce death within 6 months	–

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[170] For ease of presentation, this table includes only the words in the various legislation and does not include a discussion of how particular concepts have been interpreted.

[171] For the purpose of this article, the added complexity of whether capacity is assessed only at the time of a request for VAD, or also at the time of administration of VAD, is not separately considered.

[172] Although some jurisdictions use more precise terminology, such as ‘disease, illness or medical condition’ (*Victorian Act 2017* (Vic) s 9(1)(d)), in this table the phrase ‘medical condition’ is employed for simplicity.

Specific statement about mental illness	mental illness alone is not eligible	–	mental illness alone is not eligible	ineligible if suffering from a psychiatric or psychological disorder or depression causing impaired judgment	mental illness is not an illness, disease or disability for the purpose of assessing the eligibility criteria
Suffering					
	Victoria	**Model Bill**	**Western Australia**	**Oregon**	**Canada**
Nature and source of suffering	medical condition is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable	medical condition is causing intolerable and enduring suffering (subjective, includes suffering from treatment and can be physical, psychological and existential)	medical condition is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable	–	medical condition or state of decline causes the person enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable

A Prospect and Timing of Death

There are two key points in relation to the prospect and timing of death required under the VAD models. First, as noted in Table 1, the time expected to death varies. Some models specify a time limit: 6 months in Oregon,[173] or 6 or 12 months depending on the medical condition in Victoria and Western Australia.[174] In contrast, the Model Bill specifies no time limit or other temporal restriction on eligibility, but does require that a person has a condition that will cause death.[175] The broadest approach is the amended Canadian law, which does not require temporal proximity and in some cases permits access for those without an expected

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[173] *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

[174] *Victorian Act 2017* (Vic) ss 9(1)(d)(iii), 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii).

[175] White and Willmott, 'Model Bill' (n 21) 21 cl 9(e)(ii) simply states that the medical condition 'will cause death'.

death.[176] Although the operation in practice of these different legal approaches will be potentially qualified by interaction with other eligibility criteria, the criterion relating to prospect and timing of death plays a significant role in controlling access to VAD.

Second, there is also variability in wording about the level of certainty a doctor must have, or the 'standard of proof' that they must apply, in determining whether death will occur within that specified time. Formulations vary, with judgments about death to be made based on what is 'expected' (Victoria),[177] estimated to occur on 'the balance of probabilities' (Western Australia)[178] or assessed using 'reasonable medical judgment' (Oregon).[179] Of these three jurisdictions, perhaps most noteworthy is the Western Australian choice to use 'balance of probabilities'. This terminology was a considered departure from the Victorian drafting ('expected'), yet parliamentary debates suggest that the standard in Western Australia is not lower than under the *Victorian Act*.[180] Instead, the Western Australian government considered that the 'balance of probabilities' test was adopted because it is easily understood by clinicians and is a concept which 'provides the greatest clarity and most utility'.[181] All provide some discretion for doctors in determining prognosis, no doubt recognising the known difficulty of prognostication in relation to death. This was perhaps most explicitly recognised in the Canadian legislation between 2016 and 2021, which permitted a doctor to conclude that a person's death is reasonably foreseeable (an eligibility criterion at the time) 'without a prognosis necessarily having been made as to the specific length of time that they have remaining'.[182]

B Suffering

The models analysed also display significant variation in the level of suffering which must be experienced before a person is able to access VAD. There are three different thresholds of suffering across the five models of VAD. The first, the Oregon model, does not impose a suffering criterion (although the statute is worded to require a person to be 'suffering from a terminal disease').[183] Under the *Victorian Act* and *WA Act*, a person must be experiencing suffering, and this must not be able to 'be relieved in a manner that the person considers tolerable'.[184] The Canadian *Criminal Code* and the Model Bill contain the highest threshold, requiring that a

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[176] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2). Note though that whether a person's natural death has become reasonably foreseeable is relevant to which set of procedural safeguards must be followed before a person is eligible to access MAiD: at s 241.2 (3), (3.1).

[177] *Victorian Act 2017* (Vic) s 9(1)(d)(iii).

[178] *WA Act 2019* (WA) s 16(1)(c)(ii).

[179] *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

[180] Western Australia, *Parliamentary Debates*, Legislative Council, 26 Nov 2019, 9196 (Stephen Dawson).

[181] Ibid.

[182] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(d), as repealed by Bill C-7, 1st Sess, 43rd Parl, 2020, s 1(1).

[183] *Oregon Act*, Or Rev Stat § 127.805(1) (1994). Suffering here is used as meaning having a terminal illness.

[184] *Victorian Act 2017* (Vic) s 9(1)(d)(iv); *WA Act 2019* (WA) s 16(1)(c)(iii).

person be experiencing suffering that is 'intolerable' to them, is enduring, and (in Canada) that 'cannot be relieved under conditions that they consider acceptable'.[185]

Another key difference across models is the cause of the suffering. Under the *Victorian Act* and the *WA Act*, the terminal medical condition must be the cause of a person's suffering to be eligible for VAD.[186] The Model Bill additionally recognises that the treatment for that condition may also be considered in assessing a person's suffering.[187] The Canadian approach is different again, as either the person's 'illness, disease or disability' or their 'state of decline' (that is, their advanced state of irreversible decline in capability) can be the cause of their suffering.[188]

Despite these differences, in the four models where suffering is required, there are also a number of similarities. One is that suffering is assessed subjectively by the person seeking VAD in all models.[189] This may mean that the differences in the suffering thresholds described above are less significant in practice if the requisite suffering is to be determined subjectively. Another is that suffering is broadly understood to encompass not only physical pain, but also psychological and existential suffering.[190]

C Access to VAD and Mental Illness

The VAD models differ in their treatment of the issue of mental illness. Four jurisdictions specifically address the impact of mental illness on possible access to VAD. The *Victorian Act* and the *WA Act* specifically state that mental illness on its own will not be sufficient to render a person eligible for VAD.[191] However, a person with a mental illness who also suffers from another medical condition that otherwise meets the criteria is still capable of qualifying under these models. The Canadian *Criminal Code* states (until the sunset clause takes effect on 17 March 2023) that mental illness cannot be considered to be an illness, disease or disability for the purposes of assessing whether the patient has a serious and incurable illness, disease or disability. But, similar to the two Australian models, the Canadian law does not exclude access if mental illness is comorbid with another serious and incurable condition. The *Oregon Act* makes specific mention of mental illness, precluding access to VAD if a person is suffering from a psychological or psychiatric disorder or depression that causes impaired judgment. Once the person

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[185] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c); White and Willmott, 'Model Bill' (n 21) 21 cl 9(e)(iii).

[186] *Victorian Act 2017* (Vic) s 9(1)(d)(iv); *WA Act 2019* (WA) s 16(1)(c)(iii).

[187] White and Willmott, 'Model Bill' (n 21) 21 cl 10(2)(b).

[188] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c).

[189] In Victoria and Western Australia, whether the suffering can be relieved in a manner that the person considers tolerable is subjectively assessed: *Victorian Act 2017* (Vic) s 9(1)(d)(iv); *WA Act 2019* (WA) s 16(1)(c)(iii). Under the Model Bill and in Canada, it is the suffering itself that is subjectively assessed by a person to be intolerable (as well as the proposed methods of relief, in Canada): White and Willmott, 'Model Bill' (n 21) 21 cl 10(2)(a); Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c).

[190] Canada includes 'physical or psychological suffering': Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(c), whereas the Model Bill includes 'physical, psychological and existential suffering': White and Willmott, 'Model Bill' (n 21) 21 cl 10(2)(c).

[191] *Victorian Act 2017* (Vic) s 9(2); *WA Act 2019* (WA) s 16(2).

has been clinically assessed and determined not to have impaired judgment,[192] the person may access VAD if they have a terminal illness. Only the Model Bill does not explicitly address mental illness. However, the way in which its other eligibility criteria are drawn makes it very unlikely that access only on the basis of mental illness would occur.[193]

D Impact of Refusing Potentially Life Sustaining Treatment

A refusal of potentially life sustaining treatment has relevance for two statutory criteria: an 'incurable' condition, and a condition that will 'cause death'. This issue is handled differently under the various models, and these differences are significant in terms of access to VAD. First, can a person be said to have an 'incurable' condition if they are refusing treatment that presents a reasonable prospect of a cure? The meaning of 'incurable' and the impact of treatment refusals is not explained in the legislation of the four jurisdictions which use this pivotal criterion.

In Victoria, extrinsic material states that whether a person's medical condition is incurable is a medical assessment based on available treatments and a person will not be eligible if they are refusing treatment for an otherwise curable condition.[194] The Model Bill uses the same language as the *Victorian Act* and would be interpreted in the same way. By contrast, in Canada, the practice appears to be that incurability is being determined having regard to treatments acceptable to the patient, although there are arguments that can be made to the contrary that treatment refusals should not be considered.[195] There is no available material to assist in the interpretation of this term in the *Oregon Act*.[196] Refusal of potentially life sustaining treatment is a scenario which is likely to occur in practice. It would be desirable for legislation to give clear guidance to doctors about whether patients can make their condition incurable, and become eligible for VAD, through treatment refusal.

The impact of refusals of potentially life sustaining treatment generally appears clearer in relation to the criterion of whether a medical condition will cause death, and within a certain period of time. In Victoria, extrinsic materials show that the requirement that a condition will cause death within 6 or 12 months will take account of the right to refuse treatments the person finds unacceptable.[197] Identical language is used in the *WA Act*, so that legislation is likely to be interpreted similarly. The Model Bill makes this explicit with a provision clarifying that whether a medical condition will cause death 'is to be determined by reference to available medical

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[192] *Oregon Act*, Or Rev Stat § 127.825 (1994).

[193] This is because in general mental illnesses are not terminal conditions. The majority of mental illnesses are cyclical, and do not progress naturally towards death. Note, however, the consideration of potential eligibility for access to VAD for anorexia, given that it is a mental illness which may be said in extreme cases to cause death: see White et al, 'Who is Eligible for VAD?' (n 19).

[194] Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3–4 cl 9. See discussion above at Part II(B)(2).

[195] See discussion above at Part II(F)(2)(a).

[196] See discussion above at Part II(E)(2).

[197] Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 3–4 cl 9.

treatment that is acceptable to the person'.[198] The *Oregon Act*, however, provides no guidance on this issue for courts or medical practitioners.

Significantly, in Western Australia, the government specifically chose not to include 'incurable' as a legislative criterion. This was because it was considered implicit in the criterion of a medical condition which is advanced, progressive and will cause death. It was also considered inappropriate to require a person to exhaust all treatment options when there is a long-established right to refuse treatment.[199] Although members of both Houses of Parliament sought to amend the VAD Bill (WA) to include 'incurable' as a criterion,[200] these amendments were rejected[201] and not included in the *WA Act*. Drawing on the analysis above, this means that in Western Australia, a person with a curable or treatable condition may be able to refuse treatment and become eligible to access VAD because they then (after treatment refusal) have a condition that will cause death. Examples given in parliamentary debates were an operable tumour[202] and gangrene which was curable with amputation.[203]

This is in contrast to the *Victorian Act* and the Model Bill where incurability in the eligibility criteria functions as a limit on when access to VAD may be possible. Under those models, a person with a curable condition (such as an operable tumour or gangrene) will not be eligible for VAD, even if the person refuses the suggested treatment for that condition, because their condition will not be medically assessed to be 'incurable'. Some Members of Parliament in Western Australia have expressed concern that omitting incurability widens the category of people who may have access to VAD in that State.[204]

IV IMPLICATIONS OF COMPARATIVE ANALYSIS FOR DESIGN OF VAD REGULATION

The above analysis has demonstrated some important similarities and differences across five models of VAD laws. The purpose of eligibility criteria is to

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[198] White and Willmott, 'Model Bill' (n 21) 21 cl 10(1).

[199] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Mark McGowan); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Stephen Dawson).

[200] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6601 (Margaret Quirk); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9199 (Nick Goiran).

[201] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6605; Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9202.

[202] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6586 (Michael Nahan).

[203] Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6603–4 (Margaret Quirk); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9199 (Nick Goiran).

[204] See, eg, Western Australia, *Parliamentary Debates*, Legislative Assembly, 5 September 2019, 6602 (David Honey); Western Australia, *Parliamentary Debates*, Legislative Council, 26 November 2019, 9200 (Michael Mischin).

draw lines determining who should be able to access VAD. Within the five models considered, when analysing the criteria as a whole, it is apparent that these lines are drawn in quite different places. Canada has the most permissive eligibility criteria in its MAiD law, especially since Bill C-7 removed the reasonable foreseeability criterion introduced in Bill C-14. At the other end of the spectrum, the *Victorian Act*, *WA Act* and *Oregon Act* are much more conservative.[205] This comparative analysis has important implications for the design of VAD regulatory systems more broadly. This section shifts beyond the specifics of these legal models and considers the wider questions they give rise to for policymakers and legislators proposing laws in this area.

A Challenge of Translating Policy Goals into Legislation

One implication is the long-standing policy challenge of using words in legislation to accurately reflect a stated policy intent. The translation of broader social objectives into concrete legal rules is a challenging exercise.[206] Problems can arise not only in the selection of words, but also their interpretation, both by the courts and by those at the coalface who are charged with implementing the law. An ideal law is precise and can be applied consistently in relation to a wide variety of situations to which the law is intended to apply.[207] But legal rules are 'inherently indeterminate', both because language is imprecise, and because they are subject to interpretation by others.[208]

Precision in wording can require compromises in terms of the congruence of the law with the policy goals underpinning it. An example of this is the imposition of a specified time limit to death in Victoria, Western Australia and Oregon.[209] An advantage of such an approach is it gives a concrete frame of reference for doctors and others to use when determining eligibility (we put aside for the moment difficulties of prognostication[210]). However, a precise time limit could be seen as an inadequate proxy for the wider policy intent: namely, identifying the cohort of people (those who are dying) for whom VAD should be made available. It can also

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[205] This finding resonates with claims made by the Victorian government at the time of the *Victorian Act 2017* (Vic) passing: see Andrews Media Release (n 32).

[206] Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163, 168–70. See also White et al, 'Does the *VAD Act* (Vic) Reflect Its Stated Policy Goals?' (n 57).

[207] Law Council of Australia, 'Rule of Law Principles' (Policy Statement, March 2011) <https://www.lawcouncil.asn.au/docs/f13561ed-cb39-e711-93fb-005056be13b5/1103-Policy-Statement-Rule-of-Law-Principles.pdf>.

[208] Yeung (n 206) 169. See also Julia Black, *Rules and Regulators* (Clarendon Press, 1997).

[209] In Victoria and Western Australia, a person must be suffering from a condition which is expected to cause death within 6 months, or 12 months if the condition is neurodegenerative: *Victorian Act 2017* (Vic) ss 9(1)(d)(iii), 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii). In Oregon, death must be anticipated within 6 months: *Oregon Act*, Or Rev Stat § 127.800(12) (1994). In contrast, the Canadian *Criminal Code* includes no such time limit.

[210] Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311; Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337; James Downar et al, 'The "Surprise Question" for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-Analysis' (2017) 189(13) *Canadian Medical Association Journal* E484; Paul Glare et al, 'Predicting Survival in Patients with Advanced Disease' (2008) 44(8) *European Journal of Cancer* 1146, 1147.

operate arbitrarily, in that there may be very little to distinguish between a person who is expected to die within the specified time limit, and those with similar conditions whose prognosis is slightly longer. Rigidly applied, it also gives rise to injustices in some situations, such as where people are terminally ill and suffering, but are forced to continue to suffer until they are close enough to death to meet the eligibility time period.

An alternative is to use words that better reflect the policy intent but may be less precise. '[N]atural death' being 'reasonably foreseeable' was an example of such an approach in Canada.[211] Although this drafting technique avoids the pitfalls of arbitrary time limits, it greatly increases the uncertainty surrounding the class of person to whom the legislation applies, as the extensive debate that has occurred in Canada about this terminology demonstrates. Such imprecision is problematic for doctors and others making assessments about eligibility for VAD.[212] This uncertainty can only be definitively resolved in an individual case through court decision, which is a costly and slow process, and judicial consideration of legislative terms can still fail to provide useful guidance in practice for other cases. Such uncertainty could, however, potentially be reduced through the use of other regulatory tools, such as guidelines or policy, to supplement law and provide greater clarity.

B Operation of Eligibility Criteria Is Shaped by Wider VAD System

A second implication for VAD regulation is that the operation of eligibility criteria inevitably interacts with how the wider VAD system is designed. One illustration of this is the criterion of capacity. All models require that a person must have capacity at the point access to VAD is granted, and the concept of capacity is defined in broadly similar terms. However, differences in the way VAD is administered have significant effects on the timing of these capacity assessments, and thus on who may access VAD.

For Victoria, Western Australia and Oregon, capacity is required at the point of the final request for VAD. Where VAD occurs by self-administration, this means that capacity is last assessed when the person is approved to receive the VAD medication.[213] But this medication can be taken later, without medical or other supervision, and there is no testing of capacity at that point when the medication is actually taken. By contrast, where practitioner administration is authorised in Victoria and Western Australia, a person must have capacity at the time of

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[211] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(d), as repealed by Bill C-7, 1st Sess, 43rd Parl, 2020, s 1(1).

[212] Ministerial Advisory Panel on Voluntary Assisted Dying, Department of Health and Human Services (Vic), *Interim Report of the Ministerial Advisory Panel: Consultation Overview, Voluntary Assisted Dying Bill* (Report, April 2017) 21–3.

[213] In terms of the final stage in the self-administration process where there is a legislative requirement to have capacity: in Victoria, this is the point at which the medical practitioner applies for a self-administration permit on behalf of a person: *Victorian Act 2017* (Vic) s 47(3)(a). In Western Australia, this is at the point of final request: *WA Act 2019* (WA) s 51(3)(f)(i). In Oregon, this is immediately prior to writing a prescription: *Oregon Act*, Or Rev Stat § 127.830 (1994). See also the definition of 'qualified patient': *Oregon Act*, Or Rev Stat § 127.800(11) (1994).

administering the medication,[214] because the last request is made at the same time as VAD is administered.

For Canada, the position is similar to the extent that capacity must be assessed both when making a request for MAiD, and, with two exceptions, immediately before it is provided;[215] this latter point being at the time of administering the medication for practitioner administration and when prescribing or providing the medication for self-administration. However, if a person's death is reasonably foreseeable, there is an exception to this requirement of capacity at the time of MAiD provision if the conditions for a final consent waiver are met.[216] Whether a person's natural death is reasonably foreseeable or not, there is also an exception to the requirement of capacity at the time of MAiD provision for provider-administered MAiD where self-administration has failed and the conditions for an 'advance consent' are met.[217] Under the Model Bill, capacity must be present during assessment and when VAD is provided.[218] VAD under this latter model, whether by self-administration or practitioner administration, is always medically supervised[219] and there is a final check of capacity at that point.[220] In short, although all models require a person to have capacity to request VAD, the overarching design of the VAD law results in this having different implications for those different models.

Another illustration is that there are sometimes fluid boundaries between whether a matter is stated to be a criterion of eligibility or a procedural step. It is possible conceptually for these parts of the legislation to be seen as distinct: one deals with the threshold question of access and the other relates to procedures that must be followed to receive access. However, these five models do reflect that some legislators have conceived certain aspects of their VAD law in different ways.

One example is the issue of 'informed consent'. This is stated to be part of the eligibility criteria in Canada, but not in the Australian models nor in Oregon. However, the need to provide information and ensure it is understood is an important part of the procedural steps outlined in these latter jurisdictions. Another example is that the requirement that a decision be made freely and voluntarily is a criterion of eligibility in the Model Bill, the *WA Act*, the Canadian *Criminal Code* and the *Oregon Act*, but in Victoria is tested at various points as a procedural issue. Thirdly, that the decision is enduring is a condition of eligibility in the Model Bill and the *WA Act*, but is tested through process in the other jurisdictions.

In practice, it may not be significant whether various issues are part of the threshold question of access or tested during various procedural steps. This may simply reflect a preference of legislators in terms of drafting or their understanding

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[214] *Victorian Act 2017* (Vic) ss 64(1)(b), 65(2)(a)(i); *WA Act 2019* (WA) s 59(5)(a).

[215] *Canadian Criminal Code*, RSC 1985, c C-46, s 241.2(3)(a), referring to the eligibility criteria in s 241.2(1), including capacity in s 241.2(1)(b).

[216] Ibid s 241.2(3.2) ('final consent – waiver').

[217] Ibid s 241.2(3.5) ('advance consent – self-administration').

[218] White and Willmott, 'Model Bill' (n 21) 23 cl 16, 25 cl 21, 28 cl 26(2), 30–2 cls 29(1)(a)(ii),29(2)(a)(iii), 30(1)(b), 32(2)(a).

[219] Ibid 19–20 cl 6.

[220] Ibid 31–3 cls 30(1)(b), 32(2)(a), 33(3).

of how conceptually these matters contribute to the VAD system as safeguards. However, this distinction could potentially be significant, so reflection on whether a safeguard is better conceived as an eligibility criterion or process matter is important. For example, if the enduring nature of a person's request is imputed on the basis of them requesting VAD at three points in the process, this is different from requiring an enduring decision as a formal part of eligibility. A person could be prevaricating regularly over time and be regarded as not having made an enduring and settled decision to seek VAD, yet still have three points in time at which they were requesting it.

A final point to note about the operation of eligibility criteria is that it is shaped not only by the *design* of the wider VAD system, but it is also affected by how the system *functions in practice*. Thus, while a particular person may meet the legal eligibility criteria for VAD, their access to VAD depends upon a system that facilitates that, including access to willing doctors.[221]

C Regulation Operates Holistically

A third design point to make is that a system of regulation operates holistically. This means that looking at a single aspect of the eligibility criteria without understanding its role in the wider framework can be misleading. That is, it is important to examine eligibility criteria cumulatively and in context. This is the intention of the legislators in constructing the criteria in this way and this has significant implications for who can access VAD. As described above, the Model Bill provides a good example of this: if the focus is restricted to the fact that the Bill does not impose a time limit until death, it may seem to be very broadly drafted. But when aggregated with the requirement for a medical condition that is incurable, advanced and progressive, the scope for access to VAD is considerably narrowed. This is not to make the case for wide or narrow criteria for access to VAD, but to argue for a holistic assessment of cumulative eligibility criteria to properly represent the intent and scope of a VAD law.[222]

Taking a holistic view is also an important consideration more generally when designing VAD regulation. While it may be politically attractive to add numerous safeguards to VAD legislation, including in the eligibility criteria, there is a risk of what we have called elsewhere 'policy drift by a thousand cuts' if the cumulative effect of these individual safeguards is not properly considered.[223] For example, it is possible that a series of provisions designed to make VAD legislation safe, when aggregated, can in fact make access to VAD cumbersome or even unworkable.

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[221] We thank an anonymous reviewer for this point.

[222] This does not always happen: see, eg, comments of Archbishop Aspinall about the Model Bill (n 21) which wrongly suggest it would permit persons with dementia to access VAD in Jamie Walker, 'Euthanasia Law A Life of its Own', *The Australian* (online, 31 August 2019) <https://www.theaustralian.com.au/nation/euthanasia-law-a-life-of-its-own/news-story/86c0fdfa059b99893526f65f5a0e7987>.

[223] White et al, 'Does the *VAD Act* (Vic) Reflect Its Stated Policy Goals?' (n 57) 451.

V CONCLUSION

The purpose of eligibility criteria is to determine who will and will not be permitted to access VAD. As such, they play an important role in determining the scope of VAD laws, and are (rightly) heavily debated in parliaments considering reform. This article has analysed the key eligibility criteria relevant to the medical condition of a person seeking access to VAD under five different legal models. Three of the models were Australian: the recently enacted legislation in Victoria and Western Australia, along with a Model Bill under consideration in Queensland. The remaining two VAD models analysed were from the common law jurisdictions of Oregon and Canada.

Comparative analysis is an established part of law reform processes[224] and so the evaluation undertaken above not only sheds light on how those laws should operate locally but also provides insights for other jurisdictions considering VAD reforms. Regulation permitting VAD remains relatively novel worldwide, so analysis of these individual models provides important insight for parliamentary committees, law reform bodies and parliamentarians. The article has also considered what global lessons might be learned from how these five models operate. The preceding section considered important implications for designing VAD regulation generally, such as how eligibility criteria intersect with other parts of the VAD laws and the importance of evaluating criteria holistically to understand properly their legal effect.

The analysis undertaken in this article also provides a platform for the next article in this series. Having explained and analysed the relevant legal criteria for accessing VAD in the five jurisdictions, the second article will consider how these criteria will apply to specific medical conditions. What medical conditions might meet the criteria for access to VAD, and at what point in an illness trajectory will access be possible? This is different from the more conceptual and legal analysis already undertaken, but is critically important for optimal law reform. If parliamentarians intend to grant or deny access to VAD for particular medical conditions, then concrete testing of proposed eligibility criteria in relation to those conditions is essential.

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[224] Mark Van Hoecke, ‘Methodology of Comparative Legal Research’ [2015] *Law and Method* 1.

WHO IS ELIGIBLE FOR VOLUNTARY ASSISTED DYING? NINE MEDICAL CONDITIONS ASSESSED AGAINST FIVE LEGAL FRAMEWORKS

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ELIANA CLOSE, LAURA LEY GREAVES, JAMES CAMERON,
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Eligibility criteria in voluntary assisted dying legislation determine access to assistance to die. This article undertakes the practical exercise of analysing whether each of the following nine medical conditions can provide an individual with access to voluntary assisted dying: cancer, motor neurone disease, chronic obstructive pulmonary disease, chronic kidney disease, Alzheimer's disease, anorexia, frailty, spinal cord injury and Huntington's disease. This analysis occurs across five legal frameworks: Victoria, Western Australia, a model Bill in Australia, Oregon and Canada. The article argues that it is critical to evaluate voluntary assisted dying legislation in relation to key medical conditions to determine the law's boundaries and operation. A key finding is that some frameworks tended to grant the same access to voluntary assisted dying, despite having different eligibility criteria. The article concludes with broader regulatory insights for designing voluntary assisted dying frameworks both for jurisdictions considering reform and those reviewing existing legislation.

I INTRODUCTION

A key challenge for regulators designing a voluntary assisted dying ('VAD') system is to determine who has access to VAD and in what circumstances. The primary mechanism to control access is the eligibility criteria in VAD legislation. In the first article in this two-part series,[1] we undertook a critical and comparative

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analysis of eligibility criteria in five VAD frameworks. The Australian frameworks considered were: the *Voluntary Assisted Dying Act 2017* (Vic) ('*Victorian Act*'); the *Voluntary Assisted Dying Act 2019* (WA) ('*WA Act*'); and a model Voluntary Assisted Dying Bill 2019 ('Model Bill')[2] drafted for consideration by other Australian states and recommended by the Queensland Parliamentary Inquiry considering VAD as the proposed basis for reform.[3] The international models were Oregon's *Death with Dignity Act 1994* ('*Oregon Act*')[4] and Canada's *Criminal Code* ('Canadian *Criminal Code*').[5] A comparative analysis of these criteria across the five selected regimes

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We disclose that Ben White and Lindy Willmott were engaged by the Victorian, Western Australian and Queensland Governments to design and provide the legislatively mandated training for doctors involved in voluntary assisted dying. Jayne Hewitt was the project manager for the Victorian training project and Rebecca Meehan, Laura Ley Greaves and Eliana Close were employed on the project. Eliana Close and Katrine Del Villar were also employed on the Western Australian and Queensland training projects. James Cameron was a Senior Legal Policy Officer at the Department of Health and Human Services (Victoria) and developed and implemented the *Voluntary Assisted Dying Act 2017* (Vic). Rebecca Meehan is an employee of Queensland Parliament, but this article only represents her views. Jocelyn Downie was a member of the Royal Society of Canada Expert Panel on End-of-Life Decision-Making, a member of the plaintiffs' legal team in *Carter v Canada (Attorney General)* [2015] 1 SCR 331, a member of the Provincial-Territorial Expert Advisory Group on Physician-Assisted Dying and a member of the Council of Canadian Academies Expert Panel on Medical Assistance in Dying. Ben White is a recipient of an Australian Research Council Future Fellowship (project number FT190100410: Enhancing End-of-Life Decision-Making: Optimal Regulation of Voluntary Assisted Dying) funded by the Australian Government. The authors gratefully acknowledge the research assistance of Emily Bartels.

[1] Ben P White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663 ('Comparative and Critical Analysis of Key Eligibility Criteria for VAD').

[2] The Model Bill was drafted by two of the authors: Ben White and Lindy Willmott, '*Voluntary Assisted Dying Bill 2019'* (Model Bill, Australian Centre for Health Law Research, Faculty of Law, Queensland University of Technology, April 2019) <*https://eprints.qut.edu.au/128753/9/128753.pdf*>. The Model Bill was subsequently published as *Ben White and Lindy Willmott*, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1 ('Model Bill').

[3] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Inquiry into Aged Care, End-of-Life and Palliative Care and Voluntary Assisted Dying* (Report No 34, 31 March 2020) 105, 'Recommendation 1' ('*Queensland Parliamentary Report*'). After this article was submitted for publication, voluntary assisted dying ('VAD') laws were enacted in Queensland, as well as in Tasmania and South Australia: *Voluntary Assisted Dying Act 2021* (Qld); *End-of-Life-Choices (Voluntary Assisted Dying) Act 2021* (Tas); *Voluntary Assisted Dying Act 2021* (SA). In New South Wales, the Voluntary Assisted Dying Bill 2021 (NSW) has passed the Legislative Assembly and will be considered by the Legislative Council in 2022.

[4] *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) ('*Oregon Act*').

[5] *Criminal Code*, RSC 1985, c C-46, ss 241.1–241.4 ('Canadian *Criminal Code*'). Until recently, the Canadian *Criminal Code* prohibited all forms of assisted dying. In 2015, the blanket prohibition was found to violate the Canadian *Charter of Rights and Freedoms* ('*Charter*') and was struck down by the Supreme Court of Canada in *Carter v Canada (Attorney General)* [2015] 1 SCR 331 ('*Carter*'). In 2016,

demonstrated many similarities but also significant differences in who would be eligible to access VAD. The article concluded with implications of these analyses from a regulatory perspective for designing VAD legislation.

This second article addresses more practical implications. Drawing on the earlier legal analysis, it considers the *application* of the eligibility criteria from those five frameworks to nine medical conditions. It considers whether a person with any of those particular medical conditions may be eligible for VAD under the frameworks and, if so, at what point in their condition's trajectory. The concrete application of these eligibility criteria to medical conditions is critical to determine a VAD law's boundaries in practice. As this article demonstrates, changes in framing of eligibility criteria in the different jurisdictions can affect access to VAD, and at what stage in a person's medical condition access might be possible.

The nine medical conditions considered were: cancer (specifically colorectal cancer),[6] motor neurone disease ('MND'), chronic obstructive pulmonary disease ('COPD'), chronic kidney disease ('CKD'), dementia (specifically Alzheimer's disease),[7] anorexia, frailty, spinal cord injury ('SCI') and Huntington's disease. These conditions were chosen to illustrate how various eligibility criteria would apply to a diverse range of conditions. It was not feasible to examine all possible medical conditions, so our starting point was the typical conditions for which VAD is sought in Victoria, Oregon, and Canada (the three jurisdictions considered where data concerning VAD is available).[8] Data from Oregon and Canada on deaths due to VAD demonstrate that the three most common underlying conditions are

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the federal Parliament passed legislation (Bill C-14, *An Act to Amend the Criminal Code and to Make Related Amendments to Other Acts (Medical Assistance in Dying)*, 1st Sess, 42nd Parl, 2016 ('Bill C-14')) to amend the Canadian *Criminal Code* to make it consistent with the *Charter* and provide a regulatory framework for medical assistance in dying ('MAiD'). In 2019, a Quebec court found that Bill C-14's 'reasonably foreseeable' eligibility criterion violated the *Charter* and struck it down: *Truchon v Procureur Général du Canada* [2019] QCCS 3792 ('*Truchon*'). In 2021, the Canadian *Criminal Code* was further amended through Bill C-7, *An Act to Amend the Criminal Code (Medical Assistance in Dying)*, 2nd Sess, 43rd Parl, 2021 (as passed by the House of Commons 17 March 2021) ('Bill C-7'). Amendments of particular relevance for this article include: removing the original eligibility criterion 'natural death has become reasonably foreseeable': see Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(d), as enacted; adding a two year blanket exclusion of access for persons with mental illness as their sole underlying medical condition (in force until 17 March 2023): Bill C-7, 2nd Sess, 43rd Parl, 2021, cls 1(2), 1(2.1) and 6 (as passed by the House of Commons 17 March 2021); and permitting VAD to be provided to someone after they have lost decision-making capacity if, before losing capacity but after having been found to be eligible for VAD and after their death has become reasonably foreseeable, they came to a written arrangement with their VAD provider to provide VAD after they lose decision-making capacity ('final consent waiver'): Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(3.2); Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 1(3.2) (as passed by the House of Commons 17 March 2021).

[6] To facilitate detailed engagement with the VAD eligibility criteria, it was necessary to select one particular kind of cancer, given the variation in nature and trajectory of different kinds of cancer.

[7] As was the case for cancer, it was necessary to consider one particular type of dementia to facilitate detailed engagement with the VAD eligibility criteria.

[8] The *Voluntary Assisted Dying Act 2019* (WA) ('*WA Act*') commenced on 1 July 2021, so no data is currently available. The Model Bill (n 2) is not operational.

cancer,[9] neurological conditions (including MND)[10] and respiratory conditions (such as COPD).[11] There is only very limited publicly-reported data on VAD deaths in Victoria (due to privacy concerns), but those which are reported are consistent with the two international jurisdictions: cancer (78%), neurodegenerative diseases (15%) and 'other' diseases (7%), with listed examples of these other diseases including respiratory conditions such as COPD.[12] Anecdotal reports about the Victorian system also suggest that cancer, neurological disease and respiratory conditions are the most prevalent conditions.[13] However, considering only conditions for which VAD is commonly sought would not explore the potential boundaries of the legislation for other conditions and would be a self-limiting approach. Therefore, we also examined conditions for which people were accessing VAD in more permissive regimes such as the Netherlands, Belgium[14] and Canada.[15] We also included medical conditions discussed in the VAD literature,[16]

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[9] In Oregon in 2019, 68.1% of deaths due to VAD involved people with cancer: Oregon Health Authority, *Oregon Death with Dignity Act 2019 Data Summary* (Report, 25 February 2020) 6, 10–11 ('*Oregon Data Summary*'). In Canada in 2018, the figure was 67.2%: Health Canada*, First Annual Report on Medical Assistance in Dying in Canada 2019* (Report, July 2020) 22 ('*Canadian First Annual Report*').

[10] In Oregon in 2019, neurological disease accounted for 13.8% of VAD deaths, with 10.1% from amyotrophic lateral sclerosis, a form of Motor Neurone Disease ('MND'), alone: *Oregon Data Summary* (n 9) 10–11. In Canada in 2019, 10.4% of VAD deaths involved people with neurological conditions: *Canadian First Annual Report* (n 9) 22.

[11] In Oregon in 2019, 7.4% of VAD deaths involved people with respiratory disease: *Oregon Data Summary* (n 9) 10–11. Canada's statistics indicate 10.8% of VAD deaths involved respiratory conditions: *Canadian First Annual Report* (n 9) 22.

[12] Voluntary Assisted Dying Review Board (Vic), *Report of Operations: January to June 2020* (Report, August 2020) 10. This report contains very limited data concerning the medical condition of people accessing VAD. In addition to the above data, the only other significant information provided is a breakdown of cancer data into the four most common types of cancer for which VAD deaths occurred (but not for colorectal cancer which is considered later). As a result, the Voluntary Assisted Dying Review Board (Vic)'s VAD data is not discussed further.

[13] An oncologist involved in numerous VAD applications estimates at least 70% of cases of VAD in Victoria involve people with cancer: Cameron McLaren, 'An Update on VAD: (Almost) A Year in Review', *Dying with Dignity Victoria* (Web Page, 16 June 2020) 3 < https://www.dwdv.org.au/wp-content/uploads/2020/07/One_Year_of_VAD-Dr_Cameron_McLaren.pdf>. Another Victorian general practitioner who has provided VAD states that after one year in operation, '[c]ancer has been the most common reason, then neurological disorders like motor neurone disease, with some cardiovascular and respiratory diseases': Nick Carr, 'Choosing When to Go: What the Nation Can Learn from Victoria's Embrace of Voluntary Assisted Dying', *Crikey* (online, 18 June 2020) <https://www.crikey.com.au/2020/06/18/voluntary-assisted-dying-laws-one-year-on/>. One family's story confirms at least one Victorian with MND died from VAD in the first six months that the *Voluntary Assisted Dying Act 2017* (Vic) ('*Victorian Act*') was operational: Bridget Rollason and Mary Gearin, 'More than 130 Victorians Apply to End Their Lives in First Six Months of State's Assisted Dying Laws', *ABC News* (online, 19 February 2020) <https://www.abc.net.au/news/2020-02-19/assisted-dying-laws-victoria-used-by-more-than-50-people/11979962>.

[14] As noted in the first article in this series, these jurisdictions are not included in this article because their laws operate within quite different legal systems and they are culturally more distinct from Australia than other common law countries: White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1).

[15] Canada is one of the most permissive VAD regimes and a shared legal heritage makes Canada a natural comparator for Australia here.

[16] Jocelyn Downie and Kate Scallion, 'Foreseeably Unclear: The Meaning of the "Reasonably Foreseeable" Criterion for Access to Medical Assistance in Dying in Canada' (2018) 41(1) *Dalhousie Law Journal* 23.

including those described as controversial, such as Alzheimer's disease[17] and one kind of mental illness, anorexia.[18] The resulting list, therefore, included not only typical conditions when VAD is permitted but also conditions that help determine boundaries of VAD frameworks.

These nine conditions are structured using the Australian models as a departure point. Part II considers medical conditions where access to VAD is possible (or even likely, such as for cancer), but may depend on prognosis or illness trajectory (such as for COPD). Part III then considers medical conditions for which access to VAD is either clearly not permitted or very unlikely under the Australian models. Examples include Alzheimer's and Huntington's diseases. Part IV explores similarities and differences across models and considers the effects of differently

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See also Jocelyn Downie and Jennifer A Chandler, *Interpreting Canada's Medical Assistance in Dying Legislation* (Report, Institute for Research on Public Policy, 1 March 2018) ('*IRPP Report*').

[17] VAD for people with dementia is possible, for example, in the Netherlands and Belgium: Dominic R Mangino et al, 'Euthanasia and Assisted Suicide of Persons with Dementia in the Netherlands' (2020) 28(4) *American Journal of Geriatric Psychiatry* 466; Sigrid Dierickx et al, 'Euthanasia for People with Psychiatric Disorders or Dementia in Belgium: Analysis of Officially Reported Cases' (2017) 17(1) *BMC Psychiatry* 203. For a systematic review of public attitudes, and the attitudes of health professionals and individuals with dementia, see Emily Tomlinson and Joshua Stott, 'Assisted Dying in Dementia: A Systematic Review of the International Literature on the Attitudes of Health Professionals, Patients, Carers and the Public, and the Factors Associated With These' (2015) 30(1) *International Journal of Geriatric Psychiatry* 10. For some ethical arguments on the issue, see Paul T Menzel and Bonnie Steinbock, 'Advance Directives, Dementia, and Physician-Assisted Death' (2013) 41(2) *Journal of Law, Medicine and Ethics* 484; Inez D de Beaufort and Suzanne van de Vathorst, 'Dementia and Assisted Suicide and Euthanasia' (2016) 263(7) *Journal of Neurology* 1463. For a discussion of the recent prosecution in the Netherlands for VAD for a person with dementia, see Eva Constance, Alida Asscher and Suzanne van de Vathorst, 'First Prosecution of a Dutch Doctor since the Euthanasia Act of 2002: What Does the Verdict Mean?' (2020) 46 *Journal of Medical Ethics* 71. The Canadian *Criminal Code* allows access to VAD for some individuals with dementia (those who still have decision-making capacity and those who have lost it): Jocelyn Downie and Stefanie Green, 'For People with Dementia, Changes in MAiD Law Offer New Hope', *Policy Options* (online, 21 April 2021) <https://policyoptions.irpp.org/magazines/april-2021/for-people-with-dementia-changes-in-maid-law-offer-new-hope/>; Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(3.2).

[18] VAD is permissible for people with mental illness who meet the other eligibility criteria in the Netherlands and Belgium: Scott YH Kim, Raymond G De Vries and John R Peteet, 'Euthanasia and Assisted Suicide of Patients with Psychiatric Disorders in the Netherlands 2011 to 2014' (2016) 73(4) *JAMA Psychiatry* 362; Dierickx et al (n 17). The use of VAD for mental illness remains controversial: see, eg, Brendan Kelly and Declan McLoughlin, 'Euthanasia, Assisted Suicide and Psychiatry: A Pandora's Box' (2002) 181(4) *British Journal of Psychiatry* 278; Kathleen Sheehan, K Sonu Gaind and James Downar, 'Medical Assistance in Dying: Special Issues for Patients with Mental Illness' (2017) 30(1) *Current Opinion in Psychiatry* 26. The Canadian *Criminal Code* permits VAD for people with mental illness so long as they also have a serious and incurable physical illness, disease, or disability. The *Criminal Code* explicitly states that mental illness is not considered to be a serious and incurable illness, disease, or disability for the purposes of establishing eligibility: Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2.1). However, this exclusion will be automatically repealed on 17 March 2023, due to a 'sunset clause' set out in Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 6 (as passed by the House of Commons 17 March 2021) enacted to enable the federal government to have time to commission an independent expert panel to conduct a review and make recommendations regarding protocols, guidance and safeguards for MAiD for persons with mental illness, and to allow provincial and territorial governments time to prepare for 2023: Government of Canada, 'About Mental Illness and MAiD', *Medical Assistance in Dying* (Web Page, 18 March 2021) <https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html>.

drafted eligibility criteria. Parts V and VI discuss implications for regulators and policymakers designing VAD regulation.

This article, like the previous article, focuses on the eligibility criteria most relevant to the person's medical condition. This includes criteria dealing with the nature of the condition such as, for example, whether it needs to be incurable, advanced or progressive or likely to cause death (and, if so, within a specified period). It also includes the requirement for decision-making capacity, which is important because various medical conditions can have implications for a person's capacity.

The article does not consider other criteria unrelated to medical conditions, such as age and residency, and presumes they are met. The article also does not consider criteria about patient suffering. While suffering is linked to the nature of a medical condition, in all jurisdictions analysed, 'suffering' is assessed subjectively, that is, by the person seeking VAD.[19] Because 'suffering' is an individual experience, one person may experience the requisite suffering for one medical condition but may not for another condition. Likewise, one person with a particular medical condition may be suffering but another person in an identical medical state may not. As such, it is not possible to exclude or include a particular condition as being *capable* of satisfying the VAD criteria on the basis of the 'suffering' criterion.

This article adopts terminology used in the *Victorian Act* (subsequently mirrored in the *WA Act* and Model Bill). VAD therefore includes both 'self-administration'[20] and 'practitioner administration'.[21] 'Medical condition' refers broadly to any condition caused by disease, illness, disability, or injury, although we note some VAD laws specifically address these latter concepts.

Finally, we note the limitation that this analysis has in only considering whether a medical condition is *capable* of providing access to VAD. Whether or not a specific person would qualify depends not only on their condition, but also its progression when seeking access, whether treatments are available (and acceptable to the person), and whether they meet the other eligibility criteria. Further, we acknowledge that clinical characterisation of some conditions described may be contentious. For example, whether or not a condition should be regarded as incurable may be disputed. The article outlines our views on each medical condition, informed by the expertise of our clinical authors, and considers how that condition may typically affect a person seeking access to VAD. But in all cases, access to VAD will depend on an individual assessment of a person in relation to relevant eligibility criteria. It is possible that a person with a condition which would generally provide access to VAD is ineligible; it is also possible that a person with a condition generally not providing access to VAD meets the relevant criteria.

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[19] See, eg, *Victorian Act 2017* (Vic) s 9(1)(d)(iv); *WA Act 2019* (WA) s 16(1)(c)(iii).

[20] The person takes the prescribed medication themselves; sometimes this is called physician-assisted suicide or physician-assisted dying.

[21] The person is administered the medication by a doctor, or nurse practitioner in Western Australia or Canada; sometimes this is called voluntary euthanasia.

II MEDICAL CONDITIONS FOR WHICH ACCESS TO VAD IS POSSIBLE UNDER ALL FRAMEWORKS

A Colorectal Cancer

1 Nature of Condition

Many cancers may make a person eligible for VAD. Colorectal cancer was selected as an example because it is the second most common cause of cancer in both men and women in Australia (after prostate cancer for men and breast cancer for women) and can cause death.[22] The severity of the disease varies depending on the extent to which it has spread. Stage I of the disease, where the tumour is confined to the bowel wall, has a 90% survival rate and low risk of recurrence when treated in accordance with current clinical guidance.[23] If diagnosed later, the tumour may have invaded the bowel wall (Stage II), and/or metastasised to lymph nodes (Stage III). This may progress to metastases in other parts of the body (Stage IV), which has a 13% five-year relative survival rate in Australia.[24] Treatment options depend on the extent of disease. The majority of people with extensive metastatic disease are diagnosed as incurable[25] and have a median survival of five to six months with supportive care[26] or 11 months with multi-drug chemotherapy.[27]

2 Victoria

To be eligible under the *Victorian Act*, a person's colorectal cancer must be incurable, advanced and progressive, with a prognosis of six months or less.[28] The most significant issue in assessing eligibility is prognostication. For example, if the cancer has metastasised to lymph nodes and people in a similar condition have a survival rate of 33%, is the condition incurable? Similarly, it may be difficult to identify an exact timeframe for the disease's progression. Nevertheless, this ambiguity is unlikely to be significant when the criteria are considered collectively. For example, if it is unclear whether or not a person's cancer is curable, death is unlikely to be expected within six months, making the person ineligible regardless.

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[22] Australian Government, Australian Institute of Health and Welfare, *Cancer in Australia 2019* (Report, Cancer Series No 119, Catalogue No CAN 123, 21 March 2019) vii.

[23] Cancer Australia, 'Relative Survival by Stage at Diagnosis (Colorectal Cancer)', *National Cancer Control Indicators* (Web Page, 1 April 2019) <https://ncci.canceraustralia.gov.au/outcomes/relative-survival-rate/relative-survival-stage-diagnosis-colorectal-cancer>.

[24] Ibid.

[25] Yvette HM Claassen et al, 'Survival Differences with Immediate Versus Delayed Chemotherapy for Asymptomatic Incurable Metastatic Colorectal Cancer' (2018) 11 *Cochrane Database of Systematic Reviews* CD012326:1–33.

[26] Werner Scheithauer et al, 'Randomised Comparison of Combination Chemotherapy Plus Supportive Care with Supportive Care Alone in Patients with Metastatic Colorectal Cancer' (1993) 306(6880) *British Medical Journal* 752, 754.

[27] Ibid. See also Alex Grothey et al, 'Survival of Patients with Advanced Colorectal Cancer Improves with the Availability of Fluorouracil-Leucovorin, Irinotecan, and Oxaliplatin in the Course of Treatment' (2004) 22(7) *Journal of Clinical Oncology* 1209, reporting a median 3.5 month increase in survival following treatment with a different combination of active agents: at 1209.

[28] *Victorian Act 2017* (Vic) ss 9(1)(d)(i)–(iii).

The clearest cases are Stage IV colorectal cancer. A person's disease at this point is likely to be incurable, advanced and progressive, and their death could be expected within six months without active treatment. As such, advanced metastatic colorectal cancer is clearly capable of satisfying the eligibility criteria. Access to VAD at earlier stages of the disease would depend on the progression of an individual's condition and whether it meets the eligibility criteria.

3 Western Australia

Eligibility under the *WA Act* for colorectal cancer will be similar to the *Victorian Act*. One key difference is that the *WA Act* does not require the cancer be incurable.[29] Considered in isolation, the absence of this criterion may broaden access to earlier stages of the disease. However, when viewed holistically with other eligibility criteria – that the condition is advanced and progressive, and expected on the balance of probabilities to cause death within six months – the lack of an incurable criterion is unlikely to make a significant difference in practice.

4 Model Bill

Access to VAD under the Model Bill will be similar to the *Victorian Act*, but some people may be able to access VAD earlier in the trajectory of the disease because of the absence of a specified time limit until death. Again, the operation of the criteria holistically is significant. Determinations that the colorectal cancer is incurable, advanced and progressive, and is expected to cause death,[30] become more important in terms of controlling access in the absence of a required prognosis until death.

Whether or not there is a cure is determined objectively by the doctor; to grant access to VAD, they must be satisfied the disease is incurable and will cause death.[31] A conclusion that colorectal cancer is incurable will also likely mean it has reached an advanced state, while the presence of metastases or local advancement would indicate the disease is progressive. As with Victoria and Western Australia, patients with Stage IV advanced metastatic cancer will very likely be eligible. However, the absence of a specific time limit until death makes it more likely that access to VAD before Stage IV is also possible (again, provided the above criteria are met).

5 Oregon

In Oregon in 2019, 3.2% of VAD deaths were patients with colorectal cancer.[32] Colorectal cancer can meet the requirements to be a terminal disease in the *Oregon Act*: that is, incurable and irreversible, and expected (within reasonable medical judgment) to produce death within six months.[33]

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[29] *WA Act 2019* (WA) ss 16(1)(c)(i)–(ii).

[30] Model Bill (n 2) cl 9(e).

[31] Ibid cl 9(e)(i)–(ii).

[32] *Oregon Data Summary* (n 9) 10.

[33] *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

6 Canada

The Canadian *Criminal Code*[34] allows access to VAD for colorectal cancer[35] at an earlier stage than the other frameworks. Under the *Criminal Code*, the cancer must be 'serious and incurable',[36] but incurability appears to be interpreted in practice as the point at which the patient refuses treatment or has tried everything available for a condition that, without treatment, is fatal.[37] The person must also be 'in an advanced state of irreversible decline in capability' and this can be caused by, or be independent of, the serious and incurable disease. So, for example, a very frail elderly person with early-stage colorectal cancer refusing all treatment (including surgery at Stage I) may be eligible, while a person who is otherwise healthy and at Stage I would not be eligible (as they are not in an advanced state of irreversible decline in capability).

7 Summary

Cancers are often discussed as the paradigmatic case for access to VAD.[38] It is therefore unsurprising that advanced metastatic colorectal cancer fits within the eligibility criteria in each legislative scheme. While there may be some challenges applying an individual criterion to colorectal cancer, when the criteria are applied holistically, the boundaries of eligibility are relatively clear. Under the *Victorian Act*, *WA Act* and *Oregon Act*, Stage IV colorectal cancer is likely to be eligible, and earlier stages of the disease might also qualify, depending on an individual's circumstances. Earlier access will be more readily available under the Model Bill, as there is no six months prognosis requirement. The Canadian *Criminal Code*[39] is the most permissive, with access potentially as early as Stage I for people who refuse active treatment and are in an advanced and progressive state of decline due to other comorbid conditions. Several factors underpin this difference in Canada: incurability appears to be based on treatments acceptable to the patient; there is no requirement of temporal proximity until expected death; and a person's state of decline is considered holistically rather than being limited only to that caused by the specific condition (here colorectal cancer).

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[34] Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.1−241.2.

[35] Note that cancer is the most common underlying condition for individuals who receive VAD in Canada: *Canadian First Annual Report* (n 9) 22.

[36] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

[37] *IRPP Report* (n 16) 16–19. See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(2)(a).

[38] See, eg, Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report, June 2016) 199–202; Department of Health and Human Services (Vic), *Ministerial Advisory Panel on Voluntary Assisted Dying* (Final Report, 31 July 2017) 12, 78 ('*MAP Report*').

[39] Canadian *Criminal Code*, RSC 1985, c C-46.

B Motor Neurone Disease

1 Nature of Condition

MND[40] comprises a rare group of diseases where the nerve cells that control the body's muscles degenerate and subsequently die.[41] It has a prevalence of 8.7 per 100,000 people in Australia.[42] MND causes progressive loss of innervation to muscle groups which leads to weakness, spasticity and wasting.[43] Over time, MND impairs a person's ability to walk, speak, swallow and breathe. The disease is incurable and fatal, but its rate of progression varies significantly depending on the subtype of MND and individual factors. Fifty percent of people with MND die within thirty months and less than 20% survive beyond five years from the onset of symptoms.[44] Average life expectancy is two and a half years.[45]

In approximately half of cases, cognition is not affected, but 15% of people have significant impairment with frontotemporal dementia and the remaining 35% experience mild or moderate cognitive impairment, with executive function being most commonly affected.[46]

2 Victoria and Western Australia

People with MND are likely to qualify for access to VAD in these States at some point in their disease trajectory. MND is an incurable and progressive disease that will cause death. However, the illness would need to have progressed to an advanced stage and the person's prognosis would also need to be that death was expected within 12 months (a longer period applies to a neurological condition).[47] A lack of capacity could preclude access in some cases, given executive function is sometimes impaired, and particularly when a person experiences frontotemporal dementia.

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[40] In North America, this condition is more commonly referred to as amyotrophic lateral sclerosis or 'ALS'. It is also sometimes referred to as Lou Gehrig's disease. This was the relevant condition of a disproportionate number of applicants in court challenges to prohibitions on assisted dying: *Rodriguez v British Columbia (Attorney-General)* [1993] 3 SCR 519; *Carter* [2015] 1 SCR 331 (Gloria Taylor); *R* (*Pretty) v Director of Public Prosecutions* [2002] 1 AC 800; *R (Conway) v Secretary of State for Justice* [2017] EWHC 2447 (Admin); *R (Newby) v Secretary of State for Justice* [2019] EWHC 3118 (Admin).

[41] 'What is Motor Neurone Disease (MND)?', *MND Australia* (Web Page, 2020) <https://www.mndaustralia.org.au/mnd-connect/what-is-mnd/what-is-motor-neurone-disease-mnd>.

[42] Deloitte Access Economics, *Economic Analysis of Motor Neuron Disease in Australia* (Report, November 2015) 14 ('*Economic Analysis of MND*').

[43] Matthew C Kiernan et al, 'Amyotrophic Lateral Sclerosis' (2011) 377(9769) *Lancet* 942, 944, 948.

[44] Kevin Talbot, 'Motor Neuron Disease: The Bare Essentials' (2009) 9(5) *Practical Neurology* 303, 303.

[45] *Economic Analysis of MND* (n 42) 19, citing Susan T Paulukonis et al, 'Survival and Cause of Death among a Cohort of Confirmed Amyotrophic Lateral Sclerosis Cases' (2015) 10(7) *PLOS One* e0131965:1–11, 6.

[46] GM Ringholz et al, 'Prevalence and Patterns of Cognitive Impairment in Sporadic ALS' (2005) 65(4) *Neurology* 586.

[47] *Victorian Act 2017* (Vic) s 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii).

3 Model Bill

People with MND would also be eligible under the Model Bill. The key difference from Victoria and Western Australia is the absence of a specified time limit, which means that a person is not required to wait until they are expected to die within 12 months. This potentially provides earlier access to VAD, provided of course that the person's MND is assessed as being advanced. This might also enable access to VAD for people whose MND affects capacity before that capacity is lost.

4 Oregon

In Oregon, MND is the second most common underlying condition for which people receive VAD, after cancer; 10.1% of all persons who died in 2019 under the Oregon scheme had the disease.[48] Provided a person retains decision-making capacity, MND is a qualifying terminal illness, as it is an incurable and irreversible disease that will produce death.[49] However, the category of persons who are eligible may be narrower in Oregon than in Victoria and Western Australia, as the person must be within six months of death rather than 12 months.[50]

5 Canada

A person with MND can be eligible for VAD in Canada.[51] MND meets the serious and incurable disease criterion on diagnosis.[52] A person with MND may therefore be eligible whenever they reach an advanced state of irreversible decline in capability. Given the traditional progression of MND, this decline is unlikely to have occurred at the point of diagnosis, unless the person already had another condition that caused such a decline.

The 'final consent waiver' provision of the Canadian *Criminal Code*[53] allows a person whose natural death is reasonably foreseeable, who meets the eligibility criteria, and who is at risk of losing decision-making capacity, to make arrangements to receive VAD after they have lost capacity. To take advantage of the provision, they must make a 'written arrangement' with their provider for VAD to be provided on a specified date. Then, if they lose decision-making capacity, VAD can be provided on or before that date (in accordance with the conditions set out in the written arrangement). It has been stated that in cases of MND, a person's natural death is reasonably foreseeable at the point of diagnosis,[54] so this option of

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[48] *Oregon Data Summary* (n 9) 10–11.

[49] *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

[50] Ibid.

[51] The *Canadian First Annual Report* (n 9) does not provide data specifically on MND but indicates that neurological conditions comprised 10.4% of VAD deaths in the last reporting period: at 22.

[52] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

[53] Ibid s 241.2(3.2). See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(1).

[54] The Minister for Health in parliamentary debates stated that for MND/ALS, a person's death would be reasonably foreseeable at the point of diagnosis 'because it usually happens within a matter of months or

exercising the final consent waiver provision will be available to eligible persons with MND at risk of losing decision-making capacity.

6 Summary

A person diagnosed with MND can access VAD under all five frameworks. The key difference is the timing of this access. Oregon has the most restrictive law, requiring a person to be within six months of death, followed by Victoria and Western Australia with 12 months. The Model Bill does not impose a time limit, but access is constrained by the need for a person's condition to be advanced. This is similar to the position in Canada, but the ability to consider a person's state of decline holistically, not just the decline caused by MND, creates potentially wider access. Canada's final consent waiver provision also permits broader access, ie, when an eligible person has lost decision-making capacity.

C Chronic Obstructive Pulmonary Disease

1 Nature of Condition

COPD is an incurable and progressive lung disease characterised by chronic airflow limitation, resulting from a mix of emphysema and small airways disease, such as bronchitis.[55] It is the fifth leading cause of death in Australia for both men and women.[56] Increasing airway narrowing and lung destruction causes symptoms to worsen over time. The symptoms include breathlessness, coughing and more frequent and persistent chest infections. COPD can progress from Stage I (mild or early-stage) through to Stage IV (often called end-stage COPD), when people may struggle to breathe even at rest. If a person's respiratory function is so compromised that they lack sufficient oxygen, this may cause confusion and affect a person's decision-making capacity.[57]

People can live for many years with the disease, but it does shorten life, particularly when the COPD is advanced.[58] Prognostication is incredibly difficult because the trajectory of COPD is 'chaotic',[59] with slow, chronic decline over time interspersed with acute exacerbations, any of which may cause death.[60]

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years': Canada, *Parliamentary Debates*, Senate, 1 June 2016, 1700 (Jane Philpott). See also Downie and Scallion (n 16) 48–9.

[55] Global Initiative for Obstructive Lung Disease, *Pocket Guide to COPD Diagnosis, Management and Prevention: A Guide for Health Care Professionals* (Report, 2019) 2.

[56] Australian Government, Australian Institute of Health and Welfare, *Deaths in Australia* (Web Report, 25 June 2021) <https://www.aihw.gov.au/getmedia/743dd325-7e96-4674-bb87-9f77420a7ef5/Deaths-in-Australia.pdf.aspx?inline=true>.

[57] Fiona AHM Cleutjens et al, 'Domain-Specific Cognitive Impairment in Patients with COPD and Control Subjects' (2016) 12 *International Journal of Chronic Obstructive Pulmonary Disease* 1.

[58] Robert M Shavelle et al, 'Life Expectancy and Years of Life Lost in Chronic Obstructive Pulmonary Disease: Findings from the NHANES III Follow-up Study' (2009) 4(1) *International Journal of Chronic Obstructive Pulmonary Disease* 137.

[59] Amanda Landers et al, 'Severe COPD and the Transition to a Palliative Approach' (2017) 13(4) *Breathe* 310, 311.

[60] Ibid.

2 Victoria and Western Australia

COPD is incurable, progressive and can cause death, particularly when a person has end-stage COPD. A person would need to be at an advanced stage in their illness to be eligible for VAD, particularly given the requirement that death be expected or likely to occur within six months.[61] Challenges of prognostication with COPD may present a particular barrier to access.

Decision-making capacity must also be considered as end-stage COPD patients may experience a chronic lack of oxygen in the blood, affecting brain functioning and cognition. This may mean that a person with COPD, despite earlier qualifying for VAD, could lose the required capacity as their illness worsens.[62]

3 Model Bill

A person with COPD could access VAD under the Model Bill. Absence of a specified time until death means both that difficulties of prognostication are avoided, and that earlier access may be possible. The person's COPD would still need to be 'advanced',[63] but it would be possible for a doctor to conclude that all eligibility criteria are met at an earlier point than under the *Victorian Act* or *WA Act*. Therefore, without a requirement to predict timing of death, access to VAD may be provided once a doctor is satisfied that the disease is advanced and will ultimately cause death.

4 Oregon

In Oregon, 7.4% of deaths in 2019 listed the underlying illness as '[r]espiratory disease [eg, COPD]'.[64] COPD is 'incurable and irreversible', and so, provided the person retained capacity and reasonable medical judgment confirmed death will occur within six months, a person would be eligible for VAD.[65] Uncertainty about disease trajectory could affect the timing of access to VAD.

5 Canada

In Canada, 10.8% of VAD deaths in 2018 involved individuals with respiratory conditions.[66] Under the Canadian *Criminal Code*,[67] a person with COPD could satisfy the eligibility requirements to access VAD as it is a 'serious' and 'incurable' illness. Because there is no specified time until death required for a person to be eligible, a person would not have to have reached end-stage. However, because the person must be in an 'advanced state of irreversible decline in capability',[68]

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[61] *Victorian Act 2017* (Vic) s 9(1)(d)(iii); *WA Act 2019* (WA) s 16(1)(c)(ii).

[62] *Victorian Act 2017* (Vic) s 9(1)(c); *WA Act 2019* (WA) s 16(1)(d).

[63] Model Bill (n 2) cl 9(e)(ii).

[64] *Oregon Data Summary* (n 9) 11.

[65] *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

[66] *Canadian First Annual Report* (n 9) 22.

[67] Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(1)–(2).

[68] Ibid s 241.2(2)(b).

a person is unlikely to satisfy this criterion at a very early stage without another comorbid condition causing such decline.

As with MND, because COPD makes a person's natural death reasonably foreseeable, a person with COPD, if they were at risk of loss of capacity, would also be able to access VAD after they have lost capacity through the final consent waiver provision.[69]

6 Summary

The trajectory to death for COPD patients is unpredictable. A chronically unwell person may live for an extended period of time, experiencing a series of acute events but recovering from them. The different criteria relating to proximity to death in the five frameworks may be practically significant for this condition, with earlier access to VAD in those frameworks which do not specify a requisite time to death. Another key issue is decision-making capacity. If the progression of COPD affects capacity, this may exclude access for those who would otherwise qualify for VAD. As noted above, in Canada, a person may nevertheless be able to access VAD after losing capacity if they have completed a final consent waiver.

D Chronic Kidney Disease

1 Nature of Condition

CKD involves decreased kidney function (which is determined by the rate at which the kidneys filter wastes from the blood), or markers of kidney damage, or both, for a period of at least three months.[70] In most cases, CKD is irreversible, and therefore incurable.[71] In Australia, CKD is estimated to contribute to 11% of all deaths with it being the underlying cause in 21% of those deaths.[72]

In the early stages of CKD, people may not notice symptoms associated with their reduced kidney function, but as the disease progresses and toxins accumulate, nearly all body systems can be affected. Fluid retention, hypertension, cardiovascular dysfunction and neurological changes are some of the effects of CKD.[73] Patients with CKD are also susceptible to alterations in cognitive function, including stroke and dementia, and this may affect decision-making capacity.[74]

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[69] Ibid s 241.2(3.2).

[70] Adeera Levin et al, 'KDIGO 2012 Clinical Practice Guideline for the Evaluation and Management of Chronic Kidney Disease' (2013) 3(1) *Kidney International Supplements* 1, 19–24.

[71] Ibid 19.

[72] Australian Government, Australian Institute of Health and Welfare, *Chronic Kidney Disease* (Web Report, 15 July 2020) <https://www.aihw.gov.au/reports/chronic-kidney-disease/chronic-kidney-disease-compendium/contents/deaths-from-chronic-kidney-disease>.

[73] Carol Mattson Porth and Glenn Maftin, *Pathophysiology: Concepts of Altered Health States* (Lippincott Williams and Wilkins, 8th ed, 2009) 859.

[74] Ria Arnold et al, 'Neurological Complications in Chronic Kidney Disease' (2016) 5 *Journal of the Royal Society of Medicine Cardiovascular Disease* 1.

CKD has five stages. Stage I is the least severe, with each stage becoming progressively worse until Stage V, 'end-stage', where the kidneys fail completely.[75] Not all individuals with CKD will progress to end-stage kidney disease and for those that do, the progression is frequently non-linear.[76] This makes prognostication difficult.[77]

2 Victoria and Western Australia

By the later stages of CKD, a person would have a medical condition that is 'advanced and progressive'.[78] There are two challenging aspects under the *Victorian Act* and *WA Act*, however. First, because the disease's trajectory varies, establishing a six-month prognosis may be difficult.[79] Second, since alterations in cognitive function are possible in the latter stages, if a person loses decision-making capacity for VAD, they will not be eligible.[80]

3 Model Bill

The absence of the prognosis requirement under the Model Bill means that earlier access to VAD may be possible than in Victoria or Western Australia. However, the CKD would still need to have reached the stage of being advanced and progressive.[81] Capacity issues remain the same as under the *Victorian Act* and *WA Act*.[82]

4 Oregon

A very small percentage of Oregonians access VAD on the basis of CKD.[83] CKD satisfies the disease criterion under the *Oregon Act*, as it is incurable and irreversible and can be a terminal condition.[84] As in Australia, prognosticating about six months until death and potential loss of capacity present challenges for eligibility.

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[75] Andrew S Levey et al, 'Definition and Classification of Chronic Kidney Disease: A Position Statement from Kidney Disease: Improving Global Outcomes (KDIGO)' (2005) 67(6) *Kidney International* 2089, 2094.

[76] National Clinical Guideline Centre (UK), 'Chronic Kidney Disease (Partial Update): Early Identification and Management of Chronic Kidney Disease in Adults in Primary and Secondary Care' (Clinical Guidelines No 182, National Institute for Health Care Excellence, July 2014) ch 7 <https://www.ncbi.nlm.nih.gov/books/NBK328138/>.

[77] Depending on the person's age and stage of CKD, it can be managed conservatively with diet and observation, by renal replacement therapy with dialysis, or by kidney transplantation: Angela C Webster et al, 'Chronic Kidney Disease' (2017) 389(10075) *Lancet* 1238. The following analysis does not address those circumstances where a person with CKD may be eligible for, or has received, a kidney transplant.

[78] *Victorian Act 2017* (Vic) s 9(1)(d)(ii); *WA Act 2019* (WA) s 16(1)(c)(i).

[79] *Victorian Act 2017* (Vic) s 9(1)(d)(iii); *WA Act 2019* (WA) s 16(1)(c)(ii).

[80] *Victorian Act 2017* (Vic) s 9(1)(c); *WA Act 2019* (WA) s 16(1)(d).

[81] Model Bill (n 2) cl 9(e)(ii).

[82] Ibid cl 9(c).

[83] 'Kidney failure' is included in the 'Other illnesses' category, which comprised six individuals (3.2% of VAD deaths) in Oregon in 2019: *Oregon Data Summary* (n 9) 11, 13.

[84] *Oregon Act*, Or Rev Stat §127.800(12) (1994).

5 Canada

A person with CKD will meet the serious and incurable condition requirement on diagnosis.[85] However, they must also be in an 'advanced state of irreversible decline'.[86] Barring a comorbid condition causing such a decline, a person is unlikely to satisfy this criterion at the very early stages of CKD. However, once the CKD and/or the comorbid condition cause the required state of decline, the person may be eligible.

Because the natural death of a person with CKD can be reasonably foreseeable, a person who is at risk of losing capacity after the finding of eligibility will be able to access VAD after they lose capacity through the final consent waiver provision.[87]

6 Summary

The uncertain trajectory of CKD and difficulties for prognostication may create challenges for access to VAD in Victoria, Western Australia and Oregon, where death must be expected within six months. This is less of a barrier under the Model Bill and in Canada. The potential for cognitive decline associated with CKD may also limit access. In Canada, however, it is possible for a person to exercise the final consent waiver provision and access VAD after they have lost decision-making capacity.

III MEDICAL CONDITIONS FOR WHICH ACCESS TO VAD IS VERY UNLIKELY IN MOST JURISDICTIONS

A Alzheimer's Disease

1 Nature of Condition

Dementia, which refers to a number of neurological conditions where the major symptom is a global decline in brain function,[88] is the second leading cause of death in Australia.[89] Alzheimer's disease ('Alzheimer's') is the most common form of dementia, affecting up to 70% of people with dementia.[90] Alzheimer's is incurable and its symptoms progressively worsen over time, although the rate at which this occurs varies. Despite this variability, Alzheimer's is usually divided

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[85] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

[86] Ibid s 241.2(2)(b).

[87] Ibid s 241.2(3.2).

[88] The four most common forms of dementia, accounting for over 90% of total cases, are Alzheimer's disease, vascular dementia, frontotemporal dementia and Lewy body disease: Leela R Bolla, Christopher M Filley and Robert M Palmer, 'Dementia DDx: Office Diagnosis of the Four Major Types of Dementia' (2000) 55(1) *Geriatrics* 34.

[89] Australian Bureau of Statistics, *Causes of Death, Australia, 2018* (Catalogue No 3303.0, 25 September 2019).

[90] Kirsten Fiest et al, 'The Prevalence and Incidence of Dementia due to Alzheimer's Disease: A Systematic Review and Meta-Analysis' (2016) 43(Supp1) *Canadian Journal of Neurological Sciences* S51.

into three broad stages: mild, moderate and advanced.[91] The disease is fatal, usually through complications of the disease, such as swallowing issues or pneumonia. Life expectancy for Alzheimer's varies depending on factors such as whether a person is already of advanced age, but appears to range from three to ten years.[92]

Memory and cognition are specifically affected. For example, persons with moderate Alzheimer's may struggle to remember things that occurred minutes previously. Communication is also affected, both in terms of understanding what is being said and responding.

2 Victoria and Western Australia

It is very unlikely that a person with Alzheimer's will be eligible to access VAD under the *Victorian Act* or *WA Act*. Although Alzheimer's is an incurable disease that is progressive and will cause death,[93] it impairs decision-making capacity.[94] By the time a person has reached an advanced state of their disease and is expected to die within 12 months (the longer time limit applies to neurodegenerative conditions),[95] it is very unlikely they would have capacity to make decisions about VAD.[96]

3 Model Bill

The position is the same under the Model Bill. Even without a time limit until death, it remains very unlikely that a person would retain the requisite decision-making capacity when they have advanced Alzheimer's.[97]

4 Oregon

Access to VAD on the basis of Alzheimer's in Oregon is also very unlikely for the same reasons as in Victoria and Western Australia.[98] Indeed, access is even less likely given the shorter time limit of six months until death.[99]

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[91] There are also other scales used such as the seven stages in the 'Global Deterioration Scale for Assessment of Primary Degenerative Dementia': Barry Reisberg et al, 'The Global Deterioration Scale for Assessment of Primary Degenerative Dementia' (1982) 139(9) *American Journal of Psychiatry* 1136.

[92] O Zanetti, SB Solerte and F Cantoni, 'Life Expectancy in Alzheimer's Disease (AD)' (2009) 49(Supp 1) *Archive of Gerontology and Geriatrics* 237; Ee Heok Kua et al, 'The Natural History of Dementia' (2014) 14(3) *Psychogeriatrics* 196.

[93] *Victorian Act 2017* (Vic) s 9(1)(d)(ii); *WA Act 2019* (WA) s 16(1)(c)(i).

[94] *Victorian Act 2017* (Vic) s 9(1)(c); *WA Act 2019* (WA) s 16(1)(d).

[95] *Victorian Act 2017* (Vic) s 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii).

[96] Carmelle Peisah, Linda Sheahan and Ben White, 'Biggest Decision of Them All – Death and Assisted Dying: Capacity Assessments and Undue Influence Screening' (2019) 49(6) *Internal Medicine Journal* 792.

[97] Model Bill (n 2) cl 9(c).

[98] This is consistent with the position described here: 'Advance Care Planning for Alzheimer's Disease or Dementia', *Death with Dignity* (Web Page, 2020) <https://www.deathwithdignity.org/alzheimers-dementia-directive/>.

[99] *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

5 Canada

Alzheimer's qualifies as a serious and incurable condition upon diagnosis, so the critical issue is whether a person's Alzheimer's or another comorbid condition is causing them to be in an 'advanced state of irreversible decline in capability' before they lose decision-making capacity.[100]

There have been a small number of cases in Canada where people with dementia as their sole underlying medical condition accessed VAD.[101] For example, Mary Wilson received VAD after being diagnosed with Alzheimer's at least four years earlier. Her case was referred to the College of Physicians and Surgeons of British Columbia by the coroner, who raised concerns about whether Ms Wilson had a grievous and irremediable medical condition. The College investigated and concluded that Ms Wilson met the eligibility requirements for VAD in the Canadian *Criminal Code*,[102] and the assessing physicians acted reasonably and appropriately when considering the issues of capacity and consent.[103]

Access to VAD for people with dementia before they lose decision-making capacity is also supported in professional guidance given by the Canadian Association of MAiD Assessors and Providers.[104] The guideline indicates individuals with dementia will be in an advanced state of irreversible decline in capability just prior to when they are likely to lose capacity, so clinicians should assess and monitor a person's capacity and grant access to VAD at this point, also known as the '10 minutes to midnight' approach.

Access to VAD for some people with dementia after they lose decision-making capacity is also possible. If a person with dementia has been found to be eligible for VAD, they can exercise the final consent waiver provision of the Criminal Code and make arrangements for VAD to be provided after they lose decision-making capacity.

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[100] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

[101] Kelly Grant, 'From Dementia to Medically Assisted Death: A Canadian Woman's Journey, and the Dilemma of the Doctors Who Helped', *Globe and Mail* (online, 12 October 2019) <https://www.theglobeandmail.com/canada/article-from-dementia-to-medically-assisted-death-a-canadian-womans-journey/>. See also the case of Gayle Garlock: CBC Radio, 'B.C. Man is One of the First Canadians with Dementia to Die with Medical Assistance', *CBC* (online, 27 October 2019) <https://www.cbc.ca/radio/thesundayedition/the-sunday-edition-for-october-27-2019-1.5335017/b-c-man-is-one-of-the-first-canadians-with-dementia-to-die-with-medical-assistance-1.5335025>. These cases occurred when the legislation retained the eligibility requirement of 'natural death' being 'reasonably foreseeable'.

[102] Canadian *Criminal Code*, RSC 1985, c C-46.

[103] Letter from JG Wilson, Senior Deputy Registrar of the Complaints and Practice Investigations Department of the College of Physicians and Surgeons of British Columbia to Dr Konia Jane Trouton, Dr [redacted] and Dr Paulo Campos Pereira, 6 December 2018 (College File No IC 2018-0034) <https://www.theglobeandmail.com/files/editorial/News/nw-na-maid-1011/marywilson-decision.pdf> ('College Investigation Regarding Death of Mary Wilson').

[104] Canadian Association of MAiD Assessors and Providers, 'Medical Assistance in Dying (MAiD) in Dementia' (Clinical Guidance Document, 2019) <https://camapcanada.ca/wp-content/uploads/2019/05/Assessing-MAiD-in-Dementia-FINAL-Formatted.pdf>.

6 Summary

Access to VAD on the basis of Alzheimer's is very unlikely under the *Victorian Act*, *WA Act* and *Oregon Act*. The requirements to have both decision-making capacity and a condition which is advanced and expected to cause death within a certain time period will exclude access to VAD. The same result occurs under the Model Bill, despite a lack of timeframe until death being required, as the person with advanced Alzheimer's is similarly very unlikely to have decision-making capacity.

In contrast, under the Canadian law it is possible for a person to retain capacity at the point at which their Alzheimer's causes them to have reached an 'advanced state of irreversible decline in capability'. We consider it significant that the 'advanced' here is in relation to the person's decline and not in relation to the stage of their Alzheimer's. In addition, an individual with Alzheimer's in Canada who is assessed to have capacity and found to meet the eligibility criteria for VAD may exercise the final consent waiver provision and make a written arrangement to have VAD provided after they lose decision-making capacity.

B Anorexia

1 Nature of Condition

Anorexia nervosa is an eating disorder and serious mental illness. It is a complex condition that combines behavioural disorder, mental disorder and physical illness.[105] Anorexia commonly results in significant physical impairments, including anaemia, osteoporosis and type II diabetes. In severe cases, starvation caused by anorexia can be life-threatening, due to kidney failure, cardiac arrest, suicide, or other complications.[106] Anorexia affects between 0.3% and 1.5% of Australian women, and between 0.1% and 0.5% of Australian men.[107]

While anorexia is not in itself a terminal illness,[108] in some cases, the physical consequences of long-term starvation can become life-threatening. Some describe

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[105] Anorexia involves an intense and obsessive fear of gaining weight, leading to severe food restriction (or purging after eating), often coupled with excessive exercise, resulting in extreme weight loss: Michael J Devlin and Joanna E Steinglass 'Feeding and Eating Disorders' in Janis Cutler (ed), *Psychiatry* (Oxford University Press, 3rd ed, 2014) 291.

[106] National Eating Disorders Collaboration, *Eating Disorders Prevention, Treatment and Management: An Evidence Review* (Report, March 2010) 6 ('*NEDC Report*'); Allan S Kaplan and Blake D Woodside, 'Biological Aspects of Anorexia Nervosa and Bulimia Nervosa' (1987) 55(5) *Journal of Consulting and Clinical Psychology* 645.

[107] *NEDC Report* (n 106) 7, based on international epidemiological data reported in James I Hudson et al, 'The Prevalence and Correlates of Eating Disorders in the National Comorbidity Survey Replication' (2007) 61(3) *Biological Psychiatry* 348.

[108] Around half of patients recover to normal weight and remission of symptoms, a third experience symptom improvement, and only 20% develop chronic anorexia: Hans-Christoph Steinhausen, 'The Outcome of Anorexia Nervosa in the 20th Century' (2002) 159(8) *American Journal Psychiatry* 1284, 1286.

this as 'end-stage anorexia'[109] or 'terminal psychiatric disease'.[110] Mortality rates vary between 3% and 25%.[111] In some particularly refractory cases of anorexia, treatment has been assessed as futile, and palliative care[112] or VAD[113] has been offered, although both the terminology and the futility of ongoing treatment are disputed.[114]

It remains unresolved whether the physical sequalae of end-stage anorexia are considered to be part of the anorexia or separate, comorbid physical conditions. This is relevant for those VAD frameworks where a specific condition granting access is needed. English and Australian end-of-life cases outside of the VAD context suggest that a person's medical condition should be viewed holistically, and not atomised into separate components of illness, symptoms and consequences.[115]

A further unresolved issue is whether a severely ill anorexic person can have capacity to consent to or refuse medical treatment. Capacity can be compromised by disorders of values[116] affecting the ability to choose between treatment options,

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[109] Margery Gans and William B Gunn Jr, 'End Stage Anorexia: Criteria for Competence to Refuse Treatment' (2003) 26(6) *International Journal of Law and Psychiatry* 677; Amy T Campbell and Mark P Aulisio, 'The Stigma of "Mental" Illness: End Stage Anorexia and Treatment Refusal' (2012) 45(5) *International Journal of Eating Disorders* 627.

[110] Joseph O'Neill, Tony Crowther and Gwyneth Sampson, 'Anorexia Nervosa: Palliative Care of Terminal Psychiatric Disease' (1994) 11(6) *American Journal of Hospice and Palliative Medicine* 36.

[111] Ibid; Gans and Gunn Jr (n 109).

[112] Amy Lopez, Joel Yager and Robert E Feinstein, 'Medical Futility and Psychiatry: Palliative Care and Hospice Care as a Last Resort in the Treatment of Refractory Anorexia Nervosa' (2010) 43(4) *International Journal of Eating Disorders* 372. See also the case of Mrs Black, a 45-year-old with a 25-year history of anorexia, referred to in Gans and Gunn Jr (n 109) at 678, and the cases of 'Alison' and 'Emily' described in Campbell and Aulisio (n 109) at 628. See also *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639; *An NHS Foundation Trust v X* [2014] EWCOP 35 ('*NHS v X*').

[113] In at least two cases from the Netherlands, women with anorexia accessed VAD. The first involved a 25-year-old woman who, after 16 years of treatment, weighed 19 kilograms, whose anorexia was considered irremediable, and who was assessed to have competence to request VAD: Barney Sneiderman and Marja Verhoef, 'Patient Autonomy and the Defence of Medical Necessity: Five Dutch Euthanasia Cases' (1996) 34(2) *Alberta Law Review* 374, 393–5. The second involved a woman who suffered from anorexia nervosa, recurrent depression, a personality disorder and a somatoform pain disorder. In later years her anorexia was less significant than her other mental illnesses, and there was no suggestion that she was dying of starvation or its physical effects. She was treated extensively for many years, both in hospital and in the community, including with electroconvulsive therapy, pain medication, and cognitive behavioural therapy, but her condition continued to deteriorate: '2016-01, Psychiatrist, Psychiatric Disorders, No Reasonable Alternative', *Regional Euthanasia Review Committees* (Web Page, 1 January 2016) <https://english.euthanasiecommissie.nl/judgments/d/d-psychiatric-disorders/documents/publications/judgments/2016/2016-01/2016-01> ('Regional Euthanasia Review Committees').

[114] Cynthia Geppert, 'Futility in Chronic Anorexia Nervosa: A Concept Whose Time Has Not Yet Come' (2015) 15(7) *American Journal of Bioethics* 34, 36.

[115] The courts have determined physical illness is part of mental illness in three cases that authorised force feeding of a person who was starving themselves due to mental illness, holding that feeding was 'medical treatment' for symptoms of the person's mental illness: *Adult Guardian v Langham* [2006] 1 Qd R 1; *Australian Capital Territory v JT* (2009) 4 ACTLR 68, 77 [62] (Higgins CJ); *B v Croydon Health Authority* [1995] Fam 133, 138–9 (Hoffman LJ).

[116] Louis C Charland, 'Ethical and Conceptual Issues in Eating Disorders' (2013) 26(6) *Current Opinion in Psychiatry* 562; Jacinta AO Tan et al, 'Competence to Make Treatment Decisions in Anorexia Nervosa: Thinking Processes and Values' (2006) 13(4) *Philosophy, Psychiatry, and Psychology* 267.

and disorders of executive function affecting rationality of decisions.[117] Starvation also affects cognitive function, including comprehension and reasoning.[118] Some believe that each person with anorexia must be individually assessed to determine whether decision-making capacity is present despite these impairments.[119] However, others suggest that people with anorexia may *a priori* lack capacity, at least concerning treatment of that condition.[120] There has been at least one reported case in the Netherlands where a young woman with severe anorexia was held to have capacity to choose VAD.[121]

2 Victoria

A person with anorexia will ordinarily not be able to access VAD for this condition. This is because the *Victorian Act* specifically excludes access to VAD based solely on a mental illness.[122] Of course, access for a person with anorexia would be possible if they were eligible on the basis of another qualifying medical condition such as cancer or liver failure.[123]

However, there is an argument, drawing on one of the unresolved issues noted above, that anorexia could provide access to VAD. If a person's severe and enduring anorexia has caused substantial and ongoing physical harm (for example, heart disease or kidney failure), then access is not sought for a mental illness but rather for the person's physical condition. A weakness in this argument

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[117] Geppert (n 114).

[118] Tan et al (n 116) 270.

[119] Sam Boyle, 'How Should the Law Determine Capacity to Refuse Treatment for Anorexia?' (2019) 64 *International Journal of Law and Psychiatry* 250, 257–8; Campbell and Aulisio (n 109); Heather Draper, 'Anorexia Nervosa and Respecting a Refusal of Life-Prolonging Therapy: A Limited Justification' (2000) 14(2) *Bioethics* 120. Gans and Gunn Jr (n 109) articulate a series of specific criteria for determining whether an anorexic person has capacity to choose to die: 693–4.

[120] Christopher J Williams, Lorenzo Pieri and Andrew Sims, 'Does Palliative Care Have a Role in Treatment of Anorexia Nervosa? We Should Strive to Keep Patients Alive' (1998) 317(7152) *British Medical Journal (Clinical Research Edition)* 195, 196; Charland (n 116). In *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639, Jackson J acknowledged that a person with anorexia may never have capacity to make decisions concerning treatment for that condition: at [49]–[53]. Note though in *NHS v X* [2014] EWCOP 35, while Ms X was found to lack capacity in relation to decisions about treatment for her anorexia, she was found to have capacity to make decisions about her end-stage liver disease: at [30], [33]–[34] (Cobb J).

[121] Sneiderman and Verhoef (n 113). The second Dutch case mentioned above also involved a woman with anorexia but this condition was no longer as prominent in her overall mental condition by the time she was seeking VAD: Regional Euthanasia Review Committees (n 113). There are also reports of cases where a person with anorexia has been able to access VAD in Canada: see, eg, Joan Bryden, 'Exclusion of Mental Illness in Assisted Dying-Bill Slammed by Psychiatrists', *CFJC Today* (Web Page, 22 November 2020) <https://cfjctoday.com/2020/11/22/exclusion-of-mental-illness-in-assisted-dying-bill-slammed-by-psychiatrists/>.

[122] *Victorian Act 2017* (Vic) s 9(2). The definition of 'mental illness' in section 3 of the *Victorian Act 2017* (Vic) refers to section 4(1) of the *Mental Health Act 2014* (Vic), which defines 'mental illness' as 'a medical condition that is characterised by a significant disturbance of thought, mood, perception or memory'. Anorexia is both a thought disorder and a mood disorder and would therefore fall within this definition.

[123] For example, in *NHS v X* [2014] EWCOP 35, Ms X suffered both severe anorexia (a mental illness) and end-stage liver disease (a physical illness which was caused by her alcohol dependence disorder).

is that it relies on anorexia being seen as separate from its physical consequences. This is inconsistent with the broad approach that the courts have taken when conceptualising the physical outcomes of a mental illness. It also sits awkwardly with the proposed interpretation of the *Victorian Act* that a condition may be regarded as causing death if it causes a chain of events that will result in death.[124] Without an authoritative ruling on those issues, it is not possible to be certain about eligibility under the *Victorian Act* on the basis of anorexia.

In any event, a lack of decision-making capacity is very likely to preclude access. Currently, no English[125] or Australian cases[126] have found a person with severe anorexia to have capacity to make decisions refusing treatment for anorexia.[127] A similar outcome is likely in relation to VAD, particularly given that the application of other eligibility criteria mean that this could only arise for severe and enduring cases (see below).

In the highly unlikely event that these hurdles are passed, it is possible that the other eligibility criteria could be met in a small number of cases of severe and enduring anorexia.[128] People suffering the medical sequelae of prolonged starvation may expect death to occur within six months. By this stage, the condition is likely be considered to be advanced and progressive. Further, the person's condition may be considered 'incurable' if all available treatments have not been effective in alleviating the patient's symptoms, or if body systems are failing due to prolonged starvation.

3 Western Australia

Applying the above reasoning, there is also a very limited prospect of access to VAD for anorexia under the *WA Act*. We note, however, that as the condition does not have to be incurable, the possibility of a cure if further treatment is attempted will not be a barrier to accessing VAD.[129]

4 Model Bill

While there is a higher likelihood than in Victoria that people with severe and enduring anorexia may be permitted to access VAD under the Model Bill, access still remains unlikely given issues of decision-making capacity.

The Model Bill has two relevant differences from the *Victorian Act*. The first is that there is no specific statement precluding access to VAD on the basis of

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[124] See White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(B)(4).

[125] *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639; *An NHS Trust v L* [2013] EWHC 4313 (Fam); *NHS v X* [2014] EWCOP 35; *Re W (Medical Treatment: Anorexia)* [2016] EWCOP 13; *Cheshire & Wirral Partnership NHS Foundation Trust v Z* [2016] EWCOP 56.

[126] *Fletcher v Northern Territory* (2017) 324 FLR 11.

[127] However, a person with severe anorexia has been held to have capacity to refuse treatment for comorbid liver disease: *NHS v X* [2014] EWCOP 35.

[128] This term is defined as anorexia which is clinically severe, treatment resistant and long lasting: see Anna C Ciao, Erin C Accurso and Stephen A Wonderlich, 'What Do We Know About Severe and Enduring Anorexia Nervosa?' in Steven Touyz et al (eds), *Managing Severe and Enduring Anorexia Nervosa: A Clinician's Guide* (Routledge, 2016) 1.

[129] Contrast the result in England in the case of *Re E (Medical Treatment: Anorexia)* [2012] EWCOP 1639.

mental illness. This means there is no need to determine whether the person's physical condition is caused by anorexia or can be considered to be separate. In other words, the relevant 'medical condition' may be anorexia with its associated physical complications.

The second major difference is that a specific time until death is not required. The Model Bill still requires the condition be incurable and will cause death.[130] The causation condition is assessed on the basis of treatment that is acceptable to the person. This means that access to VAD will be limited to the identified cohort of people with severe and enduring anorexia. However, the absence of a requirement of temporal proximity may enable a person to request VAD at an earlier stage than in Victoria. This earlier assessment for VAD could potentially mean that capacity is less affected by the physical symptoms of starvation which increasingly affect cognition over time.

Despite the above, the requirement that a person retain capacity to make decisions in relation to VAD where it is sought on the basis of anorexia is likely to remain a significant barrier to access.

5 Oregon

The phrasing of the mental illness exclusion in the *Oregon Act* may make it more difficult for a person with severe and enduring anorexia to access VAD. Although not subject to judicial interpretation, the exclusion of a 'psychiatric or psychological condition or depression impairing judgment'[131] is likely to apply more broadly than a test of decision-making capacity. It would be difficult to maintain that a person with a severe and life-threatening eating disorder, which of its nature centrally affects thoughts and values about eating, did not have some form of impaired judgment, even if this impairment fell short of losing decision-making capacity. The law in Oregon states that a person with such a condition impairing judgment must not be given access to VAD until they are no longer suffering from impaired judgment.[132] This amounts to a categorical exclusion in contrast with the *Victorian Act*[133] and *WA Act*[134] which still allow access to VAD for person with a mental illness provided they have another qualifying medical condition.

6 Canada

Under the Canadian *Criminal Code*, similar to the *Victorian Act* and *WA Act*, mental illness cannot be considered an 'illness, disease or disability',[135] so a person with anorexia as a sole underlying medical condition is ineligible for VAD. However, on 17 March 2023, the mental illness exclusion will be automatically

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[130] Model Bill (n 2) cls 9(e)(i)–(ii).

[131] *Oregon Act*, Or Rev Stat (1994) § 127.825.

[132] Ibid § 127.825.

[133] *Victorian Act 2017* (Vic) s 9(2).

[134] *WA Act 2019* (WA) s 16(2).

[135] Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(2)(a), (2.1).

repealed and so people with anorexia as their sole underlying condition will be potentially eligible for VAD.

A subset of persons with anorexia – those who have 'serious and incurable' comorbid physical conditions as a result of their anorexia – may already be able to meet the criteria of an 'advanced state of irreversible decline in capability' and therefore could qualify for VAD despite the mental illness exclusion.[136]

Access to VAD for some people with anorexia and a comorbid physical condition after loss of decision-making capacity is also possible. If such a person is found to be eligible for VAD, while they have decision-making capacity, they can exercise the final consent waiver provision and make a written arrangement for VAD to be provided after they lose decision-making capacity.

7 Summary

Three of the frameworks (Victoria, Western Australia, and Canada until 2023) aim to specifically preclude people with anorexia from accessing VAD on that basis (because it is a mental illness). However, because anorexia affects eating behaviour, in some extreme cases it can cause physical conditions with life-threatening consequences. Possible access to VAD in Victoria and Western Australia depends on these physical conditions being seen as distinct from the mental illness. This is less of an issue for the Model Bill, which does not specifically prohibit access on the basis of mental illness. Under the Canadian *Criminal Code*,[137] a person's decline in capability may be caused by these resulting physical conditions or the anorexia. However, anorexia explicitly does not qualify as a 'serious and incurable illness, disease or disability' and the physical sequelae may not unless they independently amount to an 'illness, disease or disability'.

Access to VAD under all frameworks also depends on the person with severe and enduring anorexia (the application of other eligibility criteria would restrict any potential access to VAD to this cohort) having decision-making capacity. Applying the presumption of capacity, each individual should be carefully assessed to evaluate whether or not their anorexic thoughts and values undermine their capacity to choose VAD. However, as discussed above, retaining capacity is likely to be a barrier to accessing VAD for persons with severe and enduring anorexia (except in Canada for a person eligible to exercise the final consent waiver provision in the *Criminal Code*).

C Frailty

1 Nature of Condition

Frailty is a state of increased vulnerability to adverse health outcomes such as loss of mobility, falls, hospitalisation, disability and death.[138] It reflects the cumulative effects of disease and physiological changes that can occur as people age. It is

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[136] Ibid s 241.2(2)(b).

[137] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2).

[138] Andrew Clegg et al, 'Frailty in Elderly People' (2013) 381(9868) *Lancet* 752, 752.

multidimensional, and clinical manifestations vary widely. Consequently, frailty is generally considered a syndrome rather than a disease.[139] Prevalence is difficult to ascertain,[140] but estimates suggest that over 415,000 Australians experience frailty.[141] The physical indicators of frailty have traditionally included reduced activity, slowing of mobility, weight loss, and exhaustion,[142] but more recently the contribution of psychological, social and environmental factors to frailty have been acknowledged.[143] Consistently, longitudinal studies have reported that physical frailty also predicts the onset of future cognitive decline and dementia.[144] Frailty can progress through a number of stages[145] and is characterised by an inability to recover to baseline function after a minor stressor, such as an infection.[146]

Those who are frail are at increased risk of institutionalisation, morbidity and ultimately mortality, and generally experience a poorer quality of life than those who are not frail.[147] However, without a definitive diagnosis like cancer or heart disease that explains the physical decline, it is often the social, psychological and existential factors that cause the most distress.[148] The absence of a single underlying and diagnosable medical illness or disease means that it is more difficult to demarcate a point of physical decline where death becomes imminent in those who are frail.[149] Consequently, older frail people find themselves in an 'uncertain and dwindling process of dying'.[150]

2 Victoria, Western Australia, Model Bill and Oregon

Without a single underlying and diagnosable illness or disease, frailty does not provide a concrete medical condition that will cause death. This is required under

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[139] Matteo Cesari et al, 'Frailty: An Emerging Public Health Priority' (2016) 17(3) *Journal of the American Medical Directors Association* 188, 190.

[140] Shelly Sternberg et al, 'The Identification of Frailty: A Systematic Literature Review' (2011) 59(11) *Journal of the American Geriatrics Society* 2129. Prevalence of frailty ranged from 5% to 58%: at 2131.

[141] Danielle Taylor et al, 'Geospatial Modelling of the Prevalence and Changing Distribution of Frailty in Australia – 2011 to 2027' (2019) 123 *Experimental Gerontology* 57.

[142] Linda P Fried et al, 'Frailty in Older Adults: Evidence for a Phenotype' (2001) 56(3) *Journal of Gerontology: Medical Sciences* M146.

[143] RE Pel-Littel et al, 'Frailty: Defining and Measuring of a Concept' (2009) 13(4) *Journal of Nutrition, Health and Aging* 390, 392.

[144] Marco Canevelli, Matteo Cesari and Gabor Abellan van Kan, 'Frailty and Cognitive Decline: How Do They Relate?' (2015) 18(1) *Aging: Biology and Nutrition* 1363.

[145] See, eg, Kenneth Rockwood et al, 'A Global Clinical Measure of Fitness and Frailty in Elderly People' (2005) 173(5) *Canadian Medical Association Journal* 489.

[146] Clegg et al (n 138).

[147] Pel-Littel et al (n 143) 391.

[148] Anna Lloyd et al, 'Physical, Social, Psychological and Existential Trajectories of Loss and Adaptation Towards the End of Life for Older People Living with Frailty: A Serial Interview Study' (2016) 16(1) *BMC Geriatrics* 176:1–15.

[149] Ibid.

[150] C Nicholson et al, 'Living on the Margin: Understanding the Experience of Living and Dying with Frailty in Old Age' (2012) 75(8) *Social Science and Medicine* 1426, 1427.

the *Victorian Act*,[151] *WA Act*[152] and *Oregon Act*,[153] and the Model Bill,[154] so access to VAD is not possible on the basis of frailty alone under these frameworks.

3 Canada

Individuals can and have received VAD in Canada on the basis of 'complex disease/clinical frailty'.[155] This would involve a determination that a person's frailty constitutes a serious and incurable illness, disease or disability, or that one or more of the person's underlying illnesses, diseases or disabilities contributing to their overall frailty were serious and incurable.[156] To access VAD, the person must also be in an 'advanced state of irreversible decline in capability' which could be caused by a person's frailty or other conditions.[157]

4 Summary

Access to VAD for frailty is not possible under the *Victorian Act*, *WA Act*, *Oregon Act* or the Model Bill. They require a specified medical condition that will cause death, and frailty does not meet this criterion. By contrast, in Canada, VAD for frailty is possible. Although a serious and incurable illness, disease or disability is required to access VAD, there is no need to demonstrate that it will cause death. Further, in Canada, the advanced state of irreversible decline in capability is assessed globally rather than requiring it to be caused by a particular condition, allowing consideration of a person's frailty holistically.

D Spinal Cord Injury

1 Nature of Condition

SCI is damage to the spinal cord resulting in loss of mobility or sensation. This encompasses both tetraplegia (previously called quadriplegia) and paraplegia. Tetraplegia is caused by an injury to the upper spinal cord, resulting in some degree of impairment to all four limbs and pelvic organs, and which may affect breathing. Paraplegia is an injury lower down the spinal cord, resulting in loss of function

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[151] *Victorian Act 2017* (Vic) s 9(1)(d)(ii).

[152] *WA Act 2019* (WA) s 16(1)(c)(i).

[153] *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

[154] Model Bill (n 2) cl 9(e)(ii).

[155] The most recent federal report on VAD in Canada indicates that 6.1% of deaths fall in the category of 'other condition', and notes that '[t]he category of "other conditions" includes a range of conditions, with frailty commonly cited': *Canadian First Annual Report* (n 9) 22. Data from British Columbia also indicate some VAD deaths in Canada are due to frailty. From 2016–2018 on Vancouver Island, 6.3% of VAD deaths were reported as having 'complex disease/frailty' as the underlying illness: W David Robertson and Rosanne Beuthin, *A Review of Medical Assistance in Dying on Vancouver Island: The First Two Years: July 2016–2018* (Report, November 2018) 6. Likewise, data from VAD assessments in British Columbia indicated four individuals with 'extreme frailty' (and an average age of 92.3 years) had medically assisted deaths: Ellen Wiebe et al, 'Reasons for Requesting Medical Assistance in Dying' (2018) 64(9) *Canadian Family Physician* 674, 676.

[156] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a).

[157] Ibid s 241.2(2)(b).

from the chest down, sparing the arms.[158] SCI can affect sensation, control of the limbs and bowel and bladder function. This can be complete or incomplete.[159] SCI may be caused by a single traumatic incident, such as an accident, injury, stroke, or as a complication of medical care or surgery.[160] It may also result from the progression of a degenerative disease such as multiple sclerosis. The following discussion focusses on stable SCI, not degenerative SCI.[161]

The further up the spinal cord the injury occurs, the more serious the symptoms of SCI. Some individuals with tetraplegia require a ventilator to breathe,[162] but many do not. Some require artificial nutrition and hydration, but others are able to ingest food and drink orally.[163] Some are completely paralysed from the neck down, whereas others have partial movement in their arms and hands.[164] Many are wheelchair-bound, but others retain limited mobility.[165]

The prevalence of SCI in Australia is less than 0.1% of the population.[166] SCIs are generally persisting conditions[167] which are neither progressive nor fatal, but people with SCI have a higher mortality rate and lower life expectancy.[168] They appear to be more susceptible to diseases such as pneumonia, influenza and heart disease.[169]

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[158] Steven C Kirshblum et al, ‘International Standards for Neurological Classification of Spinal Cord Injury (Revised 2011)’ (2011) 34(6) *Journal of Spinal Cord Medicine* 535.

[159] This is sometimes referred to as ‘complete’ or ‘incomplete’ paralysis, using the American Spinal Injury Association Impairment Scale: Timothy T Roberts, Garrett R Leonard and Daniel J Cepela, ‘Classifications in Brief: American Spinal Injury Association (ASIA) Impairment Scale’ (2017) 475(5) *Clinical Orthopaedics and Related Research* 1499.

[160] For the causes of SCI in Australia, see Amanda Tovell, *Spinal Cord Injury, Australia, 2014–15* (Report, Australian Government, Australian Institute of Health and Welfare, Injury Research and Statistics Series No 113, Catalogue No INJCAT 202, 16 May 2018) vi, 39 (‘*SCI, Australia Statistics*’).

[161] Where a person has a progressive SCI due to a degenerative disease such as multiple sclerosis or a cancerous tumour, eligibility for VAD will be determined by the underlying condition of which the SCI is a symptom.

[162] Rita Galeiras Vázquez et al, ‘Respiratory Management in the Patient with Spinal Cord Injury’ (2013) *BioMed Research International* 168757:1–12.

[163] Ginette Thibault-Halman et al, ‘Acute Management of Nutritional Demands after Spinal Cord Injury’ (2011) 28(8) *Journal of Neurotrauma* 1497.

[164] Christopher S Ahuja et al, ‘Traumatic Spinal Cord Injury: Repair and Regeneration’ (2017) 80(3 Supp 1) *Neurosurgery* S9.

[165] Jan Mehrholz, Joachim Kugler and Marcus Pohl, ‘Locomotor Training for Walking After Spinal Cord Injury’ (2012) 11 *Cochrane Database of Systemic Reviews* CD006676:1–42.

[166] World Health Organization, The International Spinal Cord Society and Jerome Bickenbach (ed), *International Perspectives on Spinal Cord Injury* (Report, 2013) 15–16 (‘*International Perspectives on SCI*’). The figure for non-traumatic SCI is based on data from Victoria only, extrapolated to the rest of the country, and includes both children and adults. See generally PJ O’Connor, ‘Prevalence of Spinal Cord Injury in Australia’ (2005) 43 *Spinal Cord* 42.

[167] Tovell, *SCI, Australia Statistics* (n 160) 2, 4.

[168] Ibid 2.

[169] *International Perspectives on SCI* (n 166) 24–5; JW Middleton et al, ‘Life Expectancy After Spinal Cord Injury: A 50-Year Study’ (2012) 50 *Spinal Cord* 803; RJ Soden et al, ‘Causes of Death After Spinal Cord Injury’ (2000) 38 *Spinal Cord* 604.

2 Victoria and Western Australia

Under the *Victorian Act* and *WA Act*, people with SCI will not generally be eligible for VAD, because both statutes specifically state that a person is not eligible for VAD only because of disability.[170]

3 Model Bill

The Model Bill, unlike the *Victorian Act* and *WA Act*, does not specifically exclude people with disability from accessing VAD, but a person with a stable SCI will still be ineligible for VAD. Although their SCI is incurable, it is not progressive.[171]

4 Oregon

In Oregon, a person with SCI would not qualify for VAD on that basis as the legislation states that no person shall qualify for assistance to die 'solely because of … disability'.[172]

5 Canada

Individuals with SCIs as their sole underlying medical condition may be eligible for VAD in Canada if they are in an 'advanced state of irreversible decline in capability'.[173] Tetraplegia and paraplegia are serious and incurable disabilities. In the Canadian case of *Truchon v Procureur Général du Canada*, two wheelchair-bound individuals with serious and incurable disabilities were held to be eligible to access VAD.[174] However, both plaintiffs in that case had degenerative conditions,[175] not a stable SCI (the focus of this section). It is less clear whether a person satisfies the criterion of 'an advanced state of irreversible decline in capability' where the person has an SCI which involves a significant loss of function but is not progressive or degenerative. Some commentators, such as Jocelyn Downie and Jennifer Chandler, consider a decline in capability as a result of an SCI which has since stabilised to satisfy this criterion, whereas others believe the decline must be ongoing.[176]

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[170] *Victorian Act 2017* (Vic) s 9(3); *WA Act 2019* (WA) s 16(2).

[171] Model Bill (n 2) cls 9(e)(i)–(ii).

[172] *Oregon Act*, Or Rev Stat § 127.805(2) (1994).

[173] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

[174] *Truchon* [2019] QCCS 3792.

[175] Jean Truchon had cerebral palsy coupled with degenerative spinal stenosis and myelomalacia, and Nicole Gladu suffered from degenerative post-polio syndrome.

[176] White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(2)(b). Note, however, if a person with an SCI refuses life-sustaining medical treatment (or preventive care where the refusal leads to the need for life-saving medical treatment), this would eventually put them into an advanced state of irreversible decline and would be likely to render them eligible for VAD: see Jocelyn Downie and Matthew Bowes, 'Refusing Care as a Legal Pathway to Medical Assistance in Dying' (2019) 2(2) *Canadian Journal of Bioethics* 73.

6 Summary

A person with SCI will not be eligible for VAD on that basis in Victoria, Western Australia or Oregon because those jurisdictions specifically exclude disability as the sole reason for access to VAD. Under the Model Bill, a person with a stable SCI will also not be eligible for VAD, because the condition is not progressive. In Canada, however, a person with a stable SCI may be eligible for VAD if the eligibility criteria are interpreted to include a 'decline in capability' which has since stabilised, although the position is not yet resolved.

E Huntington's Disease

1 Nature of Condition

Huntington's disease ('Huntington's') is a progressive neurodegenerative disease, characterised by constant and uncontrollable jerking motions along with behavioural changes and cognitive decline.[177] This article considers adult-onset Huntington's, which typically develops between 30 to 50 years of age,[178] however it can manifest at any age from infancy.[179] If one parent has Huntington's, a child has a 50% chance of developing the condition.[180] It is incurable[181] and death typically occurs around 15 to 25 years after the first symptoms, usually from disease complications (such as pneumonia).[182]

Traditionally, five stages of Huntington's are used in research: early, early intermediate, late intermediate, early advanced and advanced.[183] Clinically, three stages – early, middle and late stages – are more often used. It is likely that during the middle to late stages, a person would lose decision-making capacity and lose independence in daily activities.[184]

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[177] Sara Parodi and Maria Pennuto, 'Huntington's Disease: From Disease Pathogenesis to Clinical Perspectives' in Kevin Guillory and Alex M Carrasco (eds), *Huntington's Disease: Symptoms, Risk Factors and Prognosis* (Nova Science Publishers, 2013) 1.

[178] National Institute of Neurological Disorders and Stroke, 'Huntington's Disease: Hope Through Research' (Publication, NIH Publication No 17-NS-19, 31 December 2018) 5 <https://www.ninds.nih.gov/Disorders/Patient-Caregiver-Education/Hope-Through-Research/Huntingtons-Disease-Hope-Through>.

[179] Francis O Walker, 'Huntington's Disease' (2007) 369(9557) *Lancet* 218, 218.

[180] Ian Freckelton, 'The Legal Ramifications of Huntington's Disease' in Kevin Guillory and Alex M Carrasco (eds), *Huntington's Disease: Symptoms, Risk Factors and Prognosis* (Nova Science Publishers, 2013) 93, 96.

[181] Ibid 98.

[182] Ibid 97.

[183] The Huntington's Disease Functional Capacity Scale was developed by Ira Shoulson: Ira Shoulson and Stanley Fahn, 'Huntington Disease: Clinical Care and Evaluation' (1979) 29 *Neurology* 1, 2; Ira Shoulson, 'Huntington Disease: Functional Capacities in Patients Treated with Neuroleptic and Antidepressant Drugs' (1981) 31(10) *Neurology* 1333.

[184] 'How Does Huntington's Disease Progress?', *Huntington's NSW and ACT* (Web Page, 2019) <https://webarchive.nla.gov.au/awa/20160301160906/http://www.huntingtonsnsw.org.au/information/hd-facts/how-does-huntingtons-disease-progress>. See Ian Freckelton, 'Huntington's Disease and the Law' (2010) 18(1) *Journal of Law and Medicine* 7.

2 Victoria and Western Australia

Huntington's is an incurable disease (required in Victoria only),[185] which is progressive and will cause death. When a person has a prognosis of 12 months until death, the disease will be in the 'late' stage, so will satisfy the 'advanced' criterion. However, at this point, the person would likely have lost decision-making capacity. As with Alzheimer's disease, these two criteria cannot be fulfilled simultaneously, precluding access to VAD.

3 Model Bill

There will be a similar outcome under the Model Bill. While the Model Bill does not require a prognostic timeframe, the disease must still be 'advanced'.[186] This is likely to be the case only when Huntington's has reached the 'late' stage, at which point a person would have lost decision-making capacity.

4 Oregon

A person with Huntington's will not be eligible for VAD in Oregon. The disease is 'incurable and irreversible',[187] but the person will likely not retain capacity at the point when the disease is expected to 'produce death within six months'.[188]

5 Canada

Huntington's is a 'serious and incurable' disease so eligibility for VAD depends on whether the patient will be in an 'advanced state of irreversible decline in capability'.[189] Particularly if this criterion is assessed by reference to the individual's prior capability rather than an objective standard,[190] a person may reach an advanced state of irreversible *physical* decline relatively early in the disease process. This criterion may therefore be satisfied in the middle stage of Huntington's, rather than the advanced stage. If a person with Huntington's retains decision-making capacity at that point, they will be able to access VAD.

Additionally, if a person wants to access VAD after losing decision-making capacity, they will be able to make arrangements under the final consent waiver provisions for VAD to be provided then. This is possible because Huntington's makes a person's natural death reasonably foreseeable (a condition for the exercise of the final consent waiver provision).[191]

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[185] *Victorian Act 2017* (Vic) s 9(1)(d)(ii).

[186] Model Bill (n 2) s 9(e)(ii).

[187] *Oregon Act*, Or Rev Stat § 127.800(12) (1994).

[188] Ibid § 127.805(1).

[189] Canadian *Criminal Code*, RSC 1985, c C-46, ss 241.2(2)(a)–(b).

[190] *IRPP Report* (n 16). See also White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part II(F)(2)(b).

[191] See *IRPP Report* (n 16).

6 Summary

A person with Huntington's will not be eligible for VAD in Victoria, Western Australia, under the Model Bill or in Oregon. The person will likely not have decision-making capacity at the requisite advanced stage of the disease, or when prognostic timelines are satisfied. By contrast, the Canadian *Criminal Code*'s framing of the person being in an 'advanced state of irreversible decline of capability',[192] rather than the condition itself being advanced, means access to VAD is possible. The physical symptoms of a person's Huntington's may have reached such a point while the person retains decision-making capacity. Also significant in Canada, given the known trajectory of Huntington's, a person may choose to exercise the final consent waiver provision to access VAD after losing capacity.

IV COMPARATIVE ANALYSIS OF ELIGIBILITY OF DIFFERENT MEDICAL CONDITIONS

This section undertakes a holistic comparative analysis of eligibility for VAD for each of the nine medical conditions across the five legal models. This comparative *practical* analysis (as opposed to the earlier comparative legal analysis[193]) is aided by Table 1 (below). This table cannot comprehensively represent all of the foregoing discussion and so focuses on those aspects critical for possible access to VAD.

We also mention two other limitations. The first is that this analysis is based on the nine medical conditions examined; other conditions may reveal other issues. The second is that because this is primarily a comparative analysis, it does not provide the basis to reach firm conclusions about what constitutes an optimal VAD model.[194] Differences observed between VAD models do not, without more, indicate which model is better or worse. However, the findings below relating to eligibility will facilitate a further (and deeper) consideration of VAD law and practice. As part of this, some comparisons reveal potentially undesirable outcomes.

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[192] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(b).

[193] White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1).

[194] Although we note that two of the authors have done this in relation to the Model Bill: see (n 2).

Table 1 Is Access to VAD Possible? Comparative Analysis of Eligibility for Nine Medical Conditions across Five Legal Frameworks

Condition/ Jurisdiction	Victoria	Western Australia	Model Bill	Oregon	Canada
Medical Conditions for Which Access to VAD is Possible under All Frameworks					
Colorectal Cancer	Yes, by later stages and once death expected within 6 months	Yes, by later stages and once death expected within 6 months	Yes, by later stages and without curative options	Yes, once death expected within 6 months and without curative options	Yes, once no curative options the person will accept, and person in advanced state of irreversible decline in capability
Motor Neurone Disease ('MND')	Yes, once death expected within 12 months, provided capacity retained	Yes, once death expected within 12 months, provided capacity retained	Yes, once condition is advanced, provided capacity retained	Yes, once death expected within 6 months, provided capacity retained	Yes, once person in advanced state of irreversible decline in capability, provided capacity retained (or final consent waiver)*
Chronic Obstructive Pulmonary Disease ('COPD')	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, once condition is advanced and will cause death, provided capacity retained	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, once person in advanced state of irreversible decline in capability, provided capacity retained (or final consent waiver)*
Chronic Kidney Disease ('CKD')	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, by later stages, provided capacity retained.	Yes, by later stages, provided capacity retained. Uncertain trajectory may present challenges for death expected within 6 months	Yes, once person in advanced state of irreversible decline in capability, provided capacity retained (or final consent waiver)*

Medical Conditions for Which Access to VAD is Very Unlikely in Most Jurisdictions (exceptions are in bold)					
Alzheimer's Disease	Very unlikely because capacity not retained when death expected within 12 months	Very unlikely because capacity not retained when death expected within 12 months	Very unlikely because capacity not retained when condition becomes advanced	Very unlikely because capacity not retained when death expected within 6 months	**Possible** if person retains decision-making capacity (or final consent waiver)* when in an advanced state of irreversible decline in capability
Anorexia	No, because a mental illness. Remote possibility for severe cases on basis of physical sequalae, provided capacity retained	No, because a mental illness. Remote possibility for severe cases on basis of physical sequalae, provided capacity retained	Possible but highly unlikely because capacity in doubt if other eligibility requirements met	No, because a mental illness 'impairing judgment'	**Possible** only if physical sequelae constitute 'a serious and incurable illness, disease or disability', and only if have capacity at that point (or final consent waiver)* Possible even where sole underlying medical condition after 17 March 2023 (when exclusion of mental illness is repealed)
Frailty	No, because no single medical condition will cause death	No, because no single medical condition will cause death	No, because no single medical condition will cause death	No, because no single medical condition will cause death	**Yes**, if person is in advanced state of irreversible decline in capability
Spinal Cord Injury ('SCI')	No, because a disability	No, because a disability	No, because not progressive	No, because a disability	**Probably**, if person interpreted to be in advanced state of irreversible decline in capability
Huntington's Disease	No, because capacity not retained when death expected within 12 months	No, because capacity not retained when death expected within 12 months	No, because capacity not retained when condition becomes advanced	No, because capacity not retained when death expected within 6 months	**Yes**, if person retains capacity (or final consent waiver)* when they are in an advanced state of irreversible decline in capability

* Where a person's natural death is reasonably foreseeable, a final consent waiver is possible in Canada, provided the person meets the eligibility criteria for VAD. This is noted in Table 1 only in relation to cases where loss of decision-making capacity was discussed in the text.

A Access to VAD Shows a Clear Distinction between the Canadian Model and All Other Models

Two clear overall conclusions emerge from the comparative practical analysis. The first is that there is a great deal of similarity across the Victorian, Western Australian, Model Bill and Oregonian frameworks in terms of access to VAD, despite significant differences in terms of whether a disease must be 'incurable' or whether death must be expected within a particular timeframe. The second is that access to VAD is much broader in Canada.

All five frameworks contemplate VAD for colorectal cancer, MND, COPD and CKD. Access is less straightforward for medical conditions with uncertain trajectories to death such as COPD and CKD, but is nonetheless possible. This is not to say, however, that timing of access to VAD is the same. Generally, access is available latest in Oregon (always six months) and in Victoria and Western Australia (generally six months but 12 months for neurodegenerative conditions). The Model Bill provides earlier access for these medical conditions as the Bill does not stipulate that death must be anticipated within a specified time limit, and indeed this helps avoid some issues with predicting timing of death for conditions with uncertain trajectories. The Canadian framework provides the earliest access to VAD for these conditions: whenever a person has reached an 'advanced state of irreversible decline in capability', which is interpreted broadly.

Our analysis demonstrates that the other medical conditions considered (Alzheimer's, anorexia, frailty, SCI and Huntington's) are generally precluded from VAD under the eligibility criteria in the *Victorian Act*,[195] *WA Act*[196] and *Oregon Act*,[197] and the Model Bill.[198] But the position is different under Canadian law where access is possible (and sometimes probable) for all of these medical conditions. The eligibility criteria in the Canadian *Criminal Code*[199] are broader, due to three (interrelated) factors.

The first is that access to VAD does not depend on proximity or likelihood of death. The second is that to establish a 'grievous and irremediable medical condition',[200] the Canadian criteria do not require a causal connection between the 'serious and incurable illness, disease or disability' and the 'advanced state of irreversible decline in capability'.[201] By contrast, the other frameworks require that the condition *cause* the relevant outcome (death in those models). The third factor is that the requirement that a person's condition is 'advanced' is framed differently: Canadian law requires an advanced decline in *capability of the person*,[202] whereas other models assess whether the person's *medical condition* itself has reached an advanced state. These last two features mean that a person's advanced state of

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[195] *Victorian Act 2017* (Vic) s 9.

[196] *WA Act 2019* (WA) s 16.

[197] *Oregon Act*, Or Rev Stat § 127.805 (1994).

[198] Model Bill (n 2) cl 9.

[199] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(1).

[200] Ibid s 241.2(1)(c).

[201] Ibid ss (2)(a)–(b).

[202] Ibid s 241.2(2)(b).

irreversible decline in capability can be assessed globally, taking into account their entire health status and all possible medical conditions (not just the qualifying condition).

B Impact of Time Limits until Death on Access to VAD

Eligibility criteria address not only the question of *whether* VAD can be accessed, but *when*. This comparative practical analysis demonstrates the impact of including an eligibility requirement that a person be expected to die within a specified time period. This is best illustrated by comparing access to VAD under the *Victorian Act*[203] (a time limit of six and sometimes 12 months until death) with the Model Bill[204] (very similar eligibility criteria, but no time limit, requiring only that the condition cause death). For eight of the nine conditions considered in this article, potential eligibility under the Model Bill was the same as in Victoria.[205] The sole possible exception was for anorexia, which possibly could be eligible under the Model Bill (although highly unlikely) since it does not specifically exclude mental illness. In other words, the six or 12 month time limit until death in Victoria had no impact on restricting the medical conditions that would permit access to VAD when compared with the Model Bill. This is because the Model Bill's requirement for a person's medical condition to be 'advanced' constrains access to similar cases.[206]

This raises questions about the utility of requiring a time until death in VAD eligibility criteria. If the purpose is to exclude access to VAD for certain medical conditions, then it does not appear to be necessary, at least in relation to these medical conditions. However, if the purpose is to reserve VAD only for those who are at the end of their lives,[207] it is effective. One of the conclusions of this comparative analysis is that the time limits in the *Victorian Act*, *WA Act* and *Oregon Act* restrict access to a later stage in a person's medical condition than under the Model Bill.

Such a time-based approach has a number of undesirable outcomes. One examined above is the difficulty a time limit can cause for prognostication, particularly for medical conditions with an unpredictable trajectory to death. This can mean that a person whose condition will cause death may not be eligible because the nature of their illness does not provide a reliable guide to how far away their death may be. Another undesirable outcome is the additional suffering that a person, who is otherwise eligible for VAD, must endure while waiting to

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[203] *Victorian Act 2017* (Vic) s 9(1)(d)(iii).

[204] Model Bill (n 2) cl 9(e).

[205] This same result also applies in relation to the *WA Act 2019* (WA) s 16(1)(c)(ii) and *Oregon Act*, Or Rev Stat § 127.800(12) (1994). The rationale for the specific comparison between the *Victorian Act* and the Model Bill is the relevant wording of the eligibility criteria in the two frameworks is almost identical but for the imposition of a time limit until death in Victoria.

[206] Model Bill (n 2) cl 9(e)(ii).

[207] Indeed, the intention of the *Victorian Act* was that VAD would only be available for those people who are 'close to death' and at the 'end of life': *MAP Report* (n 38) 13–14.

fall within the prescribed proximity until death.[208] Requiring a specified time limit until death also risks preventing otherwise eligible people from accessing VAD, if the delay until death is approaching means that they are no longer well enough to navigate the assessment process. We consider that jurisdictions contemplating reform should reflect on these undesirable outcomes and whether a specified time limit until death is justifiable.

C Impact of Decision-Making Capacity on Medical Conditions that Will Permit Access to VAD

All five frameworks require a person to have decision-making capacity to access VAD. Capacity issues specifically arose in six of the nine conditions considered: MND, COPD, CKD, Alzheimer's, anorexia and Huntington's.[209] The progression of some conditions can have a consequential impact on decision-making capacity. For example, COPD can cause a lack of oxygen to the brain. For other conditions, such as Alzheimer's and Huntington's, a lack of decision-making capacity is a defining feature of the condition and a key reason why VAD is generally not permitted for these conditions (except in Canada).

This demonstrates the significant implications that decision-making capacity has for access to VAD. Advance directives or requests for VAD have been proposed as a mechanism to address these issues, but there have been challenges with the uptake and useability of such tools in jurisdictions where they are lawful and for which there are data.[210] Nevertheless, community desire remains high for mechanisms to support access to VAD for conditions such as Alzheimer's after a loss of capacity.[211] This has led to some jurisdictions specifically identifying

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[208] Ben P White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal 417, 433 ('Does the VAD Act Reflect Its* Stated Policy Goals?').

[209] Of course, even for conditions which do not of themselves specifically impair capacity, the progression of those conditions or side effects can raise capacity issues, for example pain and symptom management can require taking medication that can impair capacity.

[210] Research also suggests advance directives or requests for VAD are often not followed in practice: Marike E de Boer et al, 'Advance Directives for Euthanasia in Dementia: Do Law-Based Opportunities Lead to More Euthanasia?' (2010) 98(2–3) *Health Policy* 256; Mette L Rurup et al, 'Physicians' Experiences with Demented Patients with Advance Euthanasia Directives in the Netherlands' (2005) 53(7) *Journal of the American Geriatrics Society* 1138. Use of these directives remains controversial: Paul Mevis et al, 'Advance Directives Requesting Euthanasia in the Netherlands: Do They Enable Euthanasia for Patients Who Lack Mental Capacity?'(2016) 4(2) *Journal of Medical Law and Ethics* 127; Karin R Jongsma, Marijke C Kars and Johannes JM van Delden, 'Dementia and Advance Directives: Some Empirical and Normative Concerns' (2019) 45(2) *Journal of Medical Ethics* 92; David Gibbes Miller, Rebecca Dresser and Scott YH Kim, 'Advance Euthanasia Directives: A Controversial Case and Its Ethical Implications' (2019) 45(2) *Journal of Medical Ethics* 84. There is not yet any data in Canada for advance requests made through 'final consent – waiver' or 'advance consent – self administration' (under ss 241.2(3.2), (3.5) of the Canadian *Criminal Code*, RSC 1985, c C-46).

[211] People with Alzheimer's desire to have access to assisted dying, including via advance directives: Alzheimer's Australia Victoria, 'A Good Death is My Right' (Discussion Paper, April 2017) 9–10; Dementia Australia, Ministerial Expert Panel on Voluntary Assisted Dying: A Response from Dementia Australia, *Ministerial Expert Panel on Voluntary Assisted Dying* (May 2019) 7; *Queensland Parliamentary Report* (n 3) 123–5.

this issue as warranting further consideration.[212] We support this, and recommend jurisdictions contemplating reform actively investigate how this complex policy issue could be addressed. Some recognition of the desire for VAD after loss of capacity is found in Canada through the final consent waiver. The '10 minutes to midnight' approach for assessing capacity of individuals with dementia has been another Canadian response to this issue (although it maintains the requirement that a person has capacity immediately prior to the provision of VAD).

D Impact of Excluding Types of Medical Conditions from Access to VAD

A legislative drafting device employed in some VAD frameworks is excluding particular categories of conditions from access to VAD. The two excluded conditions in these frameworks are disability (Victoria, Western Australia and Oregon)[213] and mental illness (all frameworks except the Model Bill).[214] One limitation of this analysis is that only one type of mental illness (anorexia) and one disability (SCI) were considered. More robust testing is needed in relation to a range of mental illnesses and disabilities but this comparative analysis does identify some important questions.

Excluding disability as a ground for VAD under some statutes did not create different outcomes between those laws and the Model Bill for stable SCI. In relation to anorexia, however, there may be a different outcome. Under the Model Bill, access to VAD, though highly unlikely, may be possible for a small cohort of persons with severe and enduring anorexia whose illness is objectively considered to be incurable, is advanced and progressive and likely to cause death. (However, the person, despite the severity of their condition, must retain capacity to seek VAD and this is highly unlikely.) Although these criteria are identical in the *Victorian Act*, and very similar in the *WA Act*, the specific exclusion of mental illness in those jurisdictions likely precludes access to VAD, assuming that the physical sequelae of the illness are not considered a separate terminal condition providing access.

As mentioned, more analysis is needed to assess access to VAD for a range of mental illnesses. We note that anorexia is atypical of mental illnesses, in that it can result in life-threatening physical conditions which can be fatal. But this analysis

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[212] In Canada, the Minister of Justice and the Minister of Health were required to initiate an independent review into advance requests for VAD within six months of the initial legislation passing: Bill C-14, 1st Sess, 42nd Parl, 2016, cl 9.1(1). The result was the following report: Council of Canadian Academies, *The State of Knowledge on Advance Requests for Medical Assistance in Dying: The Expert Panel Working Group on Advance Requests for MAiD* (Report, 12 December 2018). This issue will again be considered during a Parliamentary review in response to Bill C-7: Department of Justice, 'Canada's New Medical Assistance in Dying (MAID) Law', *Government of Canada* (Web Page, 19 March 2021) <https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html>. In Queensland, the parliamentary committee inquiring into VAD recommended further research into the issue of advance requests for VAD by persons with dementia: *Queensland Parliamentary Report* (n 3) 127 'Recommendation 7'. See also the 'Statement of Reservation' of Michael Berkman MP, supporting further research into this issue: at 197–8.

[213] *Victorian Act 2017* (Vic) s 9(3); *WA Act 2019* (WA) s 16(2); *Oregon Act*, Or Rev Stat § 127.805(2) (1994).

[214] *Victorian Act 2017* (Vic) s 9(2); *WA Act 2019* (WA) s 16(2); *Oregon Act*, Or Rev Stat § 127.825 (1994). The exclusion of access to VAD on the basis of mental illness in Canada is proposed in Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 1(2) (as passed by the House of Commons 17 March 2021), amending Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2.1).

invites the question whether a blanket exclusion from access to VAD based on mental illness is justifiable when the eligibility criteria are otherwise met.[215]

V IMPLICATIONS OF ANALYSIS OF MEDICAL CONDITIONS FOR DESIGN OF VAD REGULATION

The comparative legal analysis in the first article[216] in this two-part series identified important implications for designing VAD regulation. This Part extends that work and focuses on what the comparative *practical* analysis of access to VAD for different medical conditions reveals about design of VAD regulation.

A Test Eligibility Criteria in Relation to Medical Conditions to Ensure Criteria Operate as Intended

The purpose of eligibility criteria is to determine who will and will not be permitted to access VAD. Careful testing of these criteria by reference to a wide range of medical conditions prior to legislating enables policymakers to determine if the proposed criteria will operate in practice as intended. As the analysis presented here demonstrates, it also highlights whether when criteria are applied holistically (see below), there are some criteria that may be redundant. An example might be a specified time until death (as discussed above), depending on policymakers' intent. Evaluating which medical conditions could facilitate access to VAD should also continue *after* a VAD law is passed. Such a review requires robust data collection including about who is accessing VAD and on the basis of which medical conditions. Such data should also include who is being refused access to VAD and the role (if any) of individuals' medical conditions in those decisions.

B Eligibility Criteria Operate Holistically

As observed in the preceding article, eligibility criteria in VAD frameworks are intended to operate holistically.[217] This was clear on the face of the legislation and from the comparative legal analysis, but became particularly apparent when these

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[215] Udo Schuklenk and Suzanne van de Vathorst, 'Treatment-Resistant Major Depressive Disorder and Assisted Dying' (2015) 41(8) *Journal of Medical Ethics* 577; Justine Dembo, Udo Schuklenk and Jonathan Reggler, '"For Their Own Good": A Response to Popular Arguments Against Permitting Medical Assistance in Dying (MAiD) where Mental Illness Is the Sole Underlying Condition' (2018) 63(7) *Canadian Journal of Psychiatry* 451; Isra Black, 'Suicide Assistance for Mentally Disordered Individuals in Switzerland and the State's Positive Obligation to Facilitate Dignified Suicide' (2012) 20(1) *Medical Law Review* 157, 164–5. Note also the Canadian Council of Academies work on mental illness as sole underlying medical condition to access VAD: Council of Canadian Academies, *The State of Knowledge on Medical Assistance in Dying Where a Mental Disorder is the Sole Underlying Medical Condition: The Expert Panel Working Group on MaiD Where a Mental Disorder is the Sole Underlying Medical Condition* (Report, 12 December 2018). The Canadian government will commission an independent expert review into the requisite protocols, guidance and safeguards to apply to VAD requests based on mental illness as a sole underlying condition, with recommendations due by 17 March 2022: Bill C-7, 2nd Sess, 43rd Parl, 2021, cl 3.1 (as passed by the House of Commons 17 March 2021).

[216] White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1).

[217] Ibid Part IV(C).

criteria were applied to the nine medical conditions. An illustration of this is that differently formulated eligibility criteria can achieve the same result in terms of which medical conditions permit access to VAD.

For example, in Victoria and under the Model Bill,[218] a person's condition must be 'incurable', but this is not required in Western Australia. In Victoria and Western Australia, doctors must prognosticate about time until death, but this is not required in the Model Bill.[219] Yet across these three frameworks, applying the criteria holistically, the same medical conditions provided access to VAD (save perhaps a possible difference in the exceptional case of anorexia). This is because the absence of one aspect of the criteria in a particular framework was compensated for by the collective operation of the other components. This should alert policymakers to consider whether each individual criterion is required, or whether a particular criterion may be redundant given the presence of other, determinative, factors.

A holistic application of eligibility criteria means not only applying all criteria concurrently but also considering causal relationships between them. Systematically applying five frameworks to nine selected medical conditions revealed how causal relationships between criteria (or their absence) have a significant impact on access to VAD. All frameworks except Canada require a causal relationship between the person's medical condition and expected death, which narrows eligibility. In contrast, the Canadian model does not require a causal link between the 'serious and incurable condition' and the 'advanced state of irreversible decline' a person experiences.[220] As a result of this (and other factors), access to VAD in Canada is broader than under the other frameworks.

C Challenge of Translating Policy Goals into Legislation

The challenges of designing VAD legislation that reflects its desired policy goals and is capable of being consistently interpreted and applied as intended were noted earlier in the comparative legal analysis.[221] These challenges were further illuminated by applying the five frameworks to the nine medical conditions. In relation to reflecting policy goals, crafting eligibility criteria that are not either over-inclusive or under-inclusive when compared with the objectives underpinning the law presents a specific challenge for rule design.[222] In other words, there is a risk

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[218] *Victorian Act 2017* (Vic), s 9(1)(d)(i); Model Bill (n 2) cl 9(e)(i).

[219] *Victorian Act 2017* (Vic), ss 9(1)(d)(iii) and 9(4); *WA Act 2019* (WA) s 16(1)(c)(ii); Model Bill (n 2) cl 9(e).

[220] Canadian *Criminal Code*, RSC 1985, c C-46, s 241.2(2)(a)–(b).

[221] White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for VAD' (n 1) Part IV(A); Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163.

[222] Yeung (n 221) 168. A discussion of the policy goals underpinning these frameworks is beyond the scope of this paper. The principles guiding the Victorian VAD law are contained in *MAP Report* (n 38) 43–6 and evaluated in White et al, '*Does the VAD Act Reflect its* Stated Policy Goals?' (n 208). In relation to Western Australia, see Ministerial Expert Panel on Voluntary Assisted Dying, Department of Health (WA), *Final Report* (Report, 27 June 2019). The values underpinning the model Bill are set out in Model Bill (n 2) 6; Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model for Reform' in Ian Freckelton and Kerry Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 479. The Canadian law is based on *Charter* rights as identified in the *Charter* (n 5).

that individuals whom the policy intent was to permit access to VAD are excluded by the legislation, or a risk that those whom the intent was to exclude from VAD can obtain access.

This was demonstrated in the comparative practical analysis where mental illness is specifically excluded as a basis for VAD. To some extent, this is an attempt to create a clear rule and certainty in relation to eligibility (putting aside definitional questions such as what constitutes a mental illness and how to characterise any physical sequelae). By preferencing certainty through directly excluding a category of cases, the difficulty of determining whether a person with a mental illness could otherwise qualify for VAD is avoided. But this may not be consistent with the law's overall policy goals as reflected in the generic eligibility criteria (or at least reflects inconsistency within those goals) and risks under-inclusion.

This is illustrated in Victoria where the Ministerial Advisory Panel, whose recommendations underpinned the Act, supported a blanket exclusion of access to VAD on the basis of mental illness 'because it is not a medical condition that "will cause death"'[223] and, therefore, could not satisfy the eligibility criteria. However, this is inconsistent with the analysis above in relation to at least one mental illness: anorexia, which is capable of causing death in severe cases. If the Panel was intending only to use the blanket exclusion as a clear means of confirming the operation of the eligibility criteria, then this may not be the intended result. Further, the Panel's stated policy intent was: 'To ensure people with mental illness are afforded the same rights and protections as other members of the community and that people with mental illness who meet all of the eligibility criteria are not unreasonably denied access to voluntary assisted dying'.[224] The explicit exclusion of mental illness may be inconsistent with this stated policy intent. If the intention was to exclude mental illness because such conditions were considered an inappropriate basis to access VAD, then this additional exclusion warrants express justification at a policy level.

The other major regulatory challenge in relation to the five VAD frameworks relates to rule indeterminacy and interpretation.[225] In the process of applying the various eligibility criteria to nine medical conditions, it became clear that how and when some criteria were met for particular conditions was not straightforward. Examples include: when does a medical condition become 'advanced' and 'progressive', and what constitutes an 'advanced state of irreversible decline in capability'? But even requirements such as an expected time until death, which can ostensibly appear more concrete and certain, have been shown to be unclear and difficult to apply in practice in some situations. Indeed, challenges of prognostication could mean that determining likely time until death is more uncertain than other eligibility criteria, such as for particular conditions that have strong clinical criteria for determining when they become 'advanced' and 'progressive'.

This breadth in interpreting the criteria could be seen as positive because this permits some flexibility for doctors to apply them to individual patients in

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[223] *MAP Report* (n 38) 81.

[224] Ibid 82.

[225] Yeung (n 221) 168–9.

a meaningful way. However, this ambiguity may lead to doctors (and regulators) applying these concepts inconsistently in practice. This is a known challenge not only in designing VAD laws but in regulation more generally.[226] Another concern is that where there is uncertainty, eligibility criteria may be applied conservatively to avoid possible liability. A response to these concerns is to provide other support to guide consistent application of the criteria in practice that aligns with the framework's intent.

D Developing Guidance and Support to Interpret VAD Frameworks

Consistent interpretation of VAD frameworks to advance the intended policy goals is desirable. The comparative analysis of the medical conditions revealed how, particularly for conditions for which eligibility may be difficult to assess, it may be desirable to develop guidance about implementation of VAD frameworks in practice. From a legal perspective, clarification of legislation often occurs via case law and this has occurred in Canada during the relatively short period that VAD has been in operation.[227] However, this may not occur; we are not aware of any cases interpreting Oregon's law, despite being operational for over 20 years. Further, courts can only address issues raised by the parties' factual situation, not every situation where interpretive clarification is needed. Reliance on judicial clarification is also problematic as by definition the individuals concerned are seriously ill and suffering, and may not be able or have time to pursue legal challenges through courts.

Accordingly, other tools of regulation are needed to guide decision-making under the VAD frameworks. In Canada, guidelines and policies have been produced by medical regulators and the Canadian Association of MAiD Assessors and Providers.[228] Decisions by regulators in particular cases, if made public by the regulator or the clinician investigated, may also contribute to interpretation of statutory provisions.[229] And one of the authors, academic Jocelyn Downie, has

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[226] Ibid 168–70; Lutz-Christian Wolff, 'Law and Flexibility: Rule of Law Limits of a Rhetorical Silver Bullet' (2011) (11) *Jurisprudence* 549.

[227] Judicial interpretation of the Canadian legislative criteria has occurred in one case *AB v Canada (Attorney-General*) [2017] ONSC 3759 (meaning of 'natural death has become reasonably foreseeable'). In Victoria, the Victorian Civil and Administrative Tribunal has interpreted the meaning of the 'residence' criterion in the *Victorian Act*: *NTJ v NTJ (Human Rights)* [2020] VCAT 547. We also note that clarification of legislation can also occur by amending the legislation itself.

[228] For example, Canadian Association of MaiD Assessors and Providers, 'The Clinical Interpretation of 'Reasonably Foreseeable'' (Clinical Practice Guideline, June 2017); Canadian Association of MAiD Assessors and Providers, *Assessment for Capacity to Give Informed Consent for Medical Assistance in Dying (MAiD) Review and Recommendations* (White Paper, April 2020); Canadian Association of MAiD Assessors and Providers, 'Medical Assistance in Dying (MAiD) in Dementia' (Clinical Guideline, May 2019); College of Physicians and Surgeons of Nova Scotia, 'Professional Standard Regarding Medical Assistance in Dying (MAiD)' (Guideline, 5 May 2021) <https://cpsns.ns.ca/resource/medical-assistance-in-dying/>. Policies of other medical colleges are available at the End-of-Life Law and Policy in Canada webpage: Health Law Institute, Dalhousie University, 'Clinical Guidance Documents', *End-of-Life Law and Policy in Canada* (Web Page, 2020) <http://eol.law.dal.ca/?page_id=2657>.

[229] Two regulatory decisions that have been made publicly available are those in relation to Mary Wilson (discussed above) and Ms S: see College Investigation Regarding Death of Mary Wilson (n 103); Complaints and Practice Investigations Department, College of Physicians and Surgeons of British

worked with colleagues to clarify key terms in the Canadian *Criminal Code*. This has occurred in a variety of ways including through a policy roundtable process which produced a report with recommended interpretations.[230]

Regulatory bodies with responsibility for VAD oversight can also help guide behaviour. For example, in the Netherlands, the Regional Euthanasia Review Committees publish detailed summaries of VAD cases.[231] These summaries are also indexed in terms of various domains, most importantly for present purposes into straightforward cases and non-straightforward cases, as well as those cases where the 'due care criteria' were complied with and those where it was not. This publicly available guidance can help to promote consistent interpretation of the law. A VAD oversight body may also be able to provide prospective guidance in particular cases or on particular topics. For example, the remit of such a body could include providing advice on a complex case about which a doctor wanted reassurance, or issuing an opinion about a category of case, such as VAD for anorexia given the unresolved issues raised above.

The Canadian and other work described above has, however, been primarily reactive in that they occurred after the law had passed. It is also possible, and desirable, to utilise wider tools of regulation to promote consistent understanding and application of eligibility criteria before the law commences. One example in Australian models is the mandatory training doctors must undertake prior to assessing a patient's eligibility for VAD.[232] This establishes a minimum baseline understanding of the legislative framework and provides guidance on how it should be interpreted.[233]

VI CONCLUSION

In this article and its companion article, we have undertaken comparative legal and practical analyses of five VAD frameworks in relation to nine medical conditions. This has generated new insights into these legal models and implications

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Columbia, *Final Disposition Report of the Inquiry Committee* (Report, CPS File No IC 2017-9836, 13 February 2018) <http://eol.law.dal.ca/wp-content/uploads/2017/11/College-letter-.pdf>. In relation to the latter decision, see Jocelyn Downie, 'Has Stopping Eating and Drinking Become a Path to Assisted Dying', *Policy Options* (online, 23 March 2018) <https://policyoptions.irpp.org/magazines/march-2018/has-stopping-eating-and-drinking-become-a-path-to-assisted-dying/>.

[230] *IRPP Report* (n 16). Downie has also written a series of academic papers analysing and interpreting various aspects of the legislation: Downie and Scallion (n 16); Jocelyn Downie and Justine Dembo, 'Medical Assistance in Dying and Mental Illness Under the New Canadian Law' (2016) 9 *Journal of Ethics in Mental Health* 1; Downie and Bowes (n 176); Gus Grant and Jocelyn Downie, 'Time to Clarify Canada's Medical Assistance in Dying Law' (2018) 64(9) *Canadian Family Physician* 641.

[231] 'Judgments', *Regional Euthanasia Review Committees* (Web Page, 2018) <https://english.euthanasiecommissie.nl/judgments/>.

[232] *Victorian Act 2017* (Vic) ss 17, 26; *WA Act 2019* (WA) ss 25, 36; Model Bill (n 2) cl 14.

[233] Ben P White et al, 'Development of Voluntary Assisted Dying Training in Victoria, Australia: A Model for Consideration' (2021) 36(3) *Journal of Palliative Care* 162. Guidance for health practitioners is also provided in other forms: see, eg, Department of Health and Human Services (Vic), 'Voluntary Assisted Dying: Guidance for Health Practitioners' (Clinical Guideline, 4 July 2019).

of their design in practice. We acknowledge that the comparative methodology does not permit strong normative conclusions about an optimal VAD framework; different does not necessarily mean better or worse.[234] That said, these analyses have revealed significant undesirable outcomes in some aspects of these frameworks, highlighted doubts about their effectiveness in achieving stated policy goals, and identified important considerations for policymakers contemplating VAD reform.

VAD reform in further states is being actively considered in Australia.[235] Other countries are also contemplating reform, including the United Kingdom,[236] parts of Europe[237] and other states in the United States.[238] These papers have implications for those reform exercises. In Australia, a particular issue is whether other states should follow the 'Victorian model', as Western Australia has substantially done, or take a different path.[239] There can be a tendency to adopt an existing framework, but uncritical acceptance of the Victorian approach must be avoided.[240] These comparative analyses raise important questions about the *Victorian Act*'s operation in practice, and provide other models for policymakers to consider.

Further, the comparative practical analysis demonstrates the critical importance of testing the operation and boundaries of proposed VAD laws against a range of medical conditions. The exercise of determining which medical conditions might permit access to VAD, and when, as well as those medical conditions which

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[234] John C Reitz, 'How to Do Comparative Law' (1998) 46(4) *The American Journal of Comparative Law* 617, 624–5.

[235] After this article was submitted for publication, voluntary assisted dying laws were passed in three Australian states: the *End-of-Life-Choices (Voluntary Assisted Dying) Act 2021* (Tas); the *Voluntary Assisted Dying Act 2021* (SA) and the *Voluntary Assisted Dying Act 2021* (Qld), respectively. In NSW, the Voluntary Assisted Dying Bill 2021 (NSW) has passed the Legislative Assembly and is set to be debated in the Legislative Council in 2022.

[236] See, eg, the discussion of legislative and judicial developments in the United Kingdom in relation to VAD in *R (Conway) v Secretary of State for Justice* [2018] EWCA Civ 1431, [18]–[48] (Etherton MR, Leveson P and King J).

[237] For example, in Portugal, two laws decriminalising VAD have been passed by Parliament but vetoed by the President: 'Portugal's President Vetoes Law Legalising Euthanasia', *Euronews* (online, 30 November 2021) <https://www.euronews.com/2021/11/30/portugal-s-president-vetoes-law-legalising-euthanasia>. Spain passed the *Ley Orgánica de regulación de la euthanasia 2021* [Organic Law for the Regulation of Euthanasia] (Spain), which commenced in June 2021. In Germany, in February 2020, the Constitutional Court declared § 217 of the *Strafgesetzbuch* [Criminal Code] (Germany), which criminalised the provision of assisted suicide services, to be unconstitutional: Bundesverfassungsgericht [German Constitutional Court], 2 BvR 2347/15, 26 February 2020 reported in (2020) BVerfG, Urteil des Zweiten Senats vom 26 Februar 2020, Rn 1-343.

[238] For an updated list of ongoing legislative activity in relation to VAD in the United States, see 'In Your State', *Death with Dignity* (Web Page) <https://www.deathwithdignity.org/in-your-state/>.

[239] Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42(6) *Australian Health Review* 616.

[240] The *Victorian Act* has been the subject of critical analysis from a range of normative perspectives including: its own stated regulatory goals (White et al, 'Does the VAD Act Reflect Its Stated Policy Goals?' (n 208)); ethical and legal values (Lindy Willmott, Katrine Del Villar and Ben White, 'Voluntary Assisted Dying in Victoria, Australia: A Values-Based Critique' in Sue Westwood (ed), *Regulating the Ending of Life: Death Rights* (Routledge, 2020) 55) and human rights (Lindy Willmott, Ben White and Katrine Del Villar, 'Voluntary Assisted Dying: Human Rights Implications for Australia' in Paula Gerber and Melissa Castan (eds), *Contemporary Perspectives on Human Rights Law in Australia* (Thomson, 2020) vol 2).

would not be eligible for access to VAD, can help ensure frameworks operate as intended. Perhaps the most striking conclusion from this practical comparative analysis is how, putting aside Canada, different eligibility criteria appeared to make limited difference to access to VAD, and primarily only in relation to timing of that access. This suggests potential redundancy in some criteria. While some may argue that this redundancy does not matter (perhaps comfortable with this out of an abundance of caution), including criteria not required to control access to VAD can add unnecessary complexity and uncertainty to assessing eligibility. This can cause undesirable outcomes of inconsistency and undue conservatism in decision-making. It is also important to consider when designing reform are those areas identified in this review as problematic or challenging. They included the question of whether a requirement for a time until death is appropriate, as well as the vexing issue of capacity and VAD.

These reflections also apply to jurisdictions with existing VAD laws. It is critical that the current law continues to be reviewed to see if it can be improved. Indeed, many jurisdictions when passing VAD laws have mandated that reviews of the legislation occur after a specified period of time.[241] Such a review should include issues that new jurisdictions would grapple with (as per above) but there is also scope after a VAD law is in operation to collect data about its functioning in practice. This data was considered in the analysis above, primarily for Canada and Oregon.[242] Generating concrete evidence about who is receiving access to VAD and who is being *refused* access helps determine whether eligibility criteria are operating as intended at the time the law passed. Such a review of how the law is being interpreted in practice also provides opportunities to support current approaches or correct them as needed. We have noted a range of regulatory tools that could be utilised to achieve this.

We can expect that VAD reform efforts will continue in Australia and overseas. And even if reform occurs and law passes, attention then shifts to carefully reviewing the operation of those laws in practice. The comparative legal and practical analyses undertaken in this two-article series provide an opportunity to inform and support considered law reform and evaluation of that law in Australia and abroad.

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[241] See *Victorian Act 2017* (Vic) ss 116(1)–(3); *WA Act 2019* (WA) ss 164(1)–(2); Model Bill (n 2) pt 9; Bill C-14, 1st Sess, 42nd Parl, 2016, cls 10(1)–(2); Bill C-7, 2nd Sess, 43rd Parl, 2021, cls 3.1, 5 (as passed by the House of Commons 17 March 2021).

[242] Fewer data were available at time of publication from Victoria.

DOES THE *VOLUNTARY ASSISTED DYING ACT 2017* (VIC) REFLECT ITS STATED POLICY GOALS?

BEN P WHITE,[*] KATRINE DEL VILLAR,[**] ELIANA CLOSE[***] AND LINDY WILLMOTT[****]

With the commencement of the Voluntary Assisted Dying Act 2017 (Vic) in June 2019, Victoria became the first Australian State to permit voluntary assisted dying. This article considers the extent to which this novel Act reflects its stated policy goals. The first part of the article identifies the purported policy goals of the Act. This analysis draws on the explanatory material accompanying the law, in particular the expert Ministerial Advisory Panel Report which shaped the law. The article then critically evaluates the extent to which key aspects of the Act reflect those identified policy goals. Overall, the article concludes that the Voluntary Assisted Dying Act 2017 (Vic) is not consistent with its policy goals in some important respects.

I INTRODUCTION

When the *Voluntary Assisted Dying Act 2017* (Vic) (‘*VAD Act*’) commenced in June 2019, Victoria became the first Australian jurisdiction in over 20 years to have an operative voluntary assisted dying (‘VAD’) system. It joins just a small number of jurisdictions in a handful of countries internationally that permit VAD.[1] One reason such

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[1] Currently, nine states in the United States of America, the federal government in Canada, and one Canadian province have passed laws regulating VAD: *Death with Dignity Act*, Or Rev Stat §§ 127.800–127.995 (1994) (Oregon); *Death with Dignity Act*, Wash Rev Code §§ 70.245.010–70.245.903 (2008) (Washington); *Patient Choice and Control at End of Life Act*, Vt Stat Ann §§ 5281–93 (2013) (Vermont); *End of Life Option Act*, Cal Health and Safety Code §§ 443–443.22 (2015) (California); *Death with Dignity Act of 2016*, DC Code §§ 7–661 (2017) (District of Columbia); *End-of-Life Options Act*, Colo Rev Stat §§ 25-48-101–25-48-123 (2017)

laws are rare is that reform in this area is very difficult. VAD is seen by many as politically risky[2] and so in Australia there has been a long history of unsuccessful attempts to reform the law.[3]

The political challenges involved in VAD reform are evident in the *VAD Act* and the process leading to its enactment in three ways. The first is the staged and very consultative process adopted to facilitate reform. This began with a parliamentary committee of inquiry, which received extensive evidence[4] and numerous submissions from a large number of individuals and organisations.[5] In its report, the parliamentary committee recommended the enactment of legislation permitting VAD in certain circumstances.[6] The Victorian Government then adopted this recommendation and appointed a multidisciplinary Ministerial Advisory Panel ('the Panel'), whose role was to advise on the form of the legislation, taking into consideration a range of policy, clinical and legal issues.[7] The Panel also followed a consultative process, receiving

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(Colorado); *Our Care, Our Choice Act 2018*, Hawaii Rev Stat §§ 327-1–327-25 (2018) (Hawaii); *Medical Aid in Dying for the Terminally Ill Act*, NJ Stat Ann §§ 26:16-1–26:16-20 (2019) (New Jersey); *An Act to Enact the Maine Death with Dignity Act,* 22 Me Rev Stat Ann § 2140 (2019) (Maine), note this Act commenced in September 2019; *Criminal Code of Canada,* RSC 1985, c C-46, ss 241.1-241.4 (Canada); *An Act Respecting End-of-Life Care,* RSQ 2014, c S-32.0001 (Quebec). It is also legal in Montana by virtue of the court ruling in *Baxter v Montana* 224 P 3d 1211 (Mont, 2009), but no legislation has been passed in that State. Parts of Europe have legalised VAD through legislation: *Wet Toetsing Levensbeëindiging op Verzoek en Hulp Bij Zelfdoding* [Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001] (The Netherlands); *Loi Relative à L'euthanasie* [Act on Euthanasia 2002] (Belgium) and *Legislation Reglementant Les Soins Palliatifs Ainsi Que L'euthanasie Et L'assistance Au Suicide 2009* [Legislation Regulating Palliative Care and Euthanasia and Assisted Suicide 2009] (Luxembourg). Assisting a person's suicide is also lawful under certain circumstances in Switzerland (discussed in Samia A Hurst and Alex Mauron, 'Assisted Suicide in Switzerland: Clarifying Liberties and Claims' (2017) 31(3) *Bioethics* 199, 199) and Germany (see recent decision of the second Senate of the Federal Constitutional Court, Zum Urteil des Zweiten Senats vom 26 February 2020, Bundesverfassungsgericht), but there is no legislation regulating its provision in these countries. Finally, a court decision in Colombia permitted VAD in 1997: Constitutional Court of the Republic of Colombia, Sentence C-239/97, Ref Expedient D-1490, 20 May 1997), which was followed by Government regulations to facilitate the practice in 2015: *Protocolo Para La Aplicación Del Procedimiento De Eutanasia En Colombia*: Government of Colombia, *Protocol for the Application of the Procedure of Euthanasia in Colombia* (Report, 2015) <https://www.minsalud.gov.co/sites/rid/Lists/BibliotecaDigital/RIDE/DE/CA/Protocolo-aplicacion-procedimiento-eutanasia-colombia.pdf>. For more information on these jurisdictions, see Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-Based Model for Reform' in Ian Freckelton and Kerry Anne Petersen (eds), *Tensions and Traumas in Health Law* (Federation Press, 2017) 479, 484–8.

[2] Margaret Otlowski, 'Another Voluntary Euthanasia Bill Bites the Dust', *The Conversation* (online, 19 November 2013) <https://theconversation.com/another-voluntary-euthanasia-bill-bites-the-dust-19442>; Ben White and Lindy Willmott, 'Victoria May Soon Have Assisted Dying Laws for Terminally Ill Patients', *The Conversation* (online, 21 July 2017) <https://theconversation.com/victoria-may-soon-have-assisted-dying-laws-for-terminally-ill-patients-81401>; Giles Scofield, writing in the American context, goes so far as to say that 'promoting assisted suicide is politically suicidal': Giles Scofield, 'Privacy (or Liberty) and Assisted Suicide' (1991) 6(5) *Journal of Pain and Symptom Management* 280, 286.

[3] For a detailed discussion of the history of attempts at law reform in Australia, see Lindy Willmott et al, '(Failed) Voluntary Euthanasia Law Reform in Australia: Two Decades of Trends, Models and Politics' (2016) 39(1) *University of New South Wales Law Journal* 1. See also updated data in Ben White and Lindy Willmott, 'Future of Assisted Dying Reform in Australia' (2018) 42 *Australian Health Review* 616.

[4] The Committee conducted an extensive program of site visits and public hearings around Victoria over an eight-month period between July 2015 and February 2016. It held 17 days of public hearings and heard from 154 witnesses: Legal and Social Issues Committee, Parliament of Victoria, *Inquiry into End of Life Choices* (Final Report, 9 June 2016) xix ('*Parliamentary Report*').

[5] The Committee received 1037 submissions; 925 from individuals in a private capacity and 112 from organisations: ibid.

[6] Ibid xxxv.

[7] See Margaret M O'Connor et al, 'Documenting the Process of Developing the Victorian Voluntary Assisted Dying Legislation' (2018) 42(6) *Australian Health Review* 621, 623.

written submissions,[8] and conducting 14 consultation forums across Victoria[9] to receive views as to practical ways to 'implement a compassionate, safe and practical framework' for VAD.[10] The Panel's detailed report (the '*Report*') recommended the system and processes which were ultimately largely enacted in the *VAD Act*.

A second way in which the political challenges of VAD law reform are reflected is in the design of the *VAD Act*. It is narrow in scope in terms of eligibility, with access to VAD only for competent adult residents of Victoria with an incurable disease, illness or medical condition that is advanced, progressive and will cause death within six months (or twelve months for neurodegenerative conditions).[11] That condition must also be causing suffering that cannot be relieved in a manner that the person considers tolerable.[12] Generally, the *VAD Act* only permits a person to take the lethal medication themselves (often called physician-assisted suicide).[13] An exception allowing voluntary euthanasia (a medical practitioner administering the medication) arises only if a person cannot physically take or digest that medication themselves.[14]

The *VAD Act* also contains a large number of safeguards. When first introduced into Parliament, its 68 safeguards[15] led the Victorian Government to describe the Act as the 'safest, and most conservative model in the world'.[16] These safeguards include: the need for repeated requests by a person for VAD; ensuring requests are voluntary and made without coercion; assessment and confirmation that a person meets the eligibility criteria; medication management; and prescribing a designated process to access VAD. The *VAD Act* also contains mandatory reporting to an independent statutory authority throughout the process, and numerous offence provisions intended to ensure strict compliance with the legislation. The design of the Act, with its narrow scope and extensive safeguards, was intentionally crafted to attract the political support needed for it to pass both houses of the Victorian Parliament.

The third impact of the political challenges of VAD reform is inconsistency between the policy objectives of the Act and some of its provisions. Politics often requires compromise[17] and when this occurs in an ad hoc way, the overall scheme and objectives

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[8] One hundred and seventy-six written submissions were received, although some only expressed a view in support of or opposing assisted dying, and did not address the substantive content of the law: Victorian Government, *Ministerial Advisory Panel on Voluntary Assisted Dying* (Final Report, 21 July 2017) 36 ('*Report*').

[9] Five of these forums were held in regional Victoria. Approximately 300 people attended the forums. The Panel noted 'each forum provided stakeholders with an opportunity to discuss, with members of the Panel, the key areas of the eligibility criteria, the voluntary assisted dying request process, and the oversight and safeguards required to implement a compassionate, safe and practical framework': ibid 37.

[10] Ibid. The quality of the law reform process leading to the *VAD Act* has been commended by some commentators: Matthew Lesh, *Evidence Based Policy Research Project: 20 Case Studies* (Institute of Public Affairs, October 2018) 60–1.

[11] *Voluntary Assisted Dying Act 2017* (Vic) s 9 ('*VAD Act*'). The eligibility criteria are discussed further below.

[12] Ibid s 9(1)(d)(iv).

[13] Ibid ss 45, 47.

[14] Ibid s 48(3)(a).

[15] For a complete list of these safeguards, see *Report* (n 8) 221–8. Some of these safeguards relate to the eligibility criteria described above.

[16] Daniel Andrews, 'Voluntary Assisted Dying Model Established Ahead of Vote in Parliament' (Media Release, 25 July 2017).

[17] Baldwin, Cave and Lodge describe the conflicting interest groups and pressure that legislators are subject to: Robert Baldwin, Martin Cave and Martin Lodge, *Understanding Regulation: Theory, Strategy, and Practice* (Oxford University Press, 2nd ed, 2012) 42–6.

of an Act can be distorted. The final legislation that ultimately passes through Parliament may no longer completely align with the overall intended policy goals. An example of this, considered later in the article, is amendments to the *VAD Act* that occurred in Victoria's Upper House, the Legislative Council, during its review of the Voluntary Assisted Dying Bill 2017 (Vic) ('VAD Bill').

This article focuses on the third potential consequence of these political challenges. It aims to address the question: does the *VAD Act* reflect its stated policy goals? It is important to distinguish this inquiry from the question of whether or not VAD legislation, and this particular *VAD Act*, are 'good' or appropriate reforms. There are a range of views on whether VAD should be permitted[18] and, if so, whether the Victorian VAD system is a good one.[19] These arguments for and against VAD are outside the scope of this article. Instead, it considers a proposition that all would endorse: that legislation should reflect and advance the policy objectives that it was designed to address. This goes to the effectiveness of that legislation in guiding behaviour as intended. Whether or not it is effective in doing this, in turn, has implications for societal acceptance of that legislation or what some call its 'regulatory legitimacy'.[20]

To undertake this exercise, this article is comprised of two substantive parts. It first determines the purported policy goals of the *VAD Act*. This is done through analysing the explanatory material accompanying the *VAD Act*, in particular the Report and the second reading debate. Secondly, it evaluates whether the key aspects of the *VAD Act* reflect those identified policy goals. Overall, the article concludes that the *VAD Act* is not consistent with its policy goals in some important respects.

Before undertaking this analysis, issues of terminology and some limitations of this analysis will be addressed. In relation to terminology, VAD is the term used in the *VAD Act* and is a global concept describing the two main practices in this area: voluntary euthanasia and physician-assisted suicide. As noted above, the former involves the medical practitioner administering a lethal medication and in the *VAD Act* is referred to as 'practitioner administration'. By contrast, the latter involves the medical practitioner providing a person with the medication which they then take themselves and is labelled 'self-administration' by the *VAD Act*. It is also acknowledged that this analysis is in

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[18] Those who oppose VAD reform include Margaret Somerville, *Death Talk: The Case Against Euthanasia and Physician-Assisted Suicide* (McGill-Queen's University Press, 2nd ed, 2014); Ian Hayes, 'Ethical Challenges about Voluntary Assisted Dying' (2018) 39(3) *Australasian Science* 49; Jeremy Prichard, 'Euthanasia: A Reply to Bartels and Otlowski' (2012) 19(3) *Journal of Law and Medicine* 610; Brian H Le and Jennifer Philip, 'Voluntary Assisted Dying: Time to Consider the Details' (2018) 209(6) *Medical Journal of Australia* 279. Those who support VAD reform include Lorana Bartels and Margaret Otlowski, 'A Right to Die? Euthanasia and the Law in Australia' (2010) 17(4) *Journal of Law and Medicine* 532; Margaret Otlowski, *Voluntary Euthanasia and the Common Law* (Clarendon Press, 1997); Nicholas Cowdery, 'A Dignified Ending' (2017) 33 *LSJ* 28; Nicholas Cowdery, 'Will We Legalise Euthanasia?' (2017) 34 *LSJ* 26; Willmott and White (n 1).

[19] For some early and contrasting discussions of the *VAD Act*, see, eg, Danuta Mendelson, 'Voluntary Assisted Dying Legislation in Victoria: What Can We Learn from the Netherlands Experience?' (2017) 25(1) *Journal of Law and Medicine* 30; Ben P White, Lindy Willmott and Eliana Close, 'Victoria's Voluntary Assisted Dying Law: Clinical Implementation as the Next Challenge' (2019) 210(5) *Medical Journal of Australia* 207; Bernadette Richards and John Coggon, 'Assisted Dying in Australia and Limiting Court Involvement in Withdrawal of Nutrition and Hydration' (2018) 15(1) *Bioethical Inquiry* 15.

[20] Regulatory legitimacy is a contested concept, but Yeung reduces it to two broad aspects: whether a regime achieves its stated goals effectively, and whether it conforms with principles of good governance: see Karen Yeung, 'Regulating Assisted Dying' (2012) 23(2) *King's Law Journal* 163, 164–5. This approach draws on Yeung's earlier work: Karen Yeung, *Securing Compliance: A Principled Approach* (Hart Publishing, 2004) 30–6. This article focuses on the first of these objectives: whether the regulation achieves its stated policy goals in an effective manner.

relation to the legislation itself rather than how it might be implemented in practice. Although the *VAD Act* is supported by a suite of resources such as clinical guidance documents, models of care guidelines, medication protocols and training for medical practitioners,[21] this article is being written as the *VAD Act* commences so is focused on the legislation itself rather than the way it is implemented. The effectiveness of implementation will be important research to undertake in the future, but for present purposes, this analysis focuses on the legislation.

II WHAT ARE THE *VAD ACT*'S POLICY GOALS?

Section 1 of the *VAD Act* sets out its main purposes, which are (in summary):

a) to regulate access to VAD;
b) to establish the VAD Review Board; and
c) to make consequential amendments to other legislation.

These purposes are very broad and provide little insight into how the Act is intended to function. Instead, it is the more concrete policy goals of the Government that determine the nature of the VAD system the Act creates. In this section, those policy goals are discerned from two main (and related) sources. The first source is the Report. As described above, the *VAD Act* was developed through a staged, public process,[22] and its policy goals were explicitly set out in a manner which is unusual when developing legislation. The Panel identified nine 'guiding principles' which 'helped guide … its deliberations'.[23] These principles reflect the intended policy goals and assisted the Panel to design the legislative framework. The Panel also recommended that these principles be included in the Act to 'help guide interpretation'.[24] This was done and so the second source for discerning the policy goals of the *VAD Act* is the list of principles stated in the legislation. The Report's nine guiding principles became 10 in the Act and section 5 requires a person exercising a power or performing a function or duty under the Act to have regard to those principles. As discussed below, the *VAD Act's* principles largely reflect those set out in the Report.

Before turning to these principles, and analysing how they assist in discerning the key policy goals underpinning the *VAD Act*, an observation is made about a phrase that was frequently used in the Report which provides important context for considering the principles and policy goals in this section. A stated overarching goal in the development of the *VAD Act* was to design a legislative framework that is 'safe and compassionate'.

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[21] Department of Health and Human Services, State Government of Victoria, *Voluntary Assisted Dying* (Web Page, 2020) <https://www2.health.vic.gov.au/hospitals-and-health-services/patient-care/end-of-life-care/voluntary-assisted-dying>.

[22] See also the description of the process by the members of the Panel itself: O'Connor et al (n 7) 621–6. The Panel's contribution to policy formulation is described in Stephen Duckett, 'The Long and Winding Road to Assisted Dying in Australia' (2019) *Australian Journal of Social Issues* 1, and see also Lesh (n 10) 60–1. For criticism of this process, in particular of the *Parliamentary Report* (n 4) (although it is not the focus of this article), see John Keown, '"Voluntary Assisted Dying" in Australia: The Victorian Parliamentary Committee's Tenuous Case for Legalization' (2018) 33(1) *Issues in Law and Medicine* 55.

[23] *Report* (n 8) 43–6.

[24] Ibid 46. These guiding principles were also referred to in the second reading speech of Health Minister Jill Hennessy: Victoria, *Parliamentary Debates,* Legislative Assembly, 21 September 2017, 2944 (Jill Hennessy).

This phrase, derived from the Panel's terms of reference,[25] was used repeatedly throughout the Report.[26] 'Compassion', as used in the Report, refers to understanding, sympathy, care and concern for individuals at the end of their lives[27] who are suffering and wish to reduce that suffering.[28] The term 'safe' was most commonly employed to refer to community safety, for example in relation to the careful handling of the VAD medication,[29] or in relation to the system as a whole, encompassing a range of safeguards and oversight mechanisms.[30] Interestingly, it was only infrequently used to refer to the safety of the individual potentially receiving assistance to die, for example in ensuring there was no abuse or coercion,[31] and that a request for VAD was voluntary and properly informed.[32]

The catchphrase 'safe and compassionate' may be seen as a shorthand way to reflect some of the principles underlying the *VAD Act*: namely, compassionate respect for the autonomous choices of suffering individuals at the end of their lives, and the need to ensure the safety of the community. The need to balance these considerations is outlined in the statement of the Panel's Chair, Professor Brian Owler, in presenting the Report:

> The framework focuses on the eligible person who expresses their enduring wish to end their own suffering through access to voluntary assisted dying. It respects their personal autonomy and choice. That autonomy must of course be balanced against the safety of the community. We seek to provide a compassionate outcome for those people who are at the end of their life, while also addressing the concerns of the community.[33]

A Ten Principles

As noted above, although section 1 of the *VAD Act* contains express statements about its wider purposes, it is the 10 principles in section 5[34] that provide concrete insight into the policy goals underpinning the system. These principles are:

- valuing every human life equally;[35]
- respecting autonomy;[36]
- supporting informed decision making;[37]

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[25] The terms of reference tasked the Panel with proposing a 'compassionate and safe legislative framework for voluntary assisted dying': *Report* (n 8) 5.

[26] This phrase was used 13 times throughout: *Report* (n 8) 1, 2, 10, 11, 12 (two mentions), 21, 36, 47, 48, 188, 200 and 211. There are also four references to the inverse phrase 'compassionate and safe': *Report* (n 8) 5 (two mentions), 33 and 36. This phrase was also used four times in the second reading speech: Victoria, *Parliamentary Debates* (n 24) 2943, 2947, 2950, 2955 (Jill Hennessy). The notion of balancing compassion for the preferences of those who are suffering at the end of life with safeguards for the community was also discussed twice, using the terms 'compassion' and 'safeguards' without using the composite phrase 'safe and compassionate': Victoria, *Parliamentary Debates* (n 24) 2944, 2949 (Jill Hennessy).

[27] See *Report* (n 8) 1, 13; Victoria, *Parliamentary Debates* (n 24) 2949 (Jill Hennessy).

[28] See *Report* (n 8) 77, 79; 154; Victoria, *Parliamentary Debates* (n 24) 2944 (Jill Hennessy). There is also a single instance where 'compassion' is used to denote sensitivity to the needs of the family in undertaking monitoring to ensure compliance with the legislative requirements after a person's death by means of VAD: *Report* (n 8) 149.

[29] Panel Recommendations 31–33 (concerning safe handling of medication): *Report* (n 8) 1, 6, 17, 26, 45, 129, 131, 135–6, 156–7, 170–1, 213.

[30] For example, ibid 11, 12, 20, 21, 47, 148, 154.

[31] For example, ibid 10, 18.

[32] Ibid 15, 45.

[33] Ibid 1.

[34] See also Victoria, *Parliamentary Debates* (n 24) 2943–4 (Jill Hennessy).

[35] *VAD Act* s 5(1)(a).

[36] Ibid s 5(1)(b).

[37] Ibid s 5(1)(c), including providing information about medical treatment options and palliative care.

- providing quality care that minimises suffering and maximises quality of life;[38]
- supporting therapeutic relationships;[39]
- encouraging open discussions about dying, death and people's preferences;[40]
- supporting conversations with health practitioners and family about treatment and care preferences;[41]
- promoting genuine choices;[42]
- protecting individuals from abuse;[43] and
- respecting diversity of beliefs and values, including among health practitioners.[44]

These principles directly correspond to the nine guiding principles outlined by the Panel to underpin its recommendations.[45]

In addition to identifying these guiding principles, the Panel noted that the *Charter of Human Rights and Responsibilities Act 2006* (Vic) ('Charter') also informed its deliberations. Indeed, members of the Panel noted that the guiding principles were drawn from the Charter.[46] Seven human rights were specifically listed as being significant, including the right to equality, the right to privacy (which includes the right to personal autonomy and dignity) and the right to life.[47] The Minister's second reading speech on the introduction of the VAD Bill also contains a detailed statement of compatibility with these Charter rights.[48] She noted that the Panel 'used the [C]harter as a framework' for considering how best to respect the rights of all Victorians, and for formulating the VAD model, including the guiding principles.[49]

B Six Core Policy Goals

For the purposes of our analysis, the principles listed above can be grouped into six broader policy goals (or some may call them values).[50] Our distillation of how the 10 principles support the six policy goals that underpin the VAD legislation is represented in Table 1 (recognising of course that there are necessarily overlaps across categories).

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[38] Ibid s 5(1)(d).

[39] Ibid s 5(1)(e).

[40] Ibid s 5(1)(f).

[41] Ibid s 5(1)(g).

[42] Ibid s 5(1)(h).

[43] Ibid s 5(1)(i).

[44] Ibid s 5(1)(j).

[45] These principles are elaborated on in more detail: *Report* (n 8) 43–6. There are 10 principles in the legislation, rather than nine, because the legislative drafters chose to split the eighth principle in two. The Report stated: 'providing people with genuine choice must be balanced with the need to safeguard people who might be subject to abuse': *Report* (n 8) 11. By contrast, the *VAD Act* separates this into two distinct concepts – 'individuals are entitled to genuine choices regarding their treatment and care' and 'there is a need to protect individuals who may be subject to abuse' – and does not expressly refer to balancing: *VAD Act* ss 5(1)(h), (i).

[46] O'Connor et al (n 7) 625.

[47] The seven human rights listed were the rights to equality; life; protection from torture and cruel, inhuman or degrading treatment; privacy and reputation; freedom of thought, conscience, religion and belief; protection of the best interests of the child; and liberty and security of person: *Report* (n 8) 43 and Appendix 2.

[48] Victoria, *Parliamentary Debates* (n 24) 2943–9 (Jill Hennessy).

[49] Ibid 2943 (Jill Hennessy).

[50] For a more detailed discussion of the values underpinning the law that are relevant in the context of VAD, see Willmott and White (n 1) 479–510.

Table 1: Six Policy Goals Derived from 10 Principles

Six policy goals	Relevant principles
1. To respect all human life	• Valuing every human life equally
2. To respect personal autonomy	• Respecting autonomy • Supporting informed decision making • Promoting genuine choices • Encouraging open discussions about dying, death and people's preferences • Supporting conversations with health practitioners and family about treatment and care preferences
3. To safeguard the vulnerable and the community	• Protecting individuals from abuse
4. To provide high-quality care	• Providing quality care that minimises suffering and maximises quality of life • Supporting therapeutic relationships • Encouraging open discussions about dying, death and people's preferences • Supporting conversations with health practitioners and family about treatment and care preferences
5. To respect individual conscience	• Respecting diversity of beliefs and values, including among health practitioners
6. To alleviate human suffering (compassion)	• Providing quality care that minimises suffering and maximises quality of life
Goals 2 and 3 are bolded because, as argued below, while all goals are important, these two appeared to be the dominant ones when making decisions about the scope and nature of the legislation.	

The Minister herself summarised the principles as recognising three values: 'the value of every human life, respect for autonomy and a person's preferences, choices and values, and the provision of high-quality care'.[51] The second of these values – respect for personal autonomy – encompasses the principles of supporting informed decision-making, and promoting genuine choices. The principles of open discussions and supporting conversations will also be relevant to the provision of adequate information about treatment and care options to enable genuine and autonomous choices to be made. The Minister's third value – the provision of high-quality care – incorporates the principles of supporting therapeutic relationships with health practitioners, encouraging open discussions about dying and death, and supporting conversations with family, friends and carers about treatment and care preferences. In addition to the three goals mentioned by the Minister, three other important policy goals are discerned from those principles that underpin the legislation, namely: compassion to alleviate human suffering, safeguarding the vulnerable and the community, and

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[51] Victoria, *Parliamentary Debates* (n 24) 2951 (Jill Hennessy).

respecting individual conscience. Each of these policy goals will be discussed briefly in turn.

1 Respect All Human Life

The equal value of every human life is the first principle in the Act[52] and was also recognised as the first guiding principle by the Panel.[53] Twice in the second reading speech, the Minister stated that the right to life is the primary or supreme value in these debates.[54] However, it was also clear, for example from the Minister's statement of compatibility tabled in accordance with the Charter, that despite the significance of the right to life, it is not absolute and can be subject to justifiable limitations.[55]

2 Respect Personal Autonomy

The Panel repeatedly referred to the need for 'genuine choice' at the end of life. This included the provision of information about treatment options, and the provision of a range of choices about treatment and care, including the ability to choose the timing and manner of one's impending death.[56] This shows the importance placed on respecting a person's individual autonomy and freedom to 'choose to end their life according to their own preferences'.[57] Similarly, the deliberate choice of the term 'voluntary assisted dying', instead of the term 'dying with dignity' used in some American jurisdictions, reflected the emphasis on individual choice from a range of available end-of-life options.[58]

However, the Panel was at pains to point out that the aim of the *VAD Act* is not to give effect to *all* personal autonomy. Rather, autonomy is to be respected in a narrower set of circumstances: to provide alternative end-of-life care for people with terminal conditions who are suffering. The Panel noted respecting autonomy does not mean allowing people 'to do whatever they want' or to 'choose whether to live or die'.[59] Instead, the autonomy protected is choice over the 'timing and manner' of a death that is otherwise inevitable.[60]

3 Safeguard the Vulnerable and the Community

Another core concern expressed throughout the Report is the need to safeguard vulnerable individuals in the community from abuse or coercion. This principle, recognised in the Report and as a legislative principle,[61] was highly significant in the design of the system as the Report mentions the importance of safeguarding the vulnerable over 30 times.[62] Four potentially vulnerable groups that were discussed in

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[52] *VAD Act* s 5(1)(a).

[53] *Report* (n 8) 43.

[54] Victoria, *Parliamentary Debates* (n 24) 2943–4 (Jill Hennessy).

[55] Ibid 2944 (Jill Hennessy).

[56] There were 17 references to 'genuine choice' in the report: *Report* (n 8) 6, 10, 11, 22, 34 (twice), 38, 43, 44 (twice), 45 (twice), 46, 86 (twice), 99 and 117.

[57] Victoria, *Parliamentary Debates* (n 24) 2945 (Jill Hennessy).

[58] *Report* (n 8) 7.

[59] Ibid 44.

[60] Ibid.

[61] Ibid 11, 22, 46; *VAD Act* s 5(1)(i).

[62] *Report* (n 8) 5, 17 (twice), 18, 24, 51, 58, 63, 80, 82, 84, 87, 88 (3 times), 89, 91, 106, 127, 148, 180, 210 (3 times), 211 (3 times), 212 (3 times), 213, 215.

detail were the elderly,[63] children,[64] people with disabilities,[65] and people with mental illness.[66] The critical importance of this policy goal is also reflected in the emphasis on designing a 'safe and compassionate' VAD system as required by the Panel's terms of reference. Of note though, this policy goal of a safe system was framed to include the protection not only of potentially vulnerable groups but also the wider community.

4 Provide High-Quality Care

The Victorian model situates VAD within the healthcare system as one of a number of medical choices available to a person in the context of end-of-life care.[67] This creates the imperative, as with all healthcare, for any assessment for, or provision of, VAD to be of high quality. This is reflected in the Panel's recognition of the 'critical role of health practitioners' in VAD and the importance of continuity of care within an ongoing therapeutic relationship.[68] This was also noted by the Minister in her second reading speech.[69] In particular, the Report repeatedly recognises that open discussions within an existing therapeutic relationship would be the best way to ensure that any decisions about VAD were appropriate in the context of the person's needs and preferences.[70]

5 Respect Individual Conscience

Respecting medical practitioners' freedom of conscience was part of the terms of reference given to the Panel when advising about the form of *VAD Act*.[71] Respect for 'culture, beliefs, values and personal characteristics' was one of the Report's guiding principles[72] and was likewise included as a legislative principle in the *VAD Act*.[73] The right to freedom of thought, conscience, religion and belief was also noted as one of the core Charter rights engaged in the legislation.[74]

The Panel explains what conscientious objection to VAD means for medical practitioners, referring to this issue on several occasions in its Report.[75] The *VAD Act* respects the right of medical practitioners to choose on conscientious grounds not to participate in the provision of VAD, while continuing to provide holistic care to relieve the suffering and meet the needs of persons in their care.[76] But the Panel emphasised that this must not impede individuals who wish to access VAD from doing so.[77]

6 Alleviate Human Suffering (Compassion)

Compassion was a significant driver at the macro policy level for the *VAD Act*, as reflected in earlier discussions about the need for a 'safe and compassionate'

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[63] This was discussed in depth in ibid 88–90, and mentioned again at 180.

[64] Ibid 53–54.

[65] Ibid 84, 91.

[66] Ibid 82.

[67] Victoria, *Parliamentary Debates* (n 24) 2949–50 (Jill Hennessy).

[68] *Report* (n 8) 45.

[69] Victoria, *Parliamentary Debates* (n 24) 2952–3 (Jill Hennessy).

[70] *Report* (n 8) 186 (Panel Recommendation 58). See also *Report* (n 8) 20, 92, 99, 101, 190.

[71] Ibid 5.

[72] Ibid 11, 22.

[73] *VAD Act* s 5(1)(j).

[74] See *Report* (n 8) 211; Victoria, *Parliamentary Debates* (n 24) 2947 (Jill Hennessy).

[75] *Report* (n 8) 2, 15, 21, 40, 107, 109–11, 143, 190, 206, 214.

[76] Ibid 40.

[77] See, eg, ibid 15.

framework. This policy goal aims to alleviate the suffering of individuals at the end of their lives.[78] However, as the Panel shifted to operationalise its recommendations, compassion appeared to assume a less significant role. For example, it receives only limited recognition in the Report and legislative principles and indeed it was sometimes subsumed within two other policy goals. The first was respecting autonomy, with some references framed in terms of compassionate respect for autonomous choices to receive assistance to die.[79] The other was high-quality care, with both the Report and legislative principles referring to 'quality care to minimise the person's suffering'.[80] This may indicate that compassion played an important role in deciding whether or not to enact a VAD law, but then had less influence on the shape of that law; a notable exception is the eligibility requirement relating to suffering discussed below.

C Two Dominant Policy Goals: Respecting Autonomy and Safeguarding the Vulnerable and Community

As the discussion in relation to the policy goal of compassion shows, there are different ways in which policy goals can shape law. Some may establish important macro-level policy settings but do very little beyond that, whereas other goals may be integral in shaping the contours of the law and the detail of what is permitted and what is not. Sometimes policy goals will do both.

Although all six of the identified policy goals were important in framing the *VAD Act*, two goals were particularly dominant in determining the content of that law: respecting autonomy and safeguarding the vulnerable and community. This is evident from the number of references throughout the Report and the second reading speech to the need to balance freedom of choice with safeguards for vulnerable individuals and the wider community, as well as the frequent repetition of the key phrase: a 'safe and compassionate' system for VAD.

The eighth guiding principle in the Report explicitly states: 'providing people with genuine choice must be balanced with the need to safeguard people who might be subject to abuse'.[81] The need to balance these (potentially) competing policy objectives is also recognised in frequent statements such as: '[p]romoting individual autonomy and providing appropriate safeguards are critical, and neither aim is paramount. Instead, they must be balanced'.[82] Although all policy goals were important, this suggests that striking an appropriate balance between these two competing goals was a particular focus in the development of the *VAD Act*.

Minister Hennessy's second reading speech presenting the VAD Bill reinforces this conclusion. Although all 10 principles were listed at the outset of the speech,[83] it was her concluding paragraph that best captured the purpose of the legislation:

> This bill establishes a *safe* and compassionate framework to give Victorians who are suffering the ability to choose the timing and manner of their death. The bill provides a rigorous process with *safeguards* embedded at every step to ensure that only those who

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[78] See ibid 1, 13 and Victoria, *Parliamentary Debates* (n 24) 2949 (Jill Hennessy).

[79] *Report* (n 8) 13 and Victoria, *Parliamentary Debates* (n 24) 2949–50 (Jill Hennessy). Reference was also made to a compassionate framework allowing individual choice, and not requiring a person to demonstrate unbearable suffering to be eligible for VAD: *Report* (n 8) 77–8.

[80] *VAD Act* s 5(1)(d) and *Report* (n 8) 11.

[81] *Report* (n 8) 22.

[82] Ibid 210. See also Ibid 11, 15, 43, 87, 210, 211; Victoria, *Parliamentary Debates* (n 24) 2943 (Jill Hennessy).

[83] Victoria, *Parliamentary Debates* (n 24) 2943 (Jill Hennessy).

> meet the eligibility criteria and who are making an *informed, voluntary and enduring decision* will be able to access voluntary assisted dying. The clear and considered details reflected in this bill will provide the Victorian community with the confidence that voluntary assisted dying can be *safely* provided to give Victorians *genuine choice* at the end of their lives.[84]

For this reason, the policy goals of respecting autonomy and safeguarding the vulnerable and the community are often discussed in more detail than the other policy goals in the analysis that follows.

III DOES THE *VAD ACT* REFLECT THESE POLICY GOALS?

The following analysis of whether the *VAD Act* reflects its stated policy goals is arranged according to the main components of the Act: method of VAD permitted; eligibility criteria; the process of requesting VAD, being assessed and then accessing VAD; conscientious objection by health practitioners; and oversight, reporting and compliance. The length and complexity of the *VAD Act* means that the discussion below can be only an overview of its key provisions. Further, and again for reasons of scope, this analysis pays particular attention to aspects of the VAD Act that do *not* comply with the identified policy goals. As legislation is generally expected to implement its stated objectives, it is this divergence that is of most interest in this article. A final point to note in relation to this analysis is that, as mentioned above in relation to respecting autonomy and safeguarding the vulnerable and the community, there will sometimes be tension between different policy goals.[85] Advancing one goal may require reduced recognition of another. The process of this balancing exercise will be outlined as necessary in the analysis below.

A Method of VAD Permitted

1 Overview of Law

The default method of VAD permitted under the *VAD Act* is self-administration; in other words, a medical practitioner prescribing medication which the person takes themselves.[86] It is only if a person is 'physically incapable of the self-administration or digestion' of the medication[87] that they can ask a medical practitioner to administer it (practitioner administration). This limited exception to permit practitioner administration was included to avoid discrimination on the basis of disability where a person's condition would preclude self-administration.[88] The *VAD Act* contains additional safeguards when the person receives practitioner administration: an independent witness of the person's request to administer the VAD medication must certify the person's apparent capacity and voluntariness, and the enduring nature of the request to die.[89]

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[84] Ibid 2955 (Jill Hennessy) (emphasis added).

[85] Yeung also recognises this: Yeung, *Securing Compliance: A Principled Approach* (n 20) 31.

[86] A co-ordinating medical practitioner applies for a 'self-administration permit', which enables the medical practitioner to prescribe and supply a lethal substance in a sufficient dose, and authorises the person concerned to possess that substance and administer it to themselves: *VAD Act* ss 45, 47.

[87] Ibid s 48(3)(a).

[88] *Report* (n 8) 141; Victoria, *Parliamentary Debates* (n 24) 2953 (Jill Hennessy).

[89] *VAD Act* ss 46, 65(2).

2 Conformity with Policy Goals

The key policy goals of relevance here are: safeguarding the vulnerable, respect for autonomy and providing high-quality care. For the Panel, the most important goal appeared to be safeguarding the vulnerable, for example from coercion. Its report noted that '[w]hen a person self-administers a lethal dose of medication it is a final indication that their decision is voluntary'.[90] A person physically taking the medication themselves could also be seen as advancing the policy goal of autonomy in that it ensures the choice for VAD is truly the person's.

However, the Panel must have reached the view that practitioner administration of VAD medication is also safe with appropriate additional safeguards. This is reflected in their report and subsequently in the proposed legislation, as per the safeguards noted above. These safeguards are designed to ensure capacity and voluntariness of a person's request so that vulnerable people are not coerced into making requests for VAD. This raises the question though: if it is accepted that practitioner administration is safe, can safeguarding the vulnerable be a defensible basis for restricting VAD primarily to self-administration? Indeed, it could be argued that practitioner administration, which requires additional checks on capacity and voluntariness at the time VAD is provided, may better protect the vulnerable than permitting a person to self-administer unsupervised, which may occur at a later date when capacity has been lost. In a similar vein, later self-administration may also provide less protection against coercion.

In terms of respecting autonomy, the limitations placed on access to practitioner administration of VAD do not accord with this policy goal. The Report refers repeatedly to the importance of choosing the 'timing and *manner*' (emphasis added) of a person's death, yet only one of the two possible lawful methods of VAD is open to the majority of eligible people. The policy goal of respecting autonomy would be better achieved if a person was able to choose to self-administer the VAD medication or have assistance from a medical practitioner for practitioner administration.[91] This choice between self-administration and practitioner administration is available in a number of the other jurisdictions which permit VAD,[92] and where both options are available, available data show practitioner administration is overwhelmingly used.[93] Some people may find self-

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[90] *Report* (n 8) 141.

[91] See Willmott and White (n 1) 479, 490–492, 500–501.

[92] *Criminal Code of Canada* s 241.1 (definition of 'medical assistance in dying'); *Wet Toetsing Levensbeëindiging op Verzoek en Hulp Bij Zelfdoding* [Termination of Life on Request and Assisted Suicide (Review Procedures) Act 2001] art 2.1(f) (The Netherlands). Other countries which allow a choice between euthanasia and assisted dying are Belgium, Luxembourg and Colombia: Emanuel Ezekiel et al, 'Attitudes and Practices of Euthanasia and Physician-Assisted Suicide in the United States, Canada, and Europe' (2016) 316(1) *Journal of the American Medical Association* 79, 79. While the law in Belgium does not address physician-assisted suicide directly, the Federal Control and Evaluation Committee for Euthanasia in Belgium considers it to be a form of euthanasia: at 82.

[93] For example, in the Netherlands in 2017, of 6,585 cases reported to Euthanasia Review Committees, 6,303 were of euthanasia, 250 were of assisted suicide, and 29 cases involved a combination of both: Regional Euthanasia Review Committees, *Annual Report 2017* (Report, May 2017) 10. In Canada, drawing on the last two federal government reports covering the period from 1 January 2017 to 31 October 2018, of the 4,575 medically assisted deaths reported, only 2 were self-administered (note: this does not include data from some provinces as outlined in the report): Health Canada, *Fourth Interim Report on Medical Assistance in Dying Canada* (Report, April 2019) 5. Belgium does not differentiate in its reporting between euthanasia and assisted suicide, but data shows that for the period 2016–17, of 4337 deaths, 23 were by oral ingestion of barbiturates, 10 by other methods, and the remaining 4,304 (99%) were by intravenous injection: Commission Fédérale de Contrôle et D'évaluation de L'euthanasie*, Huitième Rapport aux Chambres Législatives Années 2016 – 2017*, (Report, 17 July 2018) 6.

administration to be an unacceptable option, or an unduly burdensome option, even if it is physically possible for them. Others may prefer practitioner administration because it may be safer (see below). It is not simply the ability to choose an option which leads to death, but the choice of a particular option for causing death which is preferred by some individuals.

The third key policy goal is to provide high-quality care and it could be argued that this goal is better served when people also have access to practitioner administered VAD rather than only self-administration. Although there is limited evidence, a Dutch study found that, while both means of providing VAD can experience complications and technical problems, the rate of these is higher with self-administration when compared with practitioner administration.[94] This suggests practitioner administration may be safer, and the legislative prohibition on practitioner administration for those able to self-administer precludes these people from accessing a potentially safer option.[95]

3 Conclusion

Limiting practitioner administration of VAD to those who are physically unable to administer or ingest the medication themselves is not consistent with the policy goals of the *VAD Act*. In particular, respecting autonomy and providing high-quality care would favour allowing eligible persons to choose whether to receive VAD by self-administration or from their medical practitioner. This allows a person both greater choice as to the manner of their death and access to the safer of the two options. Arguments about safeguarding the vulnerable lack traction in this setting, given that practitioner administration is permitted by the *VAD Act* with appropriate safeguards, therefore recognising practitioner administration as a safe VAD option.

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[94] The study reported on three types of problems: technical problems (eg, difficulty administering the medication); complications (eg, spasm, nausea, and vomiting); and problems with completion (eg, longer time than expected to death). In all categories, physician assisted suicide cases had higher rates of clinical problems compared to euthanasia. Technical problems arose in approximately 10% of cases of physician-assisted suicide (versus approximately 4% of euthanasia cases); complications arose in approximately 9% of physician assisted suicide cases (versus approximately 4% of euthanasia cases) and problems with completion arose in 14% of physician assisted suicide cases (versus 5% of euthanasia cases). The study found approximately 2% of physician assisted suicide patients awoke from a coma, and approximately 12% took longer than anticipated to die or never lost consciousness, compared to less than 1% and 4% respectively of euthanasia cases: Johanna Groenewoud et al, 'Clinical Problems with the Performance of Euthanasia and Physician-Assisted Suicide in the Netherlands' (2000) 342(8) *New England Journal of Medicine* 551, 555. More robust data from other jurisdictions which permit both euthanasia and physician assisted suicide are needed to support this conclusion: see Christopher Harty et al, 'Oral Medical Assistance in Dying (MAiD): Informing Practice to Enhance Utilization in Canada' (2019) 66(9) *Canadian Journal of Anesthesia* 1106. Data on complications from the US States of Oregon and Washington are available, but as these States permit only physician-assisted suicide, comparison with the rate of complications in euthanasia cases is not possible: Ezekiel et al (n 92) 86. Nevertheless, complication rates for physician assisted suicide appear to vary. The most recent statistics from Oregon found that just 2.8% of cases had reported complications (although in 52.6% of cases whether or not there were complications was unknown): Oregon Health Authority, *Oregon Death with Dignity Act 2018 Data Summary* (Report, 25 April 2019) 12. Riley also provides recent evidence of complications experienced with lethal injections of medication: Sean Riley, 'Navigating the New Era of Assisted Suicide and Execution Drugs' (2017) 4(2) *Journal of Law and the Biosciences* 424.

[95] In the Netherlands, it is recommended to have a physician present during an assisted suicide, to be able to administer a lethal injection if the assisted suicide fails. This occurred in 21 out of 114 cases of assisted suicide in the study in question: Groenewoud et al (n 94) 554–6.

B Eligibility Criteria

1 Overview of Law

Section 9(1) of the *VAD Act* states that '[f]or a person to be eligible for access to voluntary assisted dying':

- (a) the person must be aged 18 years or more; and
- (b) the person must–
  - (i) be an Australian citizen or permanent resident; and
  - (ii) be ordinarily resident in Victoria; and
  - (iii) at the time of making a first request, have been ordinarily resident in Victoria for at least 12 months; and
- (c) the person must have decision-making capacity in relation to voluntary assisted dying; and
- (d) the person must be diagnosed with a disease, illness or medical condition that–
  - (i) is incurable; and
  - (ii) is advanced, progressive and will cause death; and
  - (iii) is expected to cause death within weeks or months, not exceeding 6 months [or 12 months if the disease, illness or medical condition is neurodegenerative];[96] and
  - (iv) is causing suffering to the person that cannot be relieved in a manner that the person considers tolerable.

Disability and mental illness alone are not grounds to access VAD,[97] however, the Panel noted that having a disability or a mental illness does not preclude a person from accessing VAD if all the eligibility criteria are met.[98]

2 Conformity with Policy Goals

Before considering the four domains of the *VAD Act's* eligibility criteria – age, capacity, residence and nature of disease, illness or medical condition – it is noted that globally these requirements reflect a balancing of several of the identified policy goals. The threshold choice to allow VAD reflects the policy goals of respecting autonomy and the compassionate alleviation of human suffering (in relation to the latter, recognising that suffering is one of the eligibility requirements). But limiting VAD to those whose deaths are expected to occur within six months (or 12 months in the case of neurodegenerative conditions) reflects the policy goal of respecting all human life, by ensuring that only people who are close to death are eligible to request VAD. Excluding people from accessing VAD on the basis of disability or mental illness alone may be seen as safeguarding the vulnerable. The capacity and age requirements advance the policy goal of safeguarding vulnerable people by ensuring that only competent adults are able to request assistance to die, but a requirement to have capacity to access VAD also promotes autonomy. Finally, the decision to restrict access to Victorian residents was designed to ensure that VAD occurs in the context of an ongoing, caring therapeutic relationship,[99] which is part of the policy goal of providing high-quality care.

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[96] The words in square brackets have been inserted based on *VAD Act* s 9(4).

[97] *VAD Act* ss 9(2)–(3).

[98] Panel Recommendation 5: see *Report* (n 8) 80–2 (in respect of mental illness); Panel Recommendation 6: at 83–5 (in respect of disability).

[99] Ibid 56; Victoria, *Parliamentary Debates* (n 24) 2948 (Jill Hennessy).

(a) Illness, Disease or Medical Condition

Of the four domains, it is the criterion of the illness, disease or medical condition of the person seeking access to VAD that is the most complex in terms of analysing its compliance with the policy goals.

(i) Will Cause Death

The requirement to have a condition that 'will cause death' reflects a tension between both respecting autonomy and alleviating human suffering on the one hand and respecting all human life on the other. Some other jurisdictions have chosen to preference autonomous choice and the alleviation of suffering by allowing wider access to VAD by individuals who do not have a terminal illness. For example, one of the criteria in Belgium is that a person has a 'medically futile condition of constant and unbearable physical or mental suffering that cannot be alleviated'.[100] Nevertheless, on balance, the requirement in the *VAD Act* that the person have a medical condition that will cause death is a defensible balancing of its stated policy goals. As the Panel stated, the purpose of the *VAD Act* was not to foster *all* autonomous choices in relation to the end of life, but only choices concerning the timing and manner of deaths that were already inevitable and impending.[101]

(ii) Six Months until Death

The position in relation to time limits is less able to be justified in light of the policy goals. First, the policy goals individually and when balanced collectively do not necessarily indicate a particular time from death as being an appropriate point at which to grant access to VAD. The selection of a six-month period is arbitrary.[102] This is illustrated by the fact that a 12-month period was initially included in the Report[103] and the VAD Bill that was originally passed by the Victorian Legislative Assembly.[104] While this was the initial preferred policy position, as will be discussed shortly below, this time limit was halved in the Bill presented to the Legislative Council after political negotiations, ultimately resulting in the six-month limit in the *VAD Act*.

One justification for this time limit could be that balancing the policy goals of respect for autonomy and respect for human life led the Panel and Parliament to restrict access to VAD to those who are in the process of dying.[105] But selecting a time period – of six months or some other duration – to restrict access to VAD to a cohort who are in the process of dying has problems. Prognostication about time until death is notoriously difficult.[106] Different diseases have different trajectories, and some are more

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[100] *Loi Relative à L'euthanasie* [Act on Euthanasia 2002] s 3§1.

[101] See *Report* (n 8) 44.

[102] Willmott and White (n 1) 503–4.

[103] Panel Recommendation 2: *Report* (n 8) 22. See also *Report* (n 8) 13, 68, 70.

[104] The Voluntary Assisted Dying Bill 2017 (Vic) ('VAD Bill'), as introduced and passed by the Victorian Legislative Assembly, stated that a person was eligible to receive VAD if they were suffering from an incurable and progressive condition that was 'expected to cause death within … 12 months': at cl 9.

[105] This is similar to the restrictions contained within the US laws in force at that time: *Death with Dignity Act 1997*, Or Rev Stat §§ 127.800–127.995 (1994) (Oregon); *Death with Dignity Act 2009*, Wash Rev Code §§ 70.245.010–70.245.903 (2008) (Washington); *Patient Choice at End of Life Act 2013*, Vt Stat Ann §§ 5281–93 (2013) (Vermont); *End of Life Option Act 2016*, Cal Health and Safety Code §§ 443–443.22 (2015) (California); *End of Life Options Act 2016*, §§ 25-48-101–25-48-123 (2017) (Colorado). See *Report* (n 8) 221.

[106] Joanne Lynn et al, 'Defining the "Terminally Ill": Insights from SUPPORT' (1996) 35(1) *Duquesne Law Review* 311, 324; Eric Chevlen, 'The Limits of Prognostication' (1996) 35(1) *Duquesne Law Review* 337; James Downar

predictable than others.[107] Studies, as well as anecdotal reports,[108] also demonstrate that a significant percentage of people predicted to die within six months are still alive after two to three years.[109] Lynn and colleagues have concluded that, because prognoses are unavoidably ambiguous:

> Deciding who should be counted 'terminally ill' will pose such severe difficulties that it seems untenable as a criterion for permitting physician-assisted suicide. Allowing physicians (or anyone else) to decide who is terminally ill without standards or guidance will result in uneven application with unjustified variations across diseases, across physicians, and across regions.[110]

Accordingly, this criterion does not sufficiently respect the value of life, as prognostic uncertainty may inappropriately grant access to VAD to people who have more (perhaps much more) than six months of life remaining.[111] This criterion may also fail to respect autonomy and alleviation of human suffering through the inappropriate exclusion of people who are suffering and close to death, if this proximity to death is not recognised by medical practitioners.[112]

Although problematic for the reasons outlined above, perhaps the best justification for adopting a six-month time period is that it could be seen as a practical compromise representing an imperfect proxy for being close to death. This reflects a pragmatic choice to preference certainty in the legislation (although the uncertainty of this eligibility criterion is noted above) even if doing so means it can only approximately reflect the policy goals of the *VAD Act*.

(iii) Twelve Months until Death for Neurological Conditions

As noted above, when the Legislative Assembly passed the VAD Bill, the eligibility criterion required that death was expected to occur within 12 months. This was reduced to six months when the VAD Bill was presented to the Legislative Council, and this ultimately became law. An exception was made, however, for persons with neurodegenerative conditions, who remained eligible for VAD if their death was expected within 12 months. If a time limit in itself is questionable, having different time

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et al, 'The "Surprise Question" for Predicting Death in Seriously Ill Patients: A Systematic Review and Meta-analysis' (2017) 189(13) *Canadian Medical Association Journal* E484. Glare and colleagues observe that predictions estimating that a certain percentage of patients will survive for a certain time have a 50–75% accuracy rate, whereas predictions estimating the time the patient will survive are only 25% accurate: Paul Glare et al, 'Predicting Survival in Patients with Advanced Disease' (2008) 44(8) *European Journal of Cancer* 1146, 1147. In the Victorian debate on the VAD Bill, Ms Crozier also noted evidence from Washington and Oregon of a considerable proportion of people diagnosed as eligible for VAD being expected to live less than 6 months, whose deaths occur 1–2 years or longer after this diagnosis: Victoria, *Parliamentary Debates,* Legislative Council, 21 November 2017, 6221 (Georgina Crozier).

[107] Lynn et al (n 106) 326–7; Downar et al (n 106).

[108] Mr Ondarchie referred to his own father's death, which was predicted to occur within three months, but did not in fact occur for another 21 months: Victoria, *Parliamentary Debates,* Legislative Council, 14 November 2017, 5837 (Craig Ondarchie).

[109] Lynn and colleagues have demonstrated that 20–40% of those predicted to have a 50% chance to die within the next six months are still alive after two to three years. Even among those predicted to have only a 20% chance of surviving six months, up to 10% survive for two to three years: Lynn et al (n 106) 321–2.

[110] Ibid 334.

[111] Statistics from Washington and Oregon quoted in the Victorian debate bear this out: Victoria, *Parliamentary Debates* (n 106) 6221 (Georgina Crozier).

[112] Colleen Cartwright, 'The Six-Month Amendment Could Defeat the Purpose of Victoria's Assisted Dying Bill' *The Conversation* (online, 23 November 2017) <https://theconversation.com/the-six-month-amendment-could-defeat-the-purpose-of-victorias-assisted-dying-bill-87941>.

limits for different conditions requires a compelling justification. For reasons outlined below, it is argued that this justification is absent.

The stated reason for this differential treatment was a concern that people with neurodegenerative conditions might either lose capacity to apply for, or to self-administer, VAD medication if the eligibility period was restricted to six months.[113] This cannot be justified by reference to the policy objectives of the *VAD Act*. In relation to capacity, allowing only people with neurodegenerative conditions this additional time to access VAD before they lose capacity to request it gives greater protection to the autonomous choices only of a narrow class of individuals.[114] No such provision is made in relation to people with other illnesses which may affect a person's decision-making capacity.[115] Further, the concern to ensure access to self-administration is misplaced, given the law permits practitioner administration where a person is no longer physically capable of taking or ingesting the VAD medication.

(b) Adult with Decision-Making Capacity

The policy goals of respecting autonomy and safeguarding the vulnerable align with the eligibility criteria that a person must be an adult and must have decision-making capacity to access VAD.[116] In relation to the requirement to be an adult, although it may be argued that this devalues the autonomy of competent minors or that 18 years of age is an arbitrary line to draw, the Panel and the Victorian Government formed the view that children do not have sufficient maturity or capacity for abstract reasoning to make difficult decisions concerning death and dying. This accordingly renders them vulnerable, which justified the need to protect them, by imposing a prohibition on minors accessing VAD.[117] This view is not inconsistent with the legal position in Australia which recognises that there are limits on the ability of minors to request the withdrawal of life-saving medical treatment.[118] It also reflects the consensus in the majority of overseas jurisdictions that access to assisted dying be limited to adults.[119] Only Belgium, the Netherlands and Colombia permit requests for VAD to be made by children under the age of 18, and this occurs in practice only in very rare cases.[120]

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[113] Victoria, *Parliamentary Debates,* Legislative Council, 16 November 2017, 6098 (Gavin Jennings); Victoria, *Parliamentary Debates,* Legislative Council, 21 November 2017, 6216 (Gavin Jennings). No evidence was cited showing that people with neurodegenerative conditions tend to lose capacity earlier than people with other kinds of terminal illness.

[114] For example, recent data from Canada found that from 1 January to 31 October 2018, neurodegenerative conditions accounted for just 11% of all cases of medical assistance in dying, while 16% were due to circulatory and respiratory conditions, and another 9% from other causes or unknown. The majority (64%) were cancer-related: Health Canada (n 93) 6.

[115] Cartwright observes that '[p]atients suffering from conditions such as congestive cardiac failure, chronic obstructive pulmonary disease and chronic renal (kidney) failure can be given such strong medication at the end of life, which may render them incapable of clear decision-making': Cartwright (n 112).

[116] Willmott and White (n 1) 501.

[117] *Report* (n 8) 54, 215; Victoria, *Parliamentary Debates* (n 24) 2947–8 (Jill Hennessy).

[118] *X v Sydney Children's Hospitals Network* (2013) 85 NSWLR 294. See also *Royal Alexandra Hospital for Children Trading as Children's Hospital at Westmead v J* (2005) 33 Fam LR 448; *Minister for Health v AS* (2004) 33 Fam LR 223.

[119] See *Report* (n 8) 53.

[120] In the Netherlands between 2002 and 2014, only five cases of euthanasia involving minors were reported: Judith Rietjens, Lenzo Robijn and Agnes van der Heide, 'Euthanasia for Minors in Belgium' (2014) 312(12) *Journal of the American Medical Association* 1258; Ezekiel et al (n 92) 84. In Belgium, euthanasia of minors became lawful in 2014, with the first three cases involving children (aged 9, 11 and 17) reported between 2016 and 2017: Commission Fédérale de Contrôle et D'évaluation de L'euthanasie (n 93) 11–12. On 9 March 2018,

In relation to requiring decision-making capacity at the time of accessing VAD, not permitting advance requests was argued to advance the policy goals of respecting autonomy and safeguarding the vulnerable. For example, the Panel considered that the person making a final choice for VAD at the point it is provided ensures the voluntary nature of the decision and avoids 'manipulation and abuse'.[121] There are contrary views, however, and many argue, for example, that recognition of advance requests is needed to give appropriate respect to a person's autonomy.[122] Nevertheless, requiring capacity at the time of accessing VAD may be regarded as a defensible position in light of the *VAD Act's* stated policy goals. Not recognising advance requests in the *VAD Act* is also consistent with the majority of overseas jurisdictions. Only Belgium, the Netherlands and Luxembourg permit advance requests for VAD and they are only acted on infrequently in those jurisdictions.[123]

(c) Residency Requirements

From the Report, the *VAD Act's* requirements in relation to residency appear to be based primarily on it being 'Victorian legislation that is intended to apply to Victorian residents'.[124] Perhaps the only policy goal that could be said to be relevant is that of providing high-quality care. The Panel observed that while European jurisdictions do not expressly impose residency requirements, they are 'considered to be enforced' through requiring an ongoing therapeutic relationship.[125] The Panel also noted the

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Colombia passed a resolution permitting euthanasia of children aged seven or over: Ministerio de Salud y Protección Social [Department of Health and Social Protection], *Resolución Número 825 de 2018* [Resolution 825 of 2018], 9 March 2018. This resolution was issued in compliance with judgment T-544 of 2017, in which the Constitutional Court required the Department to issue a 'procedure to give effect to the right to die with dignity for children and adolescents': *Judgment T-544 of 2017* (Unreported, Constitutional Court of Colombia, Magistrate Ortiz Delgado, 25 August 2017). See Nubia Leonor Posada-González and Nora Helena Riani Llano, 'Eutanasia: Conceptos de la Fundación Colombiana de Ética y Bioética FUCEB, Dirigidos a la Corte Constitucional (Sentencia T-721-17) y al Ministerio de Salud y Protección Social (Borrador de Resolución Sobre Sentencia T-544-2017 de Eutanasia Infantil)' (2018) 22(1) *Persona y Bioética* 148.

[121] *Report* (n 8) 61–3.

[122] See, eg, Ronald Dworkin, *Life's Dominion: An Argument about Abortion, Euthanasia and Individual Freedom* (Alfred A Knopf, 1993); Paul T Menzel and Bonnie Steinbock, 'Advance Directives, Dementia, and Physician-Assisted Death' (2013) 41(2) *Journal of Law, Medicine & Ethics* 484; Thaddeus Mason Pope, 'Medical Aid in Dying: When Legal Safeguards Become Burdensome Obstacles', *The ASCO Post* (online, 25 December 2017) <https://www.ascopost.com/issues/december-25-2017/medical-aid-in-dying-when-legal-safeguards-become-burdensome-obstacles/>. See also the discussion of 'key concepts' in this area: Council of Canadian Academies, *The State of Knowledge on Advance Requests for Medical Assistance in Dying* (Report, 2018) 48–58.

[123] Emily Tomlinson and Joshua Stott, 'Assisted Dying in Dementia: A Systematic Review of the International Literature on the Attitudes of Health Professionals, Patients, Carers and the Public, and the Factors Associated with These' (2015) 30(1) *International Journal of Geriatric Psychiatry* 10, 11; Sigrid Dierickx et al, 'Euthanasia for People with Psychiatric Disorders or Dementia in Belgium: Analysis of Officially Reported Cases' (2017) 17(1) *BMC Psychiatry* 203. For some discussion of the complexity of the issue, see Johannes van Delden, 'The Unfeasibility of Requests for Euthanasia in Advance Directives' (2004) 30 *Journal of Medical Ethics* 447; Paul Mevis et al, 'Advance Directives Requesting Euthanasia in the Netherlands: Do They Enable Euthanasia for Patients Who Lack Mental Capacity?' (2016) 4(2) *Journal of Medical Law and Ethics* 127; David Gibbes Miller, Rebecca Dresser and Scott Y H Kim, 'Advance Euthanasia Directives: A Controversial Case and its Ethical Implications' (2019) 45(2) *Journal of Medical Ethics* 84; Menzel and Steinbock (n 122).

[124] *Report* (n 8) 56. Note that the requirement to be a resident 12 months prior to the first request was not recommended by the Panel but was introduced in the Legislative Council amendments.

[125] Ibid.

undesirability of 'death tourism'[126] or 'suicide tourism'[127] in jurisdictions such as Switzerland where VAD is available to non-residents, which a residency requirement would prevent.

That said, while a residence requirement might exclude some cases where a person has only limited contact with a medical practitioner who provides VAD, it does little to promote high-quality care and may in fact impede it in some cases where a non-resident's primary medical practitioner is based in Victoria.[128] In summary, the identified policy goals provide only limited support for imposing residence requirements and some other broader justification may be needed to support them.

3 Conclusion

Some of the *VAD Act's* eligibility criteria align with its stated policy goals. The need to be an adult with decision-making capacity can be said to reflect the goals of respecting autonomy and safeguarding the vulnerable. Likewise, requiring a person to have an illness that will cause death defensibly balances the goals of respecting autonomy, alleviating suffering and respecting all human life. However, the imposition of the general time limit of six months until death is harder to justify by reference to these policy goals, and having a different expected time until death for different conditions cannot be justified at all. Residency requirements are also questionable from the perspective of the stated policy goals.

C VAD Request and Assessment Process, and Access to VAD

1 Overview of Law

The process for requesting, being assessed for and then accessing VAD is very complex so the following discussion can only provide a brief overview of the main steps involved.

(a) A First Request and Two Independent Assessments

The *VAD Act* specifies a very detailed request and assessment process which is triggered by a first request made by a person to a medical practitioner. The request for VAD must be made by the person themselves and it must be clear and unambiguous.[129]

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[126] Rohith Srinivas, 'Exploring the Potential for American Death Tourism' (2009) 13(1) *Michigan State University Journal of Medicine and Law* 91; Alexander R Safyan, 'A Call for International Regulation of the Thriving Industry of Death Tourism' (2011) 33(2) *Loyola of Los Angeles International and Comparative Law Review* 287; Mary Spooner, 'Swiss Irked by Arrival of "Death Tourists"' (2003) 168(5) *Canadian Medical Association Journal* 600.

[127] The name likely stems from a documentary concerning the death in Switzerland of Chicago man Craig Ewert: 'The Suicide Tourist', *Frontline* (CTV, 14 November 2007). See Saskia Gauthier et al, 'Suicide Tourism: A Pilot Study on the Swiss Phenomenon' (2015) 41 *Journal of Medical Ethics* 611; Charles Foster, 'Suicide Tourism May Change Attitudes to Assisted Suicide, but Not through the Courts' (2015) 41 *Journal of Medical Ethics* 620.

[128] The Panel briefly acknowledged the 'potential for cross-border issues to arise' but then affirmed its position: *Report* (n 8) 57. There is an established (rebuttable) presumption of interpretation that State laws apply only to regulate conduct within the territory of the legislating State: *Jumbunna Coal Mine NL v Victorian Coal Miners' Association* (1908) 6 CLR 309, 363 (O'Connor J). See also *Interpretation of Legislation Act 1984* (Vic) s 48. However, laws that apply only to residents of one State may infringe upon the guarantee in s 117 of the *Constitution*, unless a relevant exception applies: Amelia Simpson, 'The (Limited) Significance of the Individual in Section 117 State Residence Discrimination' (2008) 32(2) *Melbourne University Law Review* 639.

[129] The patient 'may make the request verbally or by gestures or other means of communication available to the person': *VAD Act* s 11(3).

When a medical practitioner receives a first request from the person, if that practitioner is available and willing to be involved, they become the ‘co-ordinating medical practitioner’.[130] They then conduct the first eligibility assessment[131] and, if the person is eligible, the co-ordinating medical practitioner will refer the person to another medical practitioner.[132] If that second medical practitioner accepts the referral, they become the ‘consulting medical practitioner’, and will conduct the second eligibility assessment (called the ‘consulting assessment’).[133]

Two important safeguards are relevant here. The first is that the *VAD Act* specifically prohibits all registered health practitioners[134] from initiating a discussion about VAD (directly or indirectly) or suggesting VAD to a person, in the course of providing care.[135] The second safeguard is that the medical practitioners who wish to be involved with VAD must have particular qualifications and experience.[136] Both must be either a medical specialist or a vocationally registered general practitioner,[137] and one must have practised for at least five years after completing their fellowship with a specialist medical college or vocational registration.[138] One of the medical practitioners must also have expertise and experience in the disease, illness or medical condition expected to cause the person’s death.[139]

(b) Providing Information and Ensuring Voluntary and Enduring Requests

If the co-ordinating medical practitioner or the consulting medical practitioner assesses a person as being eligible for VAD, they must provide certain information to the person. This includes information about diagnosis, prognosis and possible treatment options, as well as that the person may decide at any time not to seek VAD.[140] The medical practitioners must be satisfied that this information is understood and also that the person is acting voluntarily and their request for access to VAD is enduring.[141]

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[130] Ibid s 15.

[131] Ibid s 16.

[132] Ibid s 22.

[133] Ibid ss 23–5.

[134] ‘[R]egistered health practitioner’ is defined as a person registered under the *Health Practitioner Regulation National Law*, which includes the professions of dentist, chiropractor, doctor, medical radiation practitioner, nurse, midwife, occupational therapist, optometrist, osteopath, paramedic, pharmacist, physiotherapist, podiatrist and psychologist, as well as Chinese medicine practitioner and Aboriginal and Torres Strait islander health practitioner: *Health Practitioner Regulation National Law Regulation 2018* (Cth) reg 4.

[135] *VAD Act* s 8.

[136] Ibid s 10.

[137] Vocationally registered general practitioners are those who are Fellows of the Royal Australian College of General Practitioners or of the Australian College of Rural and Remote Medicine, or on the Vocational Register with Medicare. For information, see Quality Practice Accreditation, ‘Vocationally registered GP’s’ (Information Sheet) <https://files.gpa.net.au/resources/QPA_Vocationally_registered_GPs.pdf>.

[138] *VAD Act* s 10(2).

[139] Ibid s 10(3).

[140] Ibid ss 19, 28. In full, this includes information about: their diagnosis and prognosis; the treatment options available and their likely outcomes; the palliative care options available and their likely outcomes; the potential risks of taking the VAD medication for the purpose of causing death; that the expected outcome of taking the VAD medication is death; that they may decide at any time not to continue the process; and that they are encouraged to tell their usual registered medical practitioners (eg their GP and/or specialists, if they are not the co-ordinating medical practitioner) of their VAD request.

[141] Ibid ss 20, 29.

(c) Two Further Requests and a Waiting Period

A person who has been assessed as eligible to access VAD by the co-ordinating and consulting medical practitioners must then make two further requests for VAD. One is a written declaration, witnessed by two people,[142] that VAD is sought voluntarily and that the nature and effect of seeking VAD is understood.[143] The second is the 'final request' which can be made verbally.[144] This final request must be made at least nine days after the first request and at least one day after the consulting assessment,[145] although the nine day period can be shortened if the person is likely to die first.[146]

The last step in this stage is for the person to appoint a 'contact person', whose duties include returning unused VAD medication to the pharmacy and being a contact point for the VAD Review Board ('the Board') (the Board is discussed further below).[147]

(d) Accessing VAD

After undertaking a 'final review' to ensure the VAD process has been complied with,[148] the co-ordinating medical practitioner may then apply to the Department of Health and Human Services ('the Department') for a VAD permit for either self-administration by the person or practitioner administration.[149] The Department will decide whether or not to issue the permit for the person to receive VAD within three business days.[150]

For self-administration, on prescribing the VAD medication, the co-ordinating medical practitioner must inform the person about how to take the medication, how it must be stored (in a locked box),[151] there being no obligation to proceed with VAD, and duties (including on the contact person) to return unused VAD medication to the pharmacy.[152] The dispensing pharmacist also must inform the person of this same information when dispensing the VAD medication[153] and include some of this information on the labelling statement.[154] Once dispensed, the person may take the VAD medication at a time of their choosing.

Where VAD is provided through practitioner administration, the co-ordinating medical practitioner is responsible for the VAD medication,[155] so the above information requirements do not apply. The person must make a further (fourth) request for VAD (an 'administration request'), in the presence of an independent witness,[156] immediately

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[142] Ibid s 35.

[143] Ibid s 34.

[144] Ibid s 37. This request may also be made by gestures or other means of communication available to the patient.

[145] Ibid s 38(1).

[146] Ibid s 38(2).

[147] Ibid s 39.

[148] Ibid s 41.

[149] Ibid s 43.

[150] *Voluntary Assisted Dying Regulations 2018* (Vic) reg 7.

[151] There is also a statutory duty imposed on the patient to store the VAD medication in a locked box: *VAD Act* s 61.

[152] Ibid s 57.

[153] Ibid s 58.

[154] The labelling statement must warn of the purpose of the dose, state the dangers of self-administration, state that the VAD medication is required to be stored in a locked box of certain specifications, and state that any unused or remaining medication must be returned to the dispensing pharmacy: Ibid s 59.

[155] Ibid s 46(c).

[156] Ibid s 64(4). The witness must be aged 18 or over, and be independent of the co-ordinating medical practitioner: at s 65(1). The witness must also be present when the VAD medication is administered and certify this: at s 65(2).

before the co-ordinating medical practitioner administers the VAD medication.[157] The co-ordinating medical practitioner must be satisfied that the person has capacity, is acting voluntarily and without coercion and the request for VAD is enduring.[158]

2 Conformity with Policy Goals

Many parts of the *VAD Act* outlining the VAD request and assessment process, and how access to VAD is provided, advance the legislation's stated policy goals. One example is the requirement to provide information to a person seeking VAD at key points in the process. This clearly aligns with policy goals such as respecting autonomy and promoting high-quality care by ensuring any decision to seek VAD is fully informed. Another is the waiting period of nine days between first and final requests. The policy intent of ensuring the person's request is 'enduring and well-considered'[159] reflects the policy goals of respecting human life, safeguarding the vulnerable, and respecting autonomy.

As noted above, alignment between legislation and its policy goals is unremarkable and indeed is to be expected. Accordingly, and particularly given it is not feasible to comprehensively review all of the detailed processes outlined in the *VAD Act*, this analysis focuses on three key areas where the law's stated policy goals may not be advanced: the prohibition on initiating VAD discussions, pre-authorisation permits and overall complexity of the system.

(a) Prohibition on Health Practitioners Initiating Conversations about VAD

Most problematic in the request and assessment process is the prohibition on initiating conversations about VAD. Section 8(1) of the *VAD Act* states:[160]

> A registered health practitioner who provides health services or professional care services to a person must not, in the course of providing those services to the person–
>
> (a) initiate discussion with that person that is in substance about voluntary assisted dying; or
>
> (b) in substance, suggest voluntary assisted dying to that person.

The policy intent of this provision was 'to ensure a person is not coerced or unduly influenced into accessing voluntary assisted dying and to demonstrate the request for voluntary assisted dying is the person's own voluntary decision'.[161] This prohibition attempts to further the two central goals of the *VAD Act*: safeguarding the vulnerable and promoting autonomy. The Report prefaced this recommendation with a discussion of elder abuse and abuse of persons with a disability,[162] and considered that the prohibition on raising VAD was justified because '[h]ealth practitioners have considerable influence over the decisions and treatment options their patients may consider'.[163] The Panel also recognised the importance of providing people with

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[157] Ibid s 64. The final request may be made verbally or by gestures or other means of communication: at s 64(3).

[158] Ibid ss 64(1), (5).

[159] *Report* (n 8) 125.

[160] Breach of section 8 can lead to sanctions for unprofessional conduct or professional misconduct: *VAD Act* s 8(3).

[161] *Report* (n 8) 91.

[162] Ibid 90–1.

[163] Ibid 92–3. See also the Explanatory Memorandum of the VAD Bill, which stated more explicitly that purpose of this prohibition was to 'protect individuals who may be open to suggestion or coercion by registered health practitioners': Explanatory Memorandum, Voluntary Assisted Dying Bill 2017 (Vic) 2.

appropriate information about VAD and other end-of-life options,[164] which has implications for the policy goal of providing high-quality care.

Despite the stated policy intent, this prohibition on initiating discussions about VAD conflicts with the policy goal of respecting autonomy. This is illustrated by the fact that a person asking for all possible end-of-life options to inform their treatment decisions cannot be told about VAD unless they know to ask about it first and do so. It is also highlighted by contrasting this prohibition with some of the relevant legislative principles in the *VAD Act* that underpin the policy goal of respecting autonomy: supporting informed decision making;[165] encouraging open discussions about dying, death and people's preferences;[166] supporting conversations with health practitioners and family about treatment and care preferences;[167] and promoting genuine choices.[168]

Further, the prohibition is problematic because precluding the open dialogue needed at the end of life between health practitioners and persons may compromise the policy goal of providing high-quality care. There are no other lawful medical services that health practitioners are similarly prevented from raising, and this prohibition does not exist in any overseas jurisdictions that have legalised VAD.[169] A final concern is the uncertainty about the scope of the provision:[170] what conversations would it prohibit and what would be permitted?[171] Given medical practitioners' lack of knowledge in other areas of end-of-life law,[172] this could have a chilling effect on open discussions about end-of-life care if health practitioners are uncertain about the permissible boundaries of discussions.

In summary, although this prohibition may align with the policy goal of safeguarding the vulnerable (and some may dispute the premise that medical practitioners would be influential in a person's decision to make a request), the significant conflict with respecting autonomy and the risk to high-quality care means it is not consistent with the *VAD Act's* policy goals overall.

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[164] The Report noted 'although a health practitioner should never initiate a discussion about voluntary assisted dying, when asked for information it is important that they are able to provide it, or at least explain where such information may be found': *Report* (n 8) 93.

[165] *VAD Act* s 5(1)(c).

[166] Ibid s 5(1)(f).

[167] Ibid s 5(1)(g).

[168] Ibid s 5(1)(h).

[169] Carolyn Johnston and James Cameron, 'Discussing Voluntary Assisted Dying' (2018) 26(2) *Journal of Law and Medicine* 454. We note, however, that as this article was being written, Western Australia passed its *Voluntary Assisted Dying Act 2019* (WA). That Act includes a similar prohibition on 'health care worker[s]' but is more limited in scope because it does not apply to medical practitioners or nurse practitioners if they also provide certain information to the patient about treatment options and palliative care: s 10.

[170] Johnston and Cameron (n 169) 454.

[171] For some of the complexities about permissible discussions in light of this prohibition, see Lindy Willmott et al, 'Restricting Conversations about Voluntary Assisted Dying with Patients: Implications for Clinical Practice' (2020) 10(1) *BMJ Supportive and Palliative Care* 1. See also Bryanna Moore, Courtney Hempton and Evie Kendal, 'Victoria's Voluntary Assisted Dying Act: Navigating the Section 8 Gag Clause' (2020) 212(2) *Medical Journal of Australia* 67.

[172] Ben White et al, 'Doctors' Knowledge of the Law on Withholding and Withdrawing Life-sustaining Medical Treatment' (2014) 201(4) *Medical Journal of Australia* 229; Ben White et al, 'The Knowledge and Practice of Doctors in Relation to the Law That Governs Withholding and Withdrawing Life-Sustaining Treatment from Adults Who Lack Capacity' (2016) 24(2) *Journal of Law and Medicine* 356.

(b) Pre-Authorisation of VAD by Government Permit[173]

The requirement to obtain a permit from the Department *prior* to providing VAD to a person is unusual, as most other VAD systems rely on *post hoc* reporting mechanisms.[174] The stated policy intent in the Report for the permit requirement was 'to establish clear monitoring and accountability for the safe prescription of the lethal dose of medication for voluntary assisted dying'.[175] This reflects the policy goal of safeguarding the vulnerable and the community, but it also appears to address the policy goal of respecting all human life by scrutinising proposed VAD before it is provided. In support of the permit requirement, the Panel cited stakeholder concerns that 'review after the fact may produce evidence of wrongdoing, but … voluntary assisted dying is irreversible'.[176]

Pre-authorisation permits also have implications for other policy goals. The delay of up to three business days is a constraint on a person's autonomy. This time also extends the period during which an eligible person is enduring suffering, so sits awkwardly with the policy goal of alleviating that suffering. This may represent an appropriate compromise between competing policy goals if the permit system is effective in ensuring only eligible persons can have access to VAD. However, this is unlikely to be so. Although the nature of the scrutiny proposed by the Department is unclear, the focus of the permit issuing process appears to be ensuring that all of the relevant prescribed forms have been completed appropriately and submitted. Such a procedurally-focused review is unlikely to be an effective safeguard to ensure compliance in practice with the substantive criteria of the legislation, making the cost to the policy goals of respecting autonomy and alleviating suffering unjustifiable.

(c) Overall Complexity

The final issue to note in relation to the request and assessment process and gaining access to VAD is the complexity of the scheme as a whole. As outlined earlier, the *VAD Act* was proclaimed to be the 'safest, and most conservative model in the world',[177] with much made of its extensive safeguards. Many of those safeguards are in the request and assessment process and they are specified in great detail in the *VAD Act*. This highly prescriptive detail in the legislation itself is unusual[178] and as a result, the *VAD Act* is significantly longer than other VAD legislation internationally.

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[173] There are other models that propose pre-authorisation of VAD, such as requiring prior court approval. Such approaches raise different considerations from those below; for example, court approval is more effective in safeguarding the vulnerable given the substantive review but comes with greater cost and delay. For a wider discussion of pre-authorisation in this context, see Yeung, 'Regulating Assisted Dying' (n 20).

[174] An exception is Colombia, which requires prior approval by independent committee: Ezekiel et al (n 92) 81.

[175] *Report* (n 8) 134.

[176] Ibid 133. Concerns about a retrospective review system have also been recently expressed in relation to a case of euthanasia of a patient with dementia in the Netherlands: Miller, Dresser and Kim (n 123) 88. See also more general concerns about the limits of the retrospective system of oversight in David Gibbes Miller and Scott Y H Kim, 'Euthanasia and Physician-Assisted Suicide Not Meeting Due Care Criteria in the Netherlands: A Qualitative Review of Review Committee Judgements' (2017) 7(10) *BMJ Open* 1. For example, they note that the Dutch review process, which is retrospective, in practice focuses on procedural criteria and professionalism of medical practitioners, rather than whether the substantive eligibility criteria are met.

[177] Andrews (n 16).

[178] More commonly, such prescriptive detail is placed in the Act's regulations or clinical or administrative guidelines.

As briefly described above, the VAD system requires at least three formal requests (four in the case of practitioner administration), two independent assessments of the person, and repeated checks of informed consent, the enduring nature of the decision, voluntariness and coercion. Appropriate witnesses[179] (and sometimes interpreters) must be organised and the co-ordinating medical practitioner must also obtain a permit before prescribing VAD medication or administering it.[180] An appropriate contact person must be found and properly appointed, and in the case of self-administration, the person must then obtain the medication and store it in a locked box.[181]

The goal of this process is to be rigorous in ensuring those who are not eligible do not gain access to VAD.[182] This advances the policy goal of safeguarding the vulnerable and the community, and it also promotes the goal of respect for human life by permitting VAD only in accordance with a strict process.[183] It is also designed to promote autonomy and high-quality care, with the Panel noting that the purpose behind the three request process is twofold: to ensure the request for VAD is 'voluntary, considered and enduring' and to provide 'multiple opportunities for a person and their assessing medical practitioners to discuss the person's request'.[184] The VAD system, at least on its face, meets these key goals.

However, when these procedural steps are viewed as a whole, there are concerns that persons will find accessing VAD very difficult.[185] A process that is described as rigorous could be experienced as onerous, and the process outlined above is also complex. This may complicate, or even frustrate, the policy goals of respecting autonomy and alleviating suffering by precluding, or at least delaying, eligible persons' access to VAD. These persons – who by definition must be suffering and generally be expected to die within six months – may find the process overwhelming and too difficult to navigate and consequently choose not to proceed. Those who do start the process might die (or lose capacity) before they make their way through it, or give up part way through. This complexity may be particularly difficult for persons from diverse cultural and linguistic backgrounds, especially if interpreters are required, as they must be accredited professionals and not a family member.[186] Even if a person is able to navigate the process, the hurdles involved and the stress in navigating them could intensify the person's suffering.

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[179] *VAD Act* ss 34–6, 65.

[180] Ibid ss 47, 48.

[181] Ibid s 61.

[182] *Report* (n 8) 112.

[183] The Panel justified the stages in the request and assessment process with reference to preventing 'doctor shopping', stating that

> even if a person finds one medical practitioner willing to break the law by providing an assessment that a person meets the eligibility criteria even though they do not, this medical practitioner would also need to find another medical practitioner willing to collude with them. Even if they are able to do this, the Department and the Voluntary Assisted Dying Review Board would be able to identify irregularities or wrong doing before a permit for prescription is given.

Ibid 122.

[184] Ibid 113.

[185] The Panel itself acknowledged this risk. It recognised 'that the person who has requested access to voluntary assisted dying is suffering … so the process should not create undue burden or anxiety or be a tick-box process … [and] should be undertaken in the spirit of person-centred care': Ibid 112. See also White, Willmott and Close (n 19).

[186] *VAD Act* s 115. Similar considerations apply to those with communication difficulties who require a speech pathologist to assist in interpreting.

The nature of the VAD process and what it requires may also mean that few medical practitioners will agree to be involved. For example, the duties of a co-ordinating medical practitioner, who oversees the process as a whole, are significant both from a clinical and administrative perspective. (The substantial reporting duties on medical practitioners involved in VAD and the implications for their participation are also discussed further below at Part III(E).) A lack of medical practitioners willing to participate would further compromise the policy goals of autonomy and alleviation of suffering as well as the provision of high-quality care.

In conclusion, while the policy goals of safeguarding the vulnerable and the community, and respecting all human life are advanced by the rigorous VAD process, its many stages and complexity may pose a risk to access and undermine the policy goals of respecting autonomy and alleviating suffering. Although these issues can be identified on the face of the legislation, how and whether these competing policy goals are achieved will depend on how the legislation is implemented. It is possible that good design of the VAD system may mean that its complexity can be 'internally facing' and may not impede access for eligible persons nor create burdens for the medical practitioners involved.[187] Firm conclusions on this will have to wait until after the law has commenced and its operation has been evaluated.

3 Conclusion

In general, the main parts of the process for requesting VAD, having eligibility assessed, and then receiving access to it, align with the *VAD Act's* stated policy goals. The primary policy advanced is safeguarding the vulnerable, but there is also recognition of respecting human life, respecting autonomy and promoting high-quality care. However, policy goals do not appear to be met, and may be impeded, by prohibiting health practitioners from discussing VAD with persons and through the requirement to obtain pre-authorisation for VAD via a government permit. Further, when the process is viewed in its entirety, its complexity may limit the *VAD Act's* fulfilment of the key policy goals of respecting autonomy and alleviating suffering. While individual components or safeguards may be justifiable, a global assessment of them reveals a different picture. This has implications for the overall design of VAD systems which will be revisited in the article's conclusion.

D Conscientious Objection

1 Overview of Law

The *VAD Act* allows medical practitioners and other health practitioners to conscientiously object to participate in VAD. Section 7 protects the right of health practitioners to refuse to:

- provide information about VAD;
- participate in the request and assessment process;
- apply for a VAD permit;
- supply, prescribe or administer a VAD substance;
- be present at the time of administration of a VAD substance; or

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[187] White, Willmott and Close (n 19) 207.

- dispense a prescription for a VAD substance.

Other provisions also anticipate conscientious objection. One is the requirement to accept or refuse the role of co-ordinating or consulting medical practitioner within 7 days.[188]

2 Conformity with Policy Goals

The right of medical practitioners and other health practitioners to refuse to provide information about or participate in VAD[189] clearly advances the policy goal of respect for individual conscience.[190] Notably, however, there is no duty to refer a person to another medical practitioner who is willing to be involved in VAD. The Panel considered, but rejected, such an approach,[191] instead relying on existing obligations of medical practitioners under their code of conduct not to impede persons' access to lawful care or treatment.[192] The absence of a specific legislative duty to refer stands in stark contrast to the very detailed and prescriptive process outlined for other matters in the *VAD Act*.

While promoting respect for conscience, the lack of a legislative duty to refer may impede access to a lawful end-of-life option.[193] If this happens in relation to VAD, this would compromise the realisation of other important policy goals: respect for autonomous choices, alleviation of suffering and the provision of high-quality care.

E Oversight, Reporting and Compliance

1 Overview of Law

The *VAD Act* contains a number of mechanisms for monitoring VAD and ensuring compliance with the legislative regime.

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[188] *VAD Act* ss 13(1)(b), 23(1)(b).

[189] The Report contained two recommendations specifically with the policy intent of respecting individual conscience. They are: Panel Recommendation 18 – that medical practitioners have a right to conscientiously object, and Panel Recommendation 39 – that where the co-ordinating and consulting medical practitioner both conscientiously object to administering a lethal injection, they may transfer care to a different medical practitioner who is willing to administer the medication: *Report* (n 8) 24, 27.

[190] For further discussion of the value of conscience in the Australian legal system, see Willmott and White (n 1). In Victoria, this is reflected in the right to freedom of thought, conscience, religion and belief contained in the *Charter of Human Rights and Responsibilities 2006* (Vic) s 14. See also the *Report* (n 8) 214.

[191] *Report* (n 8) 109–11.This duty exists under Victorian law governing termination of pregnancy: *Abortion Law Reform Act 2008* (Vic) s 8.

[192] *Report* (n 8) 15, 110. See Medical Board of Australia, *Good Medical Practice: A Code of Conduct for Doctors in Australia* (Guideline, March 2014) para 2.4.6 <http://www.medicalboard.gov.au/ Codes-Guidelines-Policies.aspx>.

[193] Although a legislative duty to refer may provide stronger normative force than simply relying on existing ethical duties, it still may not be effective. For example, there is evidence that the legislative duty to refer when a medical practitioner has a conscientious objection to a termination of pregnancy is being ignored or evaded by some Victorian medical practitioners: Louise Anne Keogh et al, 'Conscientious Objection to Abortion, the Law and Its Implementation in Victoria, Australia: Perspectives of Abortion Service Providers' (2019) 20 *BMC Medical Ethics* 11:1–15.

(a) Board Oversight of the System

The Board is a new independent statutory body[194] that has overall oversight of the VAD system. Its primary function is to monitor activity under the *VAD Act* to ensure compliance.[195] This includes reviewing each case where VAD has been requested, to ascertain compliance with legal requirements. The Board must also evaluate overall patterns and trends of access to VAD, such as discerning possible instances of 'doctor shopping':[196] that is, overuse of one or more medical practitioners who repeatedly find a person to be eligible for VAD despite other medical practitioners finding them to be ineligible.

The Board will be supported in its oversight function by the mandatory reporting obligations imposed on medical practitioners, dispensing pharmacists and others by the *VAD Act*, as outlined in Table 2. In addition to reporting to the Board, all deaths of people who were the subject of a VAD permit are notifiable to the Coroner,[197] although these deaths are not investigated as possible suicides.

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[194] The Board is established by the *VAD Act* s 92. This model of a separate body, independent of the health department, follows the European models in place in Belgium, the Netherlands and Luxembourg, rather than in the US States, where monitoring is done within existing health departments: *Report* (n 8) 159.

[195] *VAD Act* ss 93(1)(a), (b).

[196] *Report* (n 8) 168.

[197] A medical practitioner attending a person who has died must notify if the person was the subject of a VAD permit, and state their knowledge or belief whether or not the person died as a result of VAD, or VAD was not administered: *VAD Act* s 67(2). These deaths are also notifiable to the Registrar of Births, Deaths and Marriages: at s 67(1). However, VAD is not required to be recorded as the cause of death on the death certificate: *Report* (n 8) 150–3.

Table 2: Reporting to the Board

Matter reported	Person reporting	Form or other document	Legislative provision
That a person was assessed as eligible or ineligible for VAD after a first assessment	Coordinating medical practitioner	First assessment report form (Form 1)	*VAD Act* s 21
That a person was assessed as eligible or ineligible for VAD after a consulting assessment	Consulting medical practitioner	Consulting assessment report form (Form 2)	*VAD Act* s 30
That the request and assessment process has been completed	Coordinating medical practitioner	Final Review Form (Form 5). Note that attached to this Form are copies of Forms 1, 2, 3 (Written declaration) and 4 (Contact person appointment form).	*VAD Act* s 41
That a self-administration permit or practitioner administration permit has been issued (or has been amended)	Secretary of Department of Health and Human Services	VAD permit (or its amendment)	*VAD Act* s 49 (and s 51 for amendment)
That VAD medication was dispensed	Dispensing pharmacist	VAD substance dispensing form (Form 6)	*VAD Act* s 60
That any returned VAD medication was disposed of	Dispensing pharmacist	VAD substance disposal form (Form 7)	*VAD Act* s 63
That VAD was administered to a person by a medical practitioner	Coordinating medical practitioner	Coordinating medical practitioner administration form (Form 8)	*VAD Act* s 66
That an application for review has been lodged with VCAT That VCAT has made an order or determination	Principal Registrar of VCAT	Notice of application to VCAT Copy of VCAT's order or determination	*VAD Act* s 69(c)

(b) Victorian Civil and Administrative Tribunal Review of Eligibility Decisions

The Victorian Civil and Administrative Tribunal ('VCAT') has a more limited role in relation to VAD. It has jurisdiction only to review assessments by a co-ordinating or consulting medical practitioner about residency and decision-making capacity, as these are questions of fact.[198] VCAT does not review clinical issues such as disease-related eligibility criteria.

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[198] *VAD Act* s 68 and Part 6.

(c) Health Practitioners' Duties to Report

Registered health practitioners (including medical practitioners, nurses, allied health practitioners and pharmacists)[199] are required to report colleagues to the Australian Health Practitioner Regulation Agency (AHPRA) if they believe another registered health practitioner has initiated a discussion about VAD or suggested it to a person, or has offered to provide VAD to a person not eligible under the Act.[200] This reporting obligation also applies to health practitioners' employers, such as hospitals or institutional care providers.[201]

(d) Offences

The *VAD Act* adds several new offences, which are designed to promote compliance with the Act and deter people from intentionally acting outside the law.[202] These offences relate to:

- coercing a person to access VAD;[203]
- administering VAD medication to a person who has been issued a self-administration permit;[204]
- acting contrary to a practitioner administration permit;[205]
- a contact person failing to return unused or remaining VAD medication after the person's death;[206]
- falsifying forms and statements;[207] and
- failing to report to the Board.[208]

(e) Protection from Criminal and Civil Liability

The *VAD Act* specifically protects medical practitioners who provide VAD in accordance with the Act from any criminal or civil liability, or liability for professional misconduct or contravention of a professional code of conduct.[209] It also protects those (including health practitioners, family or carers) who assist or facilitate a request for VAD.[210] These legal protections provide certainty and confidence for those who help a person to access VAD in accordance with the Act.

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[199] See *Health Practitioner Regulation National Law Regulation 2018* (Cth) for definition of registered health practitioner.

[200] *VAD Act* s 75.

[201] Ibid s 76.

[202] The offence provisions are broadly modelled on offences in force in some US States: *Report* (n 8) 179.

[203] This includes both inducing a person to request access to VAD, and inducing a person to self-administer VAD medication: *VAD Act* ss 85, 86. The maximum penalty in both cases is 5 years imprisonment.

[204] *VAD Act* s 84. The maximum penalty is life imprisonment.

[205] Ibid s 83. The maximum penalty is life imprisonment.

[206] Ibid s 89. The maximum penalty is 12 months imprisonment or 120 penalty units or both.

[207] Ibid ss 87, 88. The maximum penalty for both offences is 5 years imprisonment for a natural person, or 2400 penalty units for a body corporate. The value of a penalty unit changes annually, and is set by the Treasurer: *Monetary Units Act 2004* (Vic) s 5(3). From 1 July 2018 to 30 June 2019, one penalty unit was $161.19, so the maximum penalty was $386,856.

[208] *VAD Act* s 90. The maximum penalty for this offence is 60 penalty units, which at the time of writing was $9,671.40.

[209] Ibid s 80. This includes protecting a health practitioner or paramedic who does not administer life-saving treatment to a person who is dying after the administration of VAD medication: at s 81.

[210] Ibid s 79.

2 Conformity with Policy Goals

Collectively, these provisions of the *VAD Act* are designed to ensure that the VAD system operates as intended: that VAD is provided within the law and that unlawful behaviour does not occur. In this way, these provisions generally advance the overall key policy goals of protecting human life and safeguarding the vulnerable and the community, while ensuring that human suffering can be alleviated through people exercising their autonomy within the law. It could be further argued, though, that some of these provisions give greater emphasis to particular policy goals. For example, the Board's oversight of all cases of VAD and the reporting that underpins this[211] are especially aimed at safeguarding the vulnerable. Offence provisions also safeguard the vulnerable and the community, and, arguably, those that prohibit the causing of death outside the Act are also aligned with the policy goal of respecting all human life.

Accordingly, when looking at these provisions in general, each can be justified as aligned with policy goals of the Act. One concern, though, is that when these provisions are considered cumulatively, they become burdensome such that the balance between permitting eligible persons access to VAD on the grounds of autonomy and compassion and safeguarding the vulnerable is tilted so as to hinder reasonable access to VAD. The prime example is the volume of reporting, particularly that required of the co-ordinating medical practitioner. This may mean that health practitioners decline to be involved in VAD due to these burdens, especially when added to the significant duties noted above in relation to the request, assessment and access processes. While the manner in which these reporting duties will be implemented is not yet clear, it is at least noted on the face of the legislation that this reporting burden may deter involvement and hinder access to VAD, thus potentially compromising the policy goals of respect for autonomy and alleviation of suffering.

IV CONCLUSION

Stepping beyond entrenched arguments for and against VAD, this article evaluated instead whether the *VAD Act* reflects its own stated policy goals. It first analysed the Report that provided the foundation for the Act, along with its legislative principles, to discern six key policy goals that underpin the legislation:

- To respect all human life;
- To respect personal autonomy;
- To safeguard the vulnerable and the community;
- To provide high-quality care;
- To respect individual conscience; and
- To alleviate human suffering (compassion).

The article then analysed the major parts of the *VAD Act* to determine whether they reflected those identified policy goals. A failure to align with goals was the focus of this analysis, as legislation that achieves intended objectives is to be anticipated. The overall conclusion was that there are important respects in which the Act fails to reflect its own

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[211] Researchers agree that reporting all cases of VAD is important to safeguard the quality of the process: Tinne Smets et al, 'Reporting of Euthanasia in Medical Practice in Flanders, Belgium: Cross Sectional Analysis of Reported and Unreported Cases' (2010) 341(7777) *British Medical Journal* 819, 825.

policy goals. Key examples of this are: having self-administration as the default means of providing VAD and allowing practitioner administration only in very limited circumstances; requiring time limits to death and those time limits varying depending on the nature of a person's illness; prohibiting medical practitioners from raising VAD with persons; and creating a system that when considered globally is very complex and arguably burdensome for persons seeking access to VAD and medical practitioners.

While being critical in relation to these findings of policy misalignment, it is important to consider how and why they occurred. It was suggested earlier that the design of the Act was a reflection of the political strategy necessary for it to pass the Victorian Parliament. Indeed, the original Bill, which was already very narrow and with many safeguards, was not conservative enough initially to pass Victoria's upper house, the Legislative Council. It is suggested that decisions about the design of the law, including by the Panel, were shaped by an awareness of what might be needed to secure necessary political support. This is not to suggest that the Panel's deliberations were purely political, and without careful regard to its nine guiding principles underpinning the six policy goals set out above. However, it is argued that the Panel, and the Victorian Government in drafting the VAD Bill, also had regard to more pragmatic considerations such as what sort of law would be capable of attracting the necessary political support. This understandable intrusion of politics into decision-making about policy is one reason the *VAD Act* does not adequately reflect its stated policy goals in some key respects.

This policy misalignment was also exacerbated by the need for more overt political compromise. As noted above, alterations to the VAD Bill were required for the Legislative Council to pass the *VAD Act*. Arguably, such late changes to Bills are not principle-based decisions but rather pragmatic concessions needed to garner sufficient support to pass a law. As such, instead of being new ways to advance the legislation's stated policy goals, these 'add-ons' can often actually be in conflict with those goals. An example of this, as mentioned earlier, is the changes to the period of time expected until the person's death. The original VAD Bill that was passed by the Victorian Legislative Assembly provided for a 12-month period. This period was then halved to six months, except for a subset of medical conditions that had a neurological basis, for which cases the 12-month period was retained.[212] The imposition of a time limit, and particularly different time limits for different conditions, was critiqued earlier in this article as inconsistent with stated policy goals. This is an obvious example of where overt but necessary political compromise caused policy misalignment.

The analysis in this article has focused on the legislation itself rather than implementation. It is acknowledged, however, that it is possible for effective implementation to address some of the ways in which the legislation fails to best reflect its policy goals.[213] One example is the complexity of, and the burdens imposed by, the VAD request and assessment processes, and the corresponding duties of reporting. It is possible that well-designed systems could facilitate access to VAD for eligible persons and avoid undue burdens for medical practitioners, while still effectively safeguarding the vulnerable. While those responsible for the law's implementation should be mindful of opportunities to better advance policy goals, this will not always be possible. Some

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[212] See Part III(B)(2)(ii) 'Six Months until Death'.

[213] White, Willmott and Close (n 19).

gaps between policy goals and the *VAD Act* are structurally embedded in the legislation and cannot be alleviated. An example is eligibility limits relating to expected times until death and the prohibition on raising VAD with persons.

A final observation is to note is that this analysis has implications for wider VAD reform in Australia as other states actively consider law reform in this area. As this article was being written, Western Australia passed its *Voluntary Assisted Dying Act 2019* (WA), following reports by a Parliamentary Committee[214] and then a Ministerial Expert Panel.[215] Both Queensland and South Australia have established Parliamentary Committees whose terms of reference include VAD, with the Queensland Committee recommending VAD reform.[216] A draft Tasmanian Bill has been released for consultation by the Hon Michael Gaffney[217] and a Bill is also expected to be introduced into the New South Wales parliament within the foreseeable future.[218] The default position for other states is likely to be adopting the Victorian model, or at least to use it as a starting point for their proposed law.[219] This was the case with the Western Australian Act which is very similar to the Victorian law. However, this analysis has concluded that the *VAD Act* does not advance its stated policy goals in important respects. This suggests critical review is needed by other states considering reform. A more principled approach is suggested,[220] with each aspect of proposed laws being tested against those principles or policy goals to ensure policy coherence of the law.

This needs to be done individually in relation to each aspect of the law but it must also be done globally in relation to the law as a whole and how it will operate. The claim of the Victorian VAD system to be the most conservative in the world has implications for access for VAD. The many safeguards and processes that form part of that claim, when considered in total, are likely to present challenges for persons seeking access to VAD and medical practitioners. These concerns were specifically identified in this article both in relation to reporting and also the processes for requesting, being assessed and then accessing VAD. It is only when the Act as a whole is considered that the complexity in the VAD system becomes clear.

When thinking about the politics of reform, it can be tempting to only consider each safeguard or process individually. Each may have merit and advance a particular policy goal. It may also be difficult politically to argue that a specific safeguard is not needed, particularly if it appears to achieve at least some useful purpose. However, when the safeguards are aggregated, the VAD system as a whole can become very complex and

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[214] Joint Select Committee on End of Life Choices, Parliament of Western Australia, *My Life, My Choice* (First Report, 23 August 2018).

[215] Government of Western Australia, Department of Health, *Ministerial Expert Panel on Voluntary Assisted Dying* (Final Report, July 2019).

[216] Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland, *Voluntary Assisted Dying* (Report No 34, 31 March 2020) 105 (Recommendation 1); Joint Committee on End of Life Choices, Parliament of South Australia, *Terms of Reference* (April 2019).

[217] End-of-Life Choices (Voluntary Assisted Dying) Bill 2020 (Tas) <http://www.parliament.tas.gov.au/LC/gaffney/EOL.pdf>.

[218] Carla Mascarenhas, 'Port Macquarie State Election Candidates Debate Assisted Dying for the Terminally Ill', *Port Macquarie News* (online, 26 February 2019) <https://www.portnews.com.au/story/5925502/state-election-candidates-debate-assisted-dying-for-the-terminally-ill/>.

[219] White and Willmott, 'Victoria May Soon Have Assisted Dying Laws for Terminally Ill Patients' (n 2). Note, however, that this is not the case in Queensland: see Health, Communities, Disability Services and Domestic and Family Violence Prevention Committee, Parliament of Queensland (n 216) 105 (Recommendation 1), which proposed instead that the starting point for reform be the draft Bill outlined in Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.

[220] Willmott and White (n 1) 484–8. Such a model is presented in Bill form in White and Willmott (n 219).

unwieldly, and slowly take the legislation away from its policy goals. This 'policy drift by a thousand cuts' – the incremental loss of policy focus through accumulation of individual safeguards without reference to the whole – is a key issue for other states to consider when evaluating their proposed VAD reforms. It is suggested that each part of the law be evaluated both on its own, and also for its impact on the functioning of the overall system. This is needed to enable VAD laws to meet their policy goals, in particular, the two key goals at the core of the design of the *VAD Act*: safeguarding the vulnerable while respecting the autonomy of eligible persons who wish to access to VAD.

From: Barbara Coombs Lee
Sent: 20 January 2023 23:30
To: PrivateMembersBill
Subject: Thoughts on legislation to authorize assisted dying

My name is Barbara Coombs Lee. I'm an attorney, nurse, advocate and author. I was among those drafting the Oregon Death with Dignity Act in 1994 and I have helped steward its implementation, and adoption of similar laws in ten other jurisdictions in the United States.

Medical aid in dying laws enable a terminally ill, mentally capable adult to request from their physician a prescription for medication they may ingest at a time of their own choosing, if their symptoms become unbearable to them. Currently ten states and the District of Columbia, where approximately 22% of the population of the United States resides, authorize the medical practice of medical aid in dying within their borders. The accumulated data from these states is comprehensive and scientifically sound.

I want to comment specifically on the impact of medical aid in dying on the quality of end-of-life care.

In 1997, Dr. Susan Tolle, Director of the Oregon Health and Science University Center for Ethics and a dedicated opponent of medical aid in dying, nevertheless observed a strong association between passage of the Oregon Death with Dignity Act in 1994 and improved end-of-life care in the state. Dr. Tolle published an article in the *Annals of Internal Medicine* titled "Oregon's Assisted Suicide Vote: The Silver Lining."[1] Dr. Tolle cited early and dramatic increases in hospice and palliative care utilization in the state, and heightened practice standards for pain and palliative care.

Over the last 22 years Dr. Tolle's insights have proven prescient, and accurate. Specific areas of verifiable improvement include:

- Rising hospice admissions, a full 20% in the first year after medical aid in dying implementation and continuing increases thereafter.

- Greater allocation of resources to advancement of hospice and palliative care services.

- Declining proportion of deaths occurring in acute care hospitals, a key quality indicator in end-of-life care. A high proportion of deaths occurring in acute care hospitals indicates excessive delivery of futile care and unnecessary suffering.

- Rising demand and delivery of post-graduate medical education in pain and symptom management at the end of life.

- More appropriate use of opioid analgesics in the treatment of pain and other distressing end-of-life symptoms.

- Scrutiny of undertreated pain at the end of life by physician licensing bodies.

- Expansion of insurance coverage for hospice and palliative care.

- Increased focus on end-of-life care in medical institutions and undergraduate medical education.

Far from adversely impacting the quality of care at the end of life, laws to authorize medical assistance in dying have the opposite effect. These laws raise awareness and improve the quality of medical care for dying patients. Dr. Tolle still does not advocate for medical aid in dying, but she does testify to its salutary effect on medical care at life’s end.

Thank you for considering my comments.

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[1] Tolle, Susan W and Lee, Melinda, “Oregon’s Assisted Suicide Vote: The Silver Lining,” Annals of Internal Medicine Vol 24 No 2, January 15, 1996 pp267-269.

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Compassion & Choices fights for the rights of people at the end of their life and pushes back against those who seek to strip those rights away. Click here to read about some of our recent efforts in courthouses across the country.

INQUIRY INTO ASSISTED DYING

I believe that the mood of the country has evolved in favour of legislation to offer people the choice of assisted dying, a right that already exists in many countries.

The Bills that have come before Parliament, and which I have supported in the Lords, are drafted very narrowly, restricting the right only to those believed to be nearing the end of a terminal illness. It is argued that palliative care should be able to ensure that no one dies in pain and therefore the emphasis should be on ensuring that everyone has access to the best palliative care. However, there are conditions which do not appear to be completely alleviated by current palliative care. In those cases, assisted dying would seem to be the humane answer.

In other cases, effective pain relief may render a patient permanently drowsy, if not virtually devoid of life. This is not how many people would choose to spend their last days.

We have all come across examples of such cases. Most recently, I heard from a friend who had determined to spend Christmas Day with his elderly father who is in the late stages of Alzheimer's disease. The patient did not open his eyes throughout the visit and uttered one word: 'Help'. If my fiend could have legally done so, he would have done – and it would have been an act of love.

We are now in the hypocritical situation of knowing that 'mercy killings', as they have become known, do occasionally occur but very rarely result in prosecution, let alone the prison sentence that murder carries. Surely the time has come to stop the hypocrisy and acknowledge that some people would choose to be helped to die and it is best that the help should come from those best qualified to administer it.

There are people with religious or conscientious objections to the concept of an assisted death. My belief is that no doctor or nurse should be compelled to be involved in the procedure. Given the tight boundaries on eligibility that have been proposed for any UK legislation, the numbers involved would in any case be very small.

However, even the very narrowly drafted legislation has so far failed. Many parliamentarians object to the proposal on religious grounds, although they rarely admit this. I believe that this is inherently unfair for the non-religious majority in this country. Those who oppose they principle of assisted dying do not have to make use of it but it is surely time to give the option to those who would feel a degree of comfort in knowing that they might have a comfortable and dignified death.

Churches Alive in Mann - Response to Assisted Dying Consultation

Churches Alive in Mann represents all the main Christian denominations on the Isle of Man. We speak with one voice in saying that we do not support any changes to the law which would permit assisted dying, more accurately described as physician assisted suicide. While it is a duty for a caring society to relieve suffering, the artificial termination of life must be resisted in the strongest terms.

Pastoral Concerns

The long-rooted experience within our Churches of supporting a wide range of people through illness, through the final stages of life, and through bereavement, has given us insight into living well and dying well. There is so much that is precious about Manx community and the care we give to one another. A concern for personal autonomy regarding end of life choices needs to be weighed against care for people who live with disabilities, physical and mental impairments, or people with obvious or hidden vulnerabilities.

It is a sad reality that a proportion of elderly people suffer from physical, emotional or financial abuse and we have deep misgivings that a change in the law would in some cases lead to a greater concern for relieving the family's suffering (or bank balance) than for the best interests of their elderly relative. Most people treat their loved ones with integrity, but for the few, existing experience shows that it is not easy to spot coercion.

Even for people who are not subjected to abuse, the existence of the proposed law would inevitably lead some people to conclude, not only that they could, but that they should end their lives to relieve burden on others. This is a well documented trend in Oregon.

In our Churches, we often find ourselves caring for people who are suicidal and helping them to find reasons to go on living. Legislation for assisted suicide would greatly weaken the message of hope we, and so many others on our Island, seek to share.

We believe that the dangers the proposed legislation poses to so many vulnerable people, far outweigh the benefits of autonomous choice for a few.

Moral Concerns

For thousands of years, "Do not kill" has been an ethical foundation of many civilisations. We believe that all human life is a sacred gift from God. The value of any member of our society is not determined by variable measures of the quality of life. If we begin to end individual lives prematurely, we will inevitably diminish the high value we place on all lives.

Living Well and Dying Well

We believe that life and death find meaning in relationship, both with God and with family, friends and wider community. To die well, we need to live well. To live well, we need to develop relationships, life practices and a depth of hope that sustains us throughout life to our dying breath. Life is just as valuable in suffering, limitations and loss of capacity, as it is in health, independence and strength.

We support the ethos of the Hospice and palliative care movement. We urge the Government to invest in extending and deepening the Island's Hospice and palliative care provision as a life-giving alternative to legalising assisted suicide.

In the words of Dame Cicely Saunders, founder of the Modern Hospice Movement:

> *You matter because you are you, and you matter to the last moment of your life.*
> *We will do all that we can to help you to die peacefully, but also to live until you die.*

Churches Alive in Mann affirm the enormous value of all lives and stands opposed to the legalising of assisted dying on the Isle of Man. Such legislation would inevitably turn us into a less compassionate society.

8 January 2023

Death Tax Planning Offshore - Euthanasia Repurposed?

Advocate Paul Beckett M.A., M.St. (Oxon.)
Visiting Research Fellow, School of Law
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On 1 December 2022 the Isle of Man Government opened a public consultation on “assisted dying”, discreetly avoiding any reference to assisted suicide.[1] One of the most divisive issues of our times, assisted suicide is defended and opposed with equal vehemence, and moral, ethical and legal arguments all fuel the debate over the right to 'self-determination'. Euthanasia and assisted suicide, killed by medical professionals or killed by one’s own hand, lead to very much the same result: death.

Many countries have legalised euthanasia or assisted suicide.[2] What sets the present Isle of Man consultation apart is not its thoughtful balancing of the emotional and clinical issues on which it seeks public comment, but something which is not stated, because it is self evident. *This debate concerns euthanasia in a low tax jurisdiction.*

Where there is death, there is a phalanx of tax planners eager to advise. For both onshore and offshore tax residents, there are heavyweight fiscal arguments to consider.

Putting the ethical issues to one side, is there are danger that euthanasia could be hijacked - repurposed to serve the needs of death tax planning?

Leaving a low tax area, intending to be euthanised

Picture a scene in which someone has relocated from their home country, in this case the United Kingdom, which is their *domicile of origin*, to the Isle of Man, their new *domicile of choice*. They are tax resident in the Isle of Man. Then imagine that because euthanasia is not

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[1] Assisted Dying https://consult.gov.im/private-members/assisted-dying/ (accessed 8 January 2023) The consultation closes on 26 January 2023. Under the proposals, “the person must administer the life-ending medication themselves”.

[2] Luke Hurst and Camille Bello, with Reuters, *Euthanasia in Europe: Where is assisted dying legal?* (Euronews, 10 December 2022) (https://www.euronews.com/next/2022/12/10/where-in-europe-is-assisted-dying-legal- (accessed 8 January 2023)

yet available in the Isle of Man,[3] this person will travel to Switzerland in order to end their life.[4]

By leaving the Isle of Man for Switzerland with the sole intention of carrying out an assisted suicide, the Isle of Man - to which they are clearly not returning - is no longer their domicile of choice. For Switzerland to become their new domicile of choice, they would need to meet Swiss tax residence requirements. An individual is deemed to be a tax-resident under Swiss domestic tax law, if:

- the individual has the intention to permanently establish his/her usual abode in Switzerland, which is usually where the individual has his/her centre of vital interest, and is registered with the municipal authorities, or if
- the individual stays in Switzerland with the intention to exercise gainful activities for a consecutive period (ignoring short absences) of at least 30 days, or if
- the individual stays in Switzerland with no intention to exercise gainful activities for a consecutive period (ignoring short absences) of at least 90 days.[5]

But they are merely visiting in order to die, and none of these criteria is met. In this limbo, their default domicile for taxation purposes becomes once again their domicile of origin; the United Kingdom. The impact on a lifetime's careful savings could be considerable, not to mention the consequences for family left behind.

Moving to a low tax area, intending to be euthanised

Now assume that euthanasia has become legal in the Isle of Man. The Isle of Man Government consultation explains the aim of the proposed legislation to be:

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[3] Section 2(1) of the Criminal Law Act 1981: *"2(1) A person who aids, abets, counsels or procures the suicide of another, or an attempt by another to commit suicide, shall be guilty of an offence and shall be liable, on conviction on information, to imprisonment for a term not exceeding fourteen years."* https://legislation.gov.im/cms/images/LEGISLATION/PRINCIPAL/1981/1981-0020/CriminalLawAct1981_7.pdf (accessed 8 January 2023)

[4] One British person travels to the Dignitas clinic near Zurich in Switzerland (www.dignitas.ch) to die every eight days: Campaign for Dignity in Dying, *The True Cost. How the UK outsources death to Dignitas* https://features.dignityindying.org.uk/true-cost-dignitas/ (accessed 8 January 2023)

[5] PwC Worldwide Tax Summaries (12 July 2022) *Switzerland - Individual - Residence* *https://taxsummaries.pwc.com/switzerland/individual/residence#:~:text=An%20individual%20is%20deemed%20to,the%20municipal%20authorities%2C%20or%20if* (accessed 8 January 2022) © 2017 - 2023 PwC

- to enable mentally competent adults who are terminally ill to be provided with assistance to end their life at their request.
- A person is deemed to be terminally ill if a registered medical practitioner has diagnosed them as having a progressive disease, which can reasonably be expected to cause their death.
- The person must be 18 years of age or over and is a permanent resident on the Isle of Man.

“A permanent resident on the Isle of Man” - would this not, as in Switzerland, be an impediment to someone wishing to be euthanised who attempts to abandon their domicile of origin in the United Kingdom or (having earlier abandoned their United Kingdom domicile of origin) their domicile of choice elsewhere, by relocating to the Isle of Man? Would they also be in limbo, unable to establish that the Isle of Man had become their “permanent residence” and hence their domicile of choice in which they were tax resident. Would they remain domiciled in (or would their domicile revert to) the United Kingdom?[6]

Not necessarily. There is no definition of residence for tax purposes in the Isle of Man.[7] The Isle of Man treats those individuals having a view or intent of establishing residence as tax resident from the date of their arrival. The Assessor of Income Tax will look at evidence showing that the presence in the Isle of Man is not for a temporary purpose.

Intending to live in the Isle of Man for the rest of one’s life is hardly a temporary purpose. And in any case, one’s appointment with death may be booked *after* residence has commenced. There is no compulsion to reveal advice received or their innermost thoughts and intentions. The Assessor of Income Tax can hardly ask a new resident how long they plan to remain among the living.

Death tax planning - euthanasia repurposed

The result? In the hands of international wealth and tax planners, euthanasia will have been

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[6] The United Kingdom is only one example - Irish Citizens and those of the Channel Islands also have automatic right of residence. Potential abuse of immigration entry clearance and right of residence provisions contained in the Isle of Man Immigration Rules must also be taken into account. https://www.gov.im/categories/travel-traffic-and-motoring/immigration/immigration-rules-and-associated-policy/immigration-rules/ (accessed 8 January 2023)

[7] Practice Note *Tax Residence in the Isle of Man* PN144/07 13 June 2007 https://www.gov.im/media/97083/pn14407taxresidenceintheisl.pdf (accessed 8 January 2023)

8 January 2023

repurposed. The Isle of Man, as a low tax jurisdiction with ill-defined tax residency rules, may become the destination of choice for a steady stream of tax-advised, terminally ill individuals. The Isle of Man is gentle and welcoming, and there are far worse places in which to spend one's final days. But what will be the social impact on the island and on the island's reputation abroad of what amounts to death tourism?

Health and Social Care Committee Inquiry into Assisted dying/assisted suicide

Written submission by SANE

SANE is a leading UK-wide mental health charity, established in 1986, that works to improve the quality of life for people affected by mental illness, their families and carers. It aims to:
1. raise awareness and understanding of all mental health conditions
2. fight to improve frontline mental health services for individuals, families and carers
3. provide emotional support and specialist services through its helpline, SANEline, email and ongoing Support Services, Textcare and Online Forum
4. promote and host research into causes, treatments and therapies at the Prince of Wales International Centre for SANE Research in Oxford.

SANE wishes to focus its submission on the point that terminally ill people who wish to control the manner and timing of their death are not suicidal. We believe it is inappropriate and insensitive to characterise a wish for an assisted death as being suicidal, because suicide and assisted dying are fundamentally different things, and the language used in the debate on assisted dying must reflect this difference. This is more than a battle over semantics.

The difference between assisted dying and suicide troubles many people, and to conflate shortening life with foreshortening death does a disservice to both suicide prevention and end-of-life care. Recognition of the distinction and an appropriate use of language are vital if we are to ensure that everyone receives compassionate care for their individual needs throughout their life, as well as at its end. We owe it to those who are directly impacted by the current law, and who may benefit from future law change, to make clear that assisted dying is not suicide.

SANE has been at the forefront of life-saving, evidence-based suicide prevention work for more than three decades. Suicide is a complex and preventable tragedy. We know from the thousands of people who call us that some are crying out for help in escaping what feels unending and unbearable mental pain, and for such people there should be immediate and experienced help. We also know that a significant number who have attempted to take their own lives are grateful to have had a second chance. While there are interventions that can alleviate such distress, and treatments, both medical and therapeutic, that can successfully ameliorate mental illness, a clear distinction needs to be drawn between suicide and assisted dying.

SANE believes that the debate on assisted dying must be informed by the experiences of those who are directly affected. The report by Dignity in Dying, *Last Resort: The hidden truth about how dying people end their own lives in the UK* , estimates that hundreds of terminally ill people are taking their lives every year under the assisted dying ban, with thousands more attempts.

People close to those who have taken their lives in these circumstances feel strongly that suicide is not an accurate description of what their terminally ill relative was forced to resort to. Invariably, they believe that their relative could have lived longer and had a better quality of life through being consoled by the knowledge they could take control of their death under a safeguarded system with medical support.

While there are treatments that can ameliorate mental illness, for those whose condition is incurable and death inevitable, assisted dying may offer a compassionate choice. For this choice to be exercised fully, legally sanctioned assisted dying with medical support needs to be available without the need to travel abroad.

As long as the option of assisted dying does not exist in this country, people may feel they need to make plans to go abroad to achieve their wish for an assisted death. But they have to be fit enough to travel, which means they may be shortening their lives. If such people knew that the option of assisted dying was available locally, they might well not take that step and work with the palliative care system, at least until they were far more advanced in their illness.

The option of assisted dying without having to travel abroad would offer psychological security and provide a fall-back reassurance to both patients and families. It would prevent the distress that making the decision to travel abroad, and doing so, could cause, and possibly avoid a needless shortening of life.

With the reassurance that assisted dying was an option, there would be more chance for palliative care to be effective for both patients and families, avoiding pitting palliative care against assisted dying, when the two should be able to work together.

Ann Jackson, MBA
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18 January 2023

Office of the Clerk of Tynwald
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Greetings,

My name is Ann Jackson. I have been a resident of Oregon all my life. I recently moved from Portland south to Wilsonville. I have worked in the field of end-of-life care for nearly 36 years, the first 20 as CEO of the Oregon Hospice and Palliative Care Association. From 1988 to 2008, I was its representative for all responsibilities related to Oregon's Death with Dignity Act (ODDA) before, during, and after it became law.

The Oregon Hospice and Palliative Care Association (OHPCA) is neutral on assisted dying and its policy statement can be read here: https://oregonhospice.org/hospice-and-dwd/. The OHPCA is a state-wide public benefit organization committed to improving the quality of life for Oregonians at the end of life and supporting the hospice and palliative care organizations that provide care.

I am now an independent and unaffiliated consultant often asked to comment about the ODDA. A link to an updated copy of my CV/Bio is on the home page at www.ann-jackson.com.

I am writing now to address issues that you will be considering as you debate voluntary assisted dying in the United Kingdom.

Palliative care and assisted dying

I voted against the ODDA twice, in 1993 and in 1997. I strongly believed that assisted dying was unnecessary if Oregonians had access to high quality hospice and palliative care. By the time the Act was implemented, all Oregonians did have access. But after its implementation, I soon recognized how arrogantly dismissive I had been. There are valid needs that hospice and palliative care professionals cannot meet effectively. *Palliative sedation*, for instance, is not an acceptable option for most persons who value autonomy.

That said, I support hospice *and* voluntary assisted dying. They complement each other very well.

In fact, between 1997 and 2021, more than 90% of persons who used the ODDA were enrolled in hospice. In 2021 98% of those who hastened their dying under provisions of the law were also hospice patients. This is evidence that they did not end their lives because symptoms were not addressed. In the USA, hospice is recognized as the gold standard of palliative care. Hospice is a legally defined benefit offered to persons who have an estimated life expectancy of 6 months or less and provides care at home and across all other settings.

Some persons with a life expectancy of fewer than 6 months, such as those continuing curative treatment, may prefer palliative care over the full array of hospice services. No person who is dying should ever have to choose the ODDA as an alternative to hospice and/or palliative care. Nor should they have to choose palliative care or hospice as an alternative to the ODDA, if they are eligible.

Nearly all persons who used the ODDA had health insurance. However, Oregon's health plan covers the cost of hospice for persons who do not have the ability to pay. All health plans offer palliative care as well.

Slippery slope arguments are fallacious

The Oregon Death with Dignity Act (ODDA) became law in 1997, the first jurisdiction in the world to make PAS or assisted dying a legal option. The Oregon Health Authority (OHA) issued its first annual report in 1999 and issued its 24th annual report on March 15, 2022. Each report is a wealth of data. As a compendium, they reflect the stability of the Act. Oregon must not ignore this information: We must learn from the science—and offer what we have learned to other jurisdictions.

There have been no abuses of Oregon's law. Those who drafted the ODDA were very, very conservative, as were those who wrote the regulations that administer it in practice. I was among them. Our primary aim was to ensure that the Act would result in no harm to the persons who used it. Nor to physicians and other health care professionals supporting the persons who used it.

Fact- and experienced-based research published in highly regarded journals support the successful implementation of Oregon's law. Oregon has very responsibly been closing the data void about assisted dying as it is practiced in a legal environment.

Deaths under the ODDA are not recorded or understood as suicide. There is a wealth of expert commentary on the differences between suicide and the wish of a dying, competent individual to control the manner and timing of their death through assisted dying.

It is important to note, contrary to the "noise", that there have been no abuses within the provisions of the ODDA. Nor has the ODDA changed other laws or values in relation to suicide. Those persons who assist in a suicide are subject to charges of manslaughter or murder in the State of Oregon.

All laws must be reviewed and examined over time and amended or repealed, as the science dictates. There were only minor house-keeping changes made to the ODDA until 2019. It was amended then, to allow a person who has a prognosis measured in days, not months, but meets all other requirements of the ODDA, to ingest medication without the required waiting periods. The legislature agreed that to deny access in these circumstances is cruel.

And in 2022, as a settlement to a lawsuit challenging its constitutionality, Oregon residency was removed as a requirement to access the ODDA.

Amendments or tweaks that have been proposed suggest that the Act, as initially passed, is too conservative and not reflecting current needs or times. It is important to note that *the fundamental eligibility criteria of the ODDA: being mentally competent and terminally ill with a prognosis of six months or less, have not changed* in the 25 years since the law came into effect.

The USA now has 41 years of experience and 10 states and the District of Columbia where citizens may hasten their deaths.

Arguments that amending the ODDA are steps down a slippery slope are fallacious. When science dictates reconsideration, actions should be taken. *"Slippery slopes" are irrelevant red herrings.*

Prognoses are overestimated

In 2015, Oregon's Legislature rejected a bill that would expand the life expectancy criteria to one year from 6 months. The question was whether a safeguard in 1997 was proving a burdensome barrier in 2015. Science suggests and research supports that 70% of physicians overestimate life expectancy—significantly more often than underestimate.

However, the Legislature and the end-of-life community agreed that consistency with the federal Medicare/Medicaid Hospice Benefit and its requirement of a six-months prognosis was an important consideration. I was a member of the federal task force that developed disease-specific guidelines for determining prognoses. Those guidelines should be an invaluable tool for physicians and assurance that persons qualify for the ODDA. However, the median length of stay in hospice in the USA remains only 20 days, far under 6 months.

Overestimating life expectancy denies patients timely admissions to hospice services, an entitlement under Medicare, and denies persons their right to use the ODDA.

In 2021, the median time between the first request for a prescription and a patient's death was only 30 days, far less than six months. Furthermore, this includes an outlier of 1 person of 238 persons who had made the request 1,095 days before death.

I see no evidence that persons hurry to use the ODDA because they have been given a six-months prognosis. In my experience, people do not want to die. They prefer to live.

They are comforted when they have a prescription, and they get on with living. They use the prescription when dying—and suffering—become too burdensome. About one-third of those who go through the process and receive a prescription under the ODDA never use it. This points to the peace of mind that having a choice brings to many dying people.

Being a burden is a specious argument

I am a co-investigator of published research that overwhelmingly determined that *all persons who are dying worry that they are a burden* to their family and loved ones. Not just those who use the ODDA.

"Growth" in number of cases

The ODDA has been used infrequently, although a graph of cases between 1998 and 2021 suggests a steep climb. In 1998, 6 of 10,000 persons who died ingested medication under provisions of the ODDA. In 2021, the number was 59 of 10,000, fewer than in 2020. From less than .01 percent to less than 1 percent over 24 years.

Disabled persons are not coerced to use ODDA

"*Disability Rights Oregon* has never received a complaint that a person with disabilities was coerced to make use of the [Oregon Death with] Dignity Act". Bob Joondeph, its executive director, confirmed that this statement, first made in 2007, remained true in 2020.

It is important to note that, in 2021, 98% of all persons who used the ODDA were enrolled in hospice. Hospice personnel include doctors, nurses, social workers, physical therapists, aides, and volunteers, all of whom visit patients in their homes. Hospice workers are in a unique position to monitor patient and family well-being.

Mental Health Evaluations

Referrals to psychiatrists/psychologists are very infrequent, although they are required if a prescribing physician questions a person's capacity to make health decisions. The referrals are infrequent because the bar is high enough that persons who lack capacity are rarely able to carry out requirements for eligibility.

Death Certificates

That a person uses the ODDA is not relevant to agencies that are routinely provided a death certificate, such as a mortgage carrier. Death certificates in Oregon are not public records. There are superior methods for collecting data. In Oregon, the state is informed when a prescription is written.

Informing Patient Families

Family members are never entitled to health care information, under federal law. A recommendation by their doctor that they do inform family is appropriate—as are reasons why.

Implications for Doctors

Doctors who accept a request from a patient to write a prescription understand their responsibilities. No doctor should be required to accede to a request. I do believe, however, that doctors and medical centers should be more open and honest about policies that would allow or restrict participation. And to be more open to conversations about options at the end of life.

It is important to note that, unless a patient's doctor is willing to write a prescription—or even to make a referral, the patient is unlikely to know the doctor who will. However, these are relationships that develop rapidly. I can attest to that statement.

Closing with a personal qualification

My life partner died of cancer on December 3, 2019. He was one of 188 persons to use the ODDA that year. William Cary Duncan III, M.D., vascular surgeon, born in Ware, Massachusetts, who morphed into a cowboy in Oregon. In October, Bill made his three required requests for a prescription, and was also admitted to hospice. He was very anxious to have the medication and adamant about using it immediately. It was to arrive on Saturday, and on Friday, at his request, I arranged to have a volunteer from End-of-Life Choices Oregon (EOLCOR) with us. EOLCOR is a not-for-profit charitable organization that provides support to persons considering a prescription.

Immediately after I informed Bill that Peter, his good friend, and medical director of EOLCOR would be arriving at 4 p.m. on Saturday, the telephone rang. My daughter and her husband invited Bill to join them on Sunday to watch the Boston Patriots game. "Well, that's an invitation I can't turn down!" Bill exclaimed.

His medication was set aside—and as for so many others who have used the ODDA, he got on with living, comforted by its proximity. On Friday, November 29, the day after Thanksgiving, Bill and his daughter, my daughter and I, and our old Afghan Hound were finally able to drive across the Santiam Pass over the Cascade Mountains. Bill had a home on an old ranch in Central Oregon. The roads were rough and icy, very hard on his exhausted and emaciating body. Blizzards and "bomb cyclones" had delayed our crossing for several weeks. While a bundled-up Bill waited in the heated car, we shoveled snow and cleared a path for his wheelchair. Then we all settled in for a few days, cozy before the wood stove, and sleeping under down comforters.

Thus, Bill, who had always lived large and did not want to die, chose to end his dying on a quiet, snowy day in his own bed at his beloved log cabin in Camp Sherman, Oregon. I was with him, as were Lisa and Meg (his daughter and mine), and a volunteer from

EOLCOR. Bill was resolute when he drank his medication. His chaser was an Old Fashioned—our favorite cocktail at the Savoy. He barely sipped it before he was sound asleep—and so very peaceful.

I remain bereft.

Thank you. Please let me know if you have questions—or if I can elaborate in some way.

Respectfully submitted,

Ann Jackson

Ann Jackson, MBA
[Contact details redacted]

www.ann-jackson.com
18 January 2023

Broadway
Baptist Church

Assisted Dying Bill Consultation
c/o Clerk of Tynwald's Office
Legislative Buildings
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24 January 2023

Response to the Proposals to Legalise Assisted Suicide on the Isle of Man

This letter is Broadway Baptist Church's response to the Government consultation regarding the Assisted Dying Private Members' Bill. It has been produced by, and has the unanimous agreement of, the leadership team on behalf of our members and wider congregation.

Questions 3, 4, 5 & 6: We are responding on behalf of Broadway Baptist Church, which has a membership of over 100. Nearly all our members are resident on the Isle of Man.

Question 7: You may publish our response.

Question 8: We disagree to the proposals to permit assisted dying for terminally ill adults on the Isle of Man.

We would not complete the rest of the questionnaire as we believe it is extremely biased towards supporting the proposals, indeed, answering most of the other questions could be construed as tacit support for the proposals.

Two Biblical commands speak powerfully into the ethical dangers of the proposed legislation.

- "Do not kill" has stood the test of time and is foundational to every civilised society.
- "Love one another" reminds us that, in considering legislation, our concern must be, not just for personal autonomy, but for those in our society who would be adversely impacted by such a seismic change in the law.

Care and compassion towards vulnerable people, who would be most threatened by a change in the law, lead us to oppose the proposals. Our points for consideration follow below.

Unnecessary

We believe changes to the current legislation are unnecessary. The current legislation does not allow for assisted suicide, but there is a residual discretion for all offences whether to prosecute or not. The main advantages therefore of the current law are its ability to provide a strong deterrent as a safeguard against wrongdoing, and its ability to be sensitive to the facts of individual cases.

Some of the heart rending situations that are seen in the news and are used as examples to support assisted suicide, would be unlikely to ever lead to prosecutions due to the residual discretion available.

The UK and Isle of Man enjoy the best palliative care in the world and the providers of hospice care on the IOM should be supported by Tynwald, not undermined, which this legislation would surely do.

Legislation is there to state social values as well as set the rules. What we are seeing in other jurisdictions, where Euthanasia/Assisted Suicide has been introduced, is an eroding of social health care values with Euthanasia/Assisted Suicide being encouraged by health care professionals who years ago would never have contemplated such actions because it was seen as being against their core beliefs of saving and prolonging life.

Unethical

We believe the proposals are unethical in several areas:

- The proposals will harm the doctor/patient relationship. Trust is at the heart of the clinician-patient relationship and if there is the thought that a doctor or nurse could instigate death when a patient is ill and seeking care, this trust will be irrevocably damaged. We must keep the premise that a doctor will never intentionally cause harm to patients.

- We would expect a caring Government to be increasing and supporting resources for such organisations as Hospice as the best way to reduce pain and suffering, rather than promoting contradictory alternatives.

- The proposals attack the fundamental belief that suicide should be prevented in all cases. Whatever words are used (such as assisted dying, euthanasia etc.) ultimately the message that Tynwald would be sending out (if such legislation was ever passed), is that suicide is something that is ok. We wonder how MHKs reconcile this with the comments on the Suicide Prevention page on gov.im 'Suicide is not inevitable and is never the only option'. To proceed would be especially reckless in light of the increasing number of suicides seen among younger people.

- We are concerned about the effect this proposal would have on those members of our society who are living with a disability. A number of our church members have a disability. Disability is at the heart of the assisted dying debate as the evidence from Oregon shows. The top five reasons for assisted suicide in Oregon are the “loss of autonomy”, “less able to engage in activities”, “loss of dignity”, “loss of control of bodily functions” and “feelings of being a burden”. These are disability issues and it is easy to see how bringing in assisted dying for these reasons will make those living with a disability feel less valued and will adversely change societal views of disability.

Dangerous to the weak, mentally challenged, disabled etc.

We believe the proposals are dangerous because the proposals do not (and cannot) protect the weak and vulnerable in society (which surely should be one of the prime responsibilities of all Governments).

Canada is held up as an example to follow in Dr Allinson's proposals. But:

- More than 10,000 Canadians availed themselves of the world's most permissive government-assisted suicide programme last year (3.3% of all deaths in Canada).

- People who are 'tired of life' can easily access the Medical Assistance in Dying Programme (MAiD) having reluctantly concluded they are better off dead when they fall through the stretched social welfare net.

- In a recent year 96% of MAiD applications were approved. Applications are now process driven and not that much more than a box-ticking exercise, with specific organisations and a minority of doctors 'specialising' in assisted dying (note most Canadian doctors refuse to euthanise people).

- Also quoted in a recent Daily Mail article (17 December 2022) are several examples of people who received assisted suicide because they were: afraid of being homeless, being in poverty, suffering hearing loss, afraid of again going through Covid in a Care Home etc.

One would say these above examples from Canada are a horrific indication of what an Euthanasia/Assisted Suicide regulatory regime could lead to.

Although Canada is the most egregious example of what can happen, we could point to deep concerns in several other jurisdictions.

In a time of increasing financial struggles, it is not hard to imagine that a number of elderly and infirm people would consider Euthanasia/Assisted Suicide if it was made available. We have seen that in Oregon last year, 54% of people who died by Physician Assisted Suicide answered that 'burden on family, friends or caregivers' was a key reason for their choice.

How sad that would be - is this what Tynwald wants for the people of the Isle of Man?

Laws will be open to challenge

In jurisdictions that have legalised Euthanasia/Assisted Dying, the legislation has been consistently challenged and protections weakened, so that the definitions have broadened and it is carried out more widely (see the examples on Canada given above). Indeed, following legal challenges, Canada which started out using a terminally ill definition, expanded it law to include chronically ill and disabled, then to mentally ill and further extensions are being prepared.

Some of the key wording in legislation is imprecise, as it has to be when talking about death, and we see this as another reason not to impose the laws. For example: How does one define terminal illness? The proposals seem to suggest an estimate on life expectancy by medical practitioners. However, no matter what time limit is used, no-one knows the time of death accurately. We are aware of examples (including those in Oregon) where people have been told they had 6 months to live and yet have lived much longer, several years in some cases.

We believe it is important not to allow the legislation to get a foothold in the Isle of Man. Now we are seeing increased pressure being put on all Governments to adopt this legislation mainly by pressure groups and their supporters.

Remember, already in the British Isles, over 500,000 elderly people are subject to psychological, physical, sexual or financial abuse. If Euthanasia/Assisted Dying legislation is passed into law, in whatever form it takes, it is not hard to imagine that the elderly will be 'encouraged' to think about the burden they are on the family, especially if finance is freed up. We refer you to the examples already mentioned above. Is this not something we should resist with all our wills?

The question is: will those with the privilege of governing in the Isle of Man protect the vulnerable people in our society who are threatened by the proposals, and thus do what is right by opposing this Bill? We hope so.

Yours sincerely

[Signature redacted]

Clive Swift

Church Secretary

www.broadway.im
A community living to make Jesus known
Alpha Centre Broadway Douglas Isle of Man IM2 4EN

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Dear Sir, Madam,

Unfortunately I didn't get far with the online survey so I am writing to express my feelings regarding the Assisted Dying Bill.
I strongly disagree with it and was most impressed with Dr. Harris' article in the Examiner, in preserving the value and sanctity of life.

The Manx way of life is disappearing before our eyes. How sad to see some in power who are determined to alter our way of life.

Please, please re-consider this Bill and the outcomes.

Thank-you.

Mrs. Ann Boyes

Submission to the Isle of Man Consultation on Assisted Dying

The All-Party Parliamentary Group for Choice at the End of Life

From Karin Smyth MP and Rt Hon Kit Malthouse MP, Co-Chairs of the Group

The All-Party Parliamentary Group for Choice at the End of Life is a group of MPs and Peers who meet to support the aim of promoting greater patient choice at the end of life, particularly over where, when and how one dies. The APPG's purpose is:

> To improve the experience of dying in the UK by promoting and expanding people's choices at the end of life. To promote a change in the law to allow the choice of assisted dying for terminally ill, mentally competent adults.

Since it was established, the APPG has worked proactively and purposefully to gather evidence from a range of experts, nationally and from overseas, on the practice of assisted dying and the impact of the blanket ban in the UK. We focus on lived experience rather than speculation. These efforts have prompted targeted actions in support of law change - for example, the then Secretary of State for Health and Social Care, the Rt Hon Matt Hancock MP's request to the Office of National Statistics for more data on suicides by terminally ill people in 2021. We also heard from supporters of Dignity in Dying's Compassion is Not a Crime campaign who called on the then Justice Secretary to launch an inquiry into the impact of the current law.

The evidence submitted below is a brief summary of the information the APPG has gathered from people who have been impacted by the blanket ban on assisted dying. These stories support our conclusion that the status quo is unjust, unsafe and unacceptable and that government time must necessarily be devoted to addressing this issue in a comprehensive and evidence-based manner.

The APPG endorses the submission by Dignity in Dying on the detailed policy questions.

The blanket ban on assisted dying has resulted in unacceptable failings in patient safety

Our outdated law on assisted dying discriminates between those who can and cannot afford an assisted death in Switzerland; criminalises grieving relatives who support their loved ones to exercise control over their deaths; and forces a small but significant number of dying people to end their lives before they are ready in lonely and sometimes violent ways.

Dying people in this country are the biggest victims of the ban and its unequal effects. Financial and logistical challenges make travelling abroad a 'business class' option for only a small number of people. In addition to the substantial cost, the process of arranging an assisted death abroad can be extremely difficult and time-consuming, meaning people often need the help of friends and family to make arrangements. Yet providing any assistance is against the law.

Ann Whaley told the APPG how she was investigated by police after an anonymous call alerted social services of her plan to accompany her terminally ill husband Geoffrey, 80, to Dignitas in February 2019.

> *"Geoffrey had been by my side for over 50 years and I was determined to be by his until the very end. But in supporting his final wish to die with dignity, I became a criminal under British law. It was utterly devastating to think that I might be arrested or that Geoffrey might be stopped from travelling to Dignitas"*

The requirement to be physically able to travel to Switzerland to have an assisted death also means people are ending their lives much sooner than they might otherwise choose to. An NHS clinician, speaking anonymously to the APPG in order to protect her loved ones, explained the realities that she has been forced to face in order to have a dignified death:

> *"I am 45 and until my diagnosis of secondary breast cancer last September I was a senior mental health professional in the NHS. (She died at Dignitas in Nov 2020). Like many of the people who have succumbed to Covid-19 this year, I am being forced to die in the presence of strangers, in unfamiliar surroundings, without my husband, family or friends to comfort me. In my case, however, it is the result of the antiquated laws on assisted dying in the UK, which have compelled me to travel to a foreign country to die alone."*

The disparity between the choices available to dying people in the UK and those in jurisdictions which offer more meaningful choice at the end of life through a safeguarded assisted dying law was brought home to the APPG by Sher and Joy's stories. Sher Safran explained:

> *"In 2017, the year both my parents turned 88 years old, each one of them was diagnosed as terminally ill, and each was given 6 months or fewer to live. Dad Charlie was failing from advanced Parkinson's and prostate cancer, and mum Francie was declining from advanced coronary disease, heart attacks and small strokes. They lived in Oregon state which 20 years before had passed the death with dignity law. My parents always believed that there should be the choice of peaceful dying wherever possible. The week before they died they had arranged for all of us in the family to come together and celebrate their life. On April 20th, at 10 am that morning, mum and dad each drank their medicine, and then they laid down together on their bed as they had done for nearly every night for 66 years. And they held hands, and closed their eyes and they fell asleep. My mum passed very peacefully in 15 minutes, and my dad passed very peacefully 45 minutes later. Their death reflected so beautifully the intent and grace of their lives."*

Meanwhile, Joy Munns told us about how her mother, Mavis Eccleston, 80, from Staffordshire, was charged with the murder and manslaughter of her husband Dennis, 81, after he ended his own life at home in February 2018 while dying of bowel cancer. Mavis, who had attempted to overdose at the same time, was resuscitated and later charged. A jury unanimously found her not guilty on both counts following a trial at Stafford Crown Court in September 2019. Joy explained:

> *"My mom would have done anything for her husband, but she had no idea that her actions, motivated purely by love, would land her in the dock. On top of losing Dad, we were terrified we would lose Mom to life in prison. Under an assisted dying law, this would never have happened. Politicians have to face facts – a law is clearly not working if it makes criminals of innocent great-grandmothers."*

In 2021 Dignity in Dying published a report, Last Resort, which tells the stories of the dying people who took their own lives in the absence of an assisted dying law. The report estimated that up to 650 terminally ill people take their own lives every year in the UK in the absence of the safe, legal choice of assisted dying. In April 2022, the Office of National Statistics published data, commissioned by the former Secretary of State for Health and Social Care, the Rt Hon Matt Hancock MP, indicating that people with severe and potentially terminal health conditions are more than twice as likely to take their own lives than the general population.

The devastating impact that the current law has on individuals and their families was revealed to the APPG by loved ones left behind. Irene explained to us that:

> *“My son Gavin was diagnosed with throat cancer in 2014 at just 50 years old. The throat cancer was rapidly advancing, he couldn’t swallow anything - we were told that the tumour would grow daily and, in effect, would slowly but surely strangle him. An assisted dying law could have eased so much of his suffering, knowing that when it became too much he could choose to die when and how he wanted. Without this choice, Gavin felt he was out of options. A few days before he died he attempted to end his life at home and was admitted to hospital. But his choices - or lack of choices - remained the same. It is a measure of his desperation that he walked out of the hospital Emergency Department onto a nearby main road and threw himself in the path of a passing lorry.The effect of the manner of Gavin’s death on me and my family is ongoing and unforgettable. I feel I failed him and grieve every day. How much easier it would have been for all of us if Gavin had been given the choice of an assisted death. My family and I could now have an image of him of dying peacefully surrounded by those whom he loved and who loved him. We wouldn’t have his violent end constantly hanging over us.”*

Palliative care and assisted dying are not mutually exclusive

The APPG supports greater investment in palliative care alongside the development of a safeguarded assisted dying law. Overseas evidence demonstrates that even with access to the highest quality of palliative care services, some people still suffer and wish to have control over the timing and manner of their death. There is evidence that palliative care can flourish alongside the introduction of assisted dying legislation.

Addressing the APPG in 2021, Dr Bill Crawley, former GP, practising palliative care lead and experienced palliative care physician, acknowledged that while the majority of people are able to have “what might be termed ‘good’ deaths” with access to palliative care, his own professional experiences have shown him that a significant minority of patients still die without adequate symptom control or pain relief. Dr Crawley said that he had often been asked by patients for more choice at the end of their lives, and that on many occasions he had witnessed suffering beyond the reach of the current options available. This included patients with motor neurone disease experiencing ‘air hunger’ when removing a ventilator in order to hasten death, and cancer patients being strangled by tumours wrapped around their trachea or vomiting faeces due to bowel obstructions. He added that:

> *“choice at the end of life, to have an assuredly dignified death in skilled hands, is the only way we can be sure that patients do not have to tolerate subjectively intolerable symptoms.”*

Professor Sir Paul Cosford, Emeritus Medical Director at Public Health England, who died of lung cancer in April 2021, shared his experiences of living with a terminal illness with the APPG in November 2020 and wrote about assisted dying in the British Medical Journal. He said:

> *“My biggest fear around dying is the lack of control…The lack of ability, if all becomes too much, to advance the end a little, to take some control in my final days. I might have a diamorphine pump at that time, and the idea of having an extra vial in the fridge for me to use if I need it is appealing. Despite helpful conversations with excellent palliative care specialists, this final element of choice and self-determination seems to evade me.”*

Overseas evidence demonstrates that legislation which balances individual autonomy and the protection of vulnerable people is possible and preferable to the status quo

Assisted dying, as supported by the APPG, describes the process of prescribing on request, life-ending medication to an individual with mental capacity who is already dying, in order to give them the means to control the manner and timing of their own death. This is the eligibility criteria which underpins the legislative models adopted in 11 US states, all six Australian States and in New Zealand.

The evidence we gathered from parliamentarians and frontline clinicians from these jurisdictions, confirms that such an approach successfully balances the importance of promoting individual autonomy at the end of life while protecting those who may be vulnerable.

The Rt Hon Helen Clark, former Prime Minister of New Zealand, said at an APPG meeting in November 2020:

> *"The central objective of the End of Life Choice Act is to offer the option of assisted dying to terminally ill New Zealanders who meet the criteria set out in the Act. You cannot access this Act if you have a mental illness. You cannot access this Act if you have a disability alone. You must have a terminal illness which is likely to end your life in the next six months….it is about enabling people to live better as they are dying – whether or not they choose this option – in addition to easing the deaths of those who do and providing protection to the most vulnerable in our society."*

Dr Catherine Forest M.D., M.P.H., is a clinical associate professor of community and family medicine as well as a public health specialist. In 2021, her spouse, Will Forest, who was terminally ill with motor neurone disease, requested and received the aid-in-dying law Catherine had championed in their home state of California. She explained what the law looks like in practice when she supports patients at the end of life:

> *"Several times, I have had tough conversations with people who do not qualify. The law requires that patients are terminal with less than six months to live, can take the medication on their own, and have the capacity to make their own medical decision Therefore, people with diagnoses like Alzheimer's disease and other dementias do not qualify. I regret that better options aren't available for these patients. However, I believe that learning from current legally defined conditions is important. We need to make sure no one is coerced or chooses assisted dying when they don't have the capacity to make the decision for themselves."*

Jill Hennessy, who was the Australian minister in charge of Victoria's Voluntary Assisted Dying Bill explained how the Government collaborated with eminent specialists, from neurologists to leaders in palliative care, as well as legal experts, in order to ensure protection and clarity through their law and clinical protocols. . She explained that while the passage of the legislation was hard-fought, once passed, politicians quickly accepted the new status quo:

> *"The sky hasn't fallen in. In fact, the highlight of my day is getting letters from people who have been with their family when their choice has been exercised and where their end of life has been achieved with dignity."*

Time and time again, British citizens have testified to the APPG that the choices at the end of life available to citizens in the US and Australia for example are the same choices they wish to have here. Kit explained:

> **"***In 2017 I was diagnosed with secondary breast cancer, but since I was born I have also lived with a mobility impairment which makes walking very painful. I know my cancer cannot be cured, but I want to explore every possible treatment to prolong my life. But the further I go, I know the drugs will become less effective and the side effects get worse. Eventually my options will run out. I've already had adverse reactions to pain meds like morphine; doctors can't guarantee they can keep me pain-free. When I reach that stage, I just want the ability to go out as 'me'. I don't want to be drugged out of my mind, not knowing what's going on, or unable to express myself. I don't want to put my death in someone else's hands, I want to go*

> *on my own terms. It feels unfair that people who don't have terminal illnesses are deciding things for people who do."*

She concluded:

> *"I don't want to die, but if I have to, then I want to die 'free' and I want to die 'me'."*

Dr Stephen Duckworth OBE, a veteran disability rights campaigner who has been a wheelchair-user for 40 years, highlighted the important distinction that needs to be made between disabled people and those who are terminally ill in debates on assisted dying. In addition to talking about his own strong support for greater end-of-life choice which is shared by 86% of disabled people, Dr Duckworth criticised non-disabled opponents who "exploit the experiences of disabled people and the inequalities and fears we endure in our daily lives", using this "as a smokescreen for their own agenda to block progress on this issue". He added that:

> *"There is no hierarchy of rights. Equality for disabled people cannot be addressed by denying dying people the autonomy, choice and control that they want and deserve over their lives."*

Conclusion

Former Health Minister in Victoria, Australia, Jill Hennessy, who was the Minister in charge of Victoria's Voluntary Assisted Dying Bill summarised what legislators in the UK now need to do:

> *"The Victorian laws have been used safely, they've been used compassionately and all of the risks and reasons that people have used as objections, none of those fears, none of the fearmongering that we've seen during the debates on assisted dying has materialised. The Parliamentary Committee had made some recommendations and we used the resources of government to help develop the model. We took those recommendations and we established a panel of eminent people in the medical and legal world. With the use of the experts, we were able to, with political consensus, work through each of these issues and we developed our model of assisted dying.*
>
> *"We should never let our political leaders get away with saying that the status quo is acceptable. When people are engaged in a debate about the reasons not to embrace law reform, they must engage in why the status quo is unacceptable. An important part of the debate in Australia was evidence from the coroner about these tragic stories. Evidence from our judiciary who were having to preside and prosecutors who were having to look at these cases they didn't want to prosecute. Nurses who were working in an unregulated area with some patients having the privileged access to terminal sedation while others did not. Others had to die lonely private deaths, with paramedics and police officers discovering them. Others who were given no legal choice, made a choice of their own. We've got to continue to highlight the complete unacceptability of the status quo. But we must build models of assisted dying that have the backing of expertise."*

Similarly, the Rt Hon Helen Clark, former Prime Minister of New Zealand, shared that:

> *"Having examined the evidence and looked back on my 27.5 years of parliamentary experience, I am confident that enacting this [assisted dying] law is the safe, compassionate and right thing to do."*

The APPG for Choice at the End of Life looks forward to colleagues and Parliamentarians in British jurisdictions taking steps towards the legalisation of choice at the end of life. By doing so they will be following the example of other free-thinking, liberal and compassionate democracies around the world. Those countries have shown that assisted dying is safe, fair and compassionate for dying people and offers protection to those who are potentially vulnerable. Our own experiences demonstrate that the blanket ban on assisted dying is no longer fit for purpose, providing neither compassion nor protection.

We would be delighted to discuss this further with colleagues from other jurisdictions and help where we can to ensure that the rights of the Crown Dependencies to legislate in this area are upheld.

Submission to the Isle of Man Government consultation on “assisted dying” on behalf of Care Not Killing (CNK Alliance Ltd) and Our Duty of Care

January 2023

Introduction

1. What is your name?

2. What is your email address?

campaign@carentkilling.org.uk

3. Are you responding on behalf of an organisation?

Yes

4. If you answered "yes" to the previous question please state which organisation

Care Not Killing and Our Duty of Care

Care Not Killing (CNK) is a UK-based alliance working to:

- promote more and better palliative care;
- ensure that existing laws against euthanasia and assisted suicide are not weakened or repealed;
- influence the balance of public opinion against any further weakening of the law.

Formed in 2005 to oppose Lord Joffe's Assisted Dying for the Terminally Ill Bill, CNK has since campaigned on the MacDonald and Harvie Bills at Holyrood, and the Falconer, Marris and Meacher Bills at Westminster, as well as intervening in major court cases including those of Tony Nicklinson, Noel Conway and 'Y'.

Our Duty Of Care (ODOC) is a group of UK healthcare workers who oppose the intentional killing of patients by assisted suicide or euthanasia, supported financially and administratively by CNK. Working with a wide range of healthcare professionals across the UK, ODOC has campaigned during the membership polls run by the Royal College of Physicians, Royal College of General Practitioners and British Medical Association.

5. Are you responding as an individual or a group?

Group

6. Are you resident on the Isle of Man?

No

7. May we publish your response?

Yes, you can publish my response in full

Support for Proposal

8. In principle, do you agree or disagree that assisted dying should be permitted for terminally ill adults on the Isle of Man?

Disagree

Please explain the reasons for your response

We hold that legal change to permit assisted suicide and/or euthanasia would be uncontrollable, unethical and unnecessary.

1. Uncontrollable, as we shall see, because the current law rests on a natural frontier with all forms of legalisation susceptible to escalating numbers of deaths, expansion and abuse including under-reporting.
2. Unethical owing to the effect on patients, making them feel burdensome due to the extra care and support they need, and on doctors and other healthcare professionals with conscientious objections.
3. Unnecessary because of the high quality of care Manx residents have recourse to, thanks to a comprehensive palliative care service and community support driven by families, friends, neighbours, the health and social care service and a range of charities. Hospice Isle of Man's Chief Executive and Lead Clinician have said in a statement that: 'the Isle of Man Hospice experience to date has been that request by patients even to discuss artificially hastening their death have been extremely rare on-Island" and any legislation for "assisted dying" would "undermine palliative care."[1]

There is evidence from neighbouring jurisdictions of significant public misunderstanding concerning "assisted dying".

Former Supreme Court justice Lord Sumption has observed that although law change advocates claim "the public is overwhelmingly in favour, a lot of polling evidence suggests that that rather depends on the degree of detail which goes into the asking of the question."[2] 2014 ComRes polling[3] (UK) found that respondents moved from 73%-12% in favour to 43%-43% once just a few arguments against legalisation had been heard. A July 2021 UK survey found that more than half of respondents thought the term "assisted dying" meant "providing hospice-type care to people who are dying" or "giving people who are dying the right to stop life-prolonging treatment."[4] Only 42% realised that it refers to giving lethal drugs to a patient to end their life intentionally.

The Association for Palliative Medicine (APM) published feedback[5] from a membership survey in 2022, which found that more than half of respondents (67%) said patients and families think they are definitely or probably practicing covert euthanasia:

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[1] manxradio.com/news/isle-of-man-news/mhk-supports-public-conversation-over-assisted-dying/

[2] downloads.bbc.co.uk/radio4/reith2019/Reith_2019_Sumption_lecture_1.pdf

[3] carenotkilling.org.uk/public-opinion/assisted-dying-public-opinion/

[4] dyingwell.co.uk/wp-content/uploads/2021/09/Survation-Assisted-Dying-Survey-July-2021-Summary-3.pdf

[5] apmonline.org/wp-content/uploads/2022/01/APM-Member-Survey-2021-final.pdf

> "Palliative care is already equivalent to euthanasia in the public's mind here – they associate syringe pumps with euthanasia and this is a myth we have to dispel on a daily basis when interacting with patients and their families in the hospital."

Most respondents (87%) felt there has not been enough press coverage of good deaths: might the persistence of "assisted dying" advocates in fact eclipse public awareness of life-changing palliative care, to the detriment of both patients and professionals?

Throughout the rest of our submission, we will refer to "assisted suicide" (or "euthanasia", or "E&AS" where appropriate), rather than "assisted dying", a campaigning euphemism intended to cushion the reality. In 2019, the American Medical Association's Council on Ethical and Judicial Affairs (CEJA) reported[6] that:

> "Proponents of physician participation often use language that casts the practice in a positive light… However… CEJA believes ethical deliberation and debate is best served by using plainly descriptive language. In the council's view, despite its negative connotations, the term "physician assisted suicide" describes the practice with the greatest precision. Most importantly, it clearly distinguishes the practice from euthanasia. The terms "aid in dying" or "death with dignity" could be used to describe either euthanasia or palliative/hospice care at the end of life and this degree of ambiguity is unacceptable for providing ethical guidance."

The Netherlands legalised E&AS via the "Termination of Life on Request and Assisted Suicide (Review Procedures) Act"; how can any legislator justify considering legalising a practice if they can't bring themselves to describe it "with the greatest precision"?

That same CEJA report found that "physician-assisted suicide is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks."

We note a worrying trend of medically eligible people applying for E&AS in Canada not because of their conditions but because of a lack of support. Recent examples include:

- 54-year-old Amir Farsoud who hit the headlines in November 2022 when he applied for MAiD because he was in danger of losing his housing and feared being made homeless[7]
- Roger Foley, who recorded a hospital employee offering him a MAiD death, citing the financial cost of his care and being unwilling to provide the care package best suited to Mr Foley[8]
- Paralympian Christine Gauthier, who applied for financial support as a veteran and was told, "if you're so desperate, madam, we can offer you MAID, medical assistance in dying"[9]

At the heart of the debate on assisted suicide is a balancing of rights and responsibilities. The compatibility of the blanket ban on assisted suicide with the European Convention on Human Rights has been repeatedly tested in the highest courts. Lord Justice Sales, Mrs Justice Whipple and Mr Justice Garnham concluded in 2017 that:

> 'It is legitimate in this area for the legislature to seek to lay down clear and defensible standards in order to provide guidance for society, to avoid distressing and difficult

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[6] ama-assn.org/system/files/2019-05/a19-ceja2.pdf

[7] toronto.citynews.ca/2022/10/13/medical-assistance-death-maid-canada/

[8] dyingwell.co.uk/stories/roger-foley/

[9] independent.co.uk/news/world/americas/christine-gauthier-paralympian-euthanasia-canada-b2238319.html

> disputes at the end of life and to avoid creating a slippery slope leading to incremental expansion over time of the categories of people to whom similar assistance for suicide might have to [be] provided… we find that section 2 [of England & Wales’ Suicide Act, containing essentially the same provision as the Isle of Man’s] is compatible with the Article 8 rights [private and family life].’[10]

9. Do you think that there should be a limit on their life expectancy?

We decline to answer

10. Do you support the provision of assisted dying for someone who has a condition which causes unbearable suffering that cannot be alleviated by other means but which may not give a terminal diagnosis?

No

11. If they are unable to take oral medication should a health care professionally be permitted to administer medication intravenously to achieve death?

No

Eligibility

12. Do you agree that assisted dying should be available only to people over the age of 18 Years?

We decline to answer

13. Should they have to be permanent residents of the Isle of Man?

Yes

14. If you agree they should be permanent residents please state for how long.

We decline to answer

Process

15. Do you agree with the proposal that two different doctors should meet with the person independently and establish they are mentally competent to make an informed decision without pressure or coercion?

We decline to answer

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[10] carenotkilling.org.uk/articles/appeal-judges-dismiss-conway-bid/
judiciary.uk/wp-content/uploads/2017/10/r-conway-v-ssj-art-8-right-to-die-20171006.pdf

16. Should any health professional be able to conscientiously object to being part of an assisted dying programme?

Yes

17. Do you agree that if either doctor is unsure about the person’s capacity to request an assisted death, the person should be referred to a psychiatrist for a further capacity assessment?

Yes

18. Do you agree that the two doctors should ensure that the person has been fully informed of palliative, hospice and other treatment and care options?

Yes

19. Do you support the proposal that the person signs a written declaration of their request, which is witnessed and signed by both doctors?

We decline to answer

20. Do you agree that there should be a waiting period of 14 days from this time to the provision of life ending medication to allow the person to reconsider their decision?

We decline to answer

21. Do you feel that this period should be shortened to 7 days if the person is expected to die within 30 days?

No

22. Should the person themselves or a relative be able to collect the relevant medication from a designated pharmacist?

No

23. Should this be able to be stored securely in the person’s home until they decide whether they want to take it or not?

No

24. If they change their mind should the medication be returned to the pharmacy immediately?

We decline to answer

25. Should a health care professional be required to be with the patient once they have taken the medication until they are certified to have died?

We decline to answer

26. Should an annual report be produced regarding the number of people who have taken advantage of assisted dying, and be published?

Yes

27. Should it be possible to include the provision of assisted dying in a “living will” or advanced directive?

No

28. Do you have any comments on the process to provide Assisted Dying which will be included in the draft Bill

Eligibility (Qs 9, 10, 12, 13 & 14)

The Oregon model has been central to efforts to legalise assisted suicide across the British Isles: terminally ill, adult residents who doctors expect to die within six months. Disability rights campaigner Baroness Campbell of Surbiton, who is living with spinal muscular atrophy, has said of such proposals in Westminster:

> “The [present] law [in England & Wales[11], which was almost identical[12] to the offence contained within the Isle of Man’s Criminal Law Act 1981[13]] combines deterrence with discretion… [and] rests on a natural frontier. It rests on the principle that we do not involve ourselves in deliberately bringing about the deaths of other people. What the proponents of "assisted dying" want is to replace that clear and bright line with an arbitrary and permeable one… If terminal illness, why not chronic and progressive conditions? And, if chronic and progressive conditions, why not seriously disabled people? I am already on the list.”[14]

Without any amendment to Oregon’s statute, health officials now interpret the law as including chronically ill people who forego “administration of life-sustaining treatment”.[15] Recent annual reports have listed underlying illnesses including anorexia, arthritis, arteritis and complications from a fall.[16] Those same reports frequently show patients far exceeding[17] six months between approval and ingestion of the lethal drugs, and of course this doesn’t reflect how long they might have lived without doing so. Predicting life expectancy, especially many months from death, is imprecise: a 2017 UCL study found that over half (54%) of those predicted to die within a specified time period lived longer than expected.[18] (We have left Q9 blank, both because any answer

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[11] legislation.gov.uk/ukpga/Eliz2/9-10/60

[12] legislation.gov.uk/ukpga/1961/60/pdfs/ukpga_19610060_en.pdf

[13] legislation.gov.im/cms/images/LEGISLATION/PRINCIPAL/1981/1981-0020/CriminalLawAct1981_4.pdf

[14] telegraph.co.uk/comment/10717795/It-sends-a-shiver-down-my-spine.html

[15] carenotkilling.org.uk/articles/six-months-redefined/

[16] Oregon Death with Dignity Act Data Summary 2021, Footnote 3, Page 14. oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

[17] carenotkilling.org.uk/articles/longer-than-expected/

[18] carenotkilling.org.uk/articles/longer-than-expected/

implies support for the principle, and because even six months would be too unreliable a prognosis.)

It is important to note examples of compromises in the framing of assisted suicide legislation being accepted in the short term, and later pushed back against. One year after New Zealand's E&AS law came into effect, the politician who championed its passage, David Seymour, called for one of its defining "safeguards" – a six-month prognosis being required – to be excised[19].

If the Isle of Man breaks step with the rest of the British Isles, even with a minimum residency time requirement, additional dependent patients would likely be attracted to the island wanting the option of assisted suicide in the future, in which case there would be additional social and health costs and workload. While legislators must guard against "suicide tourism" and suicide migration – which is why we have answered "yes" to Q13 – it should be noted that just last year, the same campaign group which co-wrote Oregon's assisted suicide law forced the state, through the courts, to abandon its residency requirement[20], and is now engaged in similar action against Vermont[21].

Canada's law is not yet seven years old, and specialists[22] and parliamentarians there are considering expansion to "mature minors" – having already extended from terminal illnesses to chronic illnesses, and with a further extension to mental illnesses in 2023 only "temporarily" paused in December. Belgium extended its law to children in 2014 by primary legislation, but politicians in the Netherlands – where the current laws already apply to children as young as 12 – are considering a similar move by regulation. The Groningen Protocol in the Netherlands, applying to disabled infants, has never been written into law by the Dutch Parliament. Once euthanasia has become accepted medical practice, incremental extension to those who cannot give informed consent can occur without Parliamentary scrutiny. (We have left Q12 blank because while we oppose inclusion of minors in E&AS legislation, the wording of the question means that "yes" could be taken to indicate support for adult assisted suicide.)

While we do not support providing assisted suicide in response to *any* diagnosis, we have responded "no" to Q10 to emphasise the point that references to "unbearable suffering" are entirely subjective: how can doctors be expected to judge whether the suffering is at a degree to qualify for an assisted suicide? The Netherlands' law uses similar language, requiring that "there was no reasonable alternative solution for the situation in which he [the applicant] found himself."[23] This broad criterion has not only seen the numbers of deaths rise year on year, but has also seen the rate of increase accelerate (as explored further later in this submission.) Belgian law also uses the concept of 'unbearable' suffering. The number of deaths by euthanasia has risen over time in Belgium from just 24 in 2004 to 2,699 in 2021. The Belgian Federal Control Committee itself has stated: "the unbearable nature of the suffering is largely subjective and depends on the patient's personality, ideas and values."[24]

Baroness Campbell is right: the only clear, defensible, non-arbitrary line is to maintain the current law.

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[19] nzherald.co.nz/nz/euthanasia-laws-too-strict-and-should-be-relaxed-act-leader-david-seymour-says/AEC6XMXQRJG35CAAZ42KDU7Y5M/

[20] npr.org/2022/03/30/1089647368/oregon-physician-assisted-death-state-residents

[21] cbsnews.com/news/woman-sues-over-residency-requirement-for-assisted-suicide-vermont/

[22] carenotkilling.org.uk/articles/canada-plans-for-child-euthanasia/

[23] wetten.overheid.nl/BWBR0012410/2021-10-01/0

[24] Federal Control Committee, First Report, 2004, p.16

Conscience (Q16)

The World Medical Association is clear that doctors should not be required to participate in E&AS deaths and *"nor should any physician be obliged to make referral decisions to this end"*.[25] All proposals brought forward pay lip service to rights of conscience, but demands are invariably placed upon healthcare professionals (including doctors, nurses and pharmacists.)

Belgium passed a new law in 2020, prohibiting bans on euthanasia in institutional care settings and forcing doctors with conscientious objections to make "effective referrals" (to doctors willing to process E&AS requests).[26] Canada also requires effective referrals from objecting physicians, with judges there endorsing the assertions of Dying with Dignity Canada that:

> "If a doctor is unwilling to take the less onerous step of structuring their practice in a manner that ensures that their personal views do not stand in the way of [facilitating E&AS] … then the more onerous requirement of a transfer into a new specialty is a reasonable burden for that doctor to bear."[27]

What importance do MHKs place on conscience rights? What of the rights of patients in units not permitted to exclude assisted suicide? Do MHKs agree that it is better for doctors to leave their specialties, or medicine itself, than impede an assisted suicide? The Isle of Man has the same health and social care recruitment problems as England, with the additional difficulty of being an island which adds issues around relocation, especially when two in a household are both working.

It is worth remembering that BMA[28], RCP[29] and APM[30] surveys have all shown that doctors working in specialties closest to dying people – palliative medicine, geriatric medicine, respiratory medicine and general practice – are most opposed. A 2019 joint statement issued by the Canadian Hospice Palliative Care Association and Canadian Society of Palliative Care Physicians stated that:

> "MAiD [Medical Assistance in Dying – E&AS] is not part of hospice palliative care; it is not an "extension" of palliative care nor is it one of the tools "in the palliative care basket"… Hospice palliative care and MAiD substantially differ in multiple areas including in philosophy, intention and approach."[31]

Would funding be in question for homes and hospices which refused permission?[32] At least one hospice in Canada has lost funding owing to its unwillingness to provide euthanasia deaths on its premises, and a New Zealand judge has ruled that health authorities would be within their rights to consider willingness to permit E&AS when reviewing funding for hospices.[33]

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[25] wma.net/policy-tags/euthanasia/#:~:text=The%20WMA%20reiterates%20its%20strong,euthanasia%20and%20physician%2Dassisted%20suicide.

[26] ieb-eib.org/en/news/end-of-life/euthanasia-and-assisted-suicide/breaking-news-the-belgian-constitutional-court-rejects-the-appeal-relating-to-the-2020-law-on-euthanasia-2086.html?backto=search

[27] canlii.org/en/on/onca/doc/2019/2019onca393/2019onca393.html

[28] carenotkilling.org.uk/articles/bma-assisted-dying-poll-takeaways/

[29] carenotkilling.org.uk/articles/rcp-consultation-key-takeaways/

[30] apmonline.org/wp-content/uploads/2015/05/APM-survey-on-Assisted-Suicide-website.pdf

[31] cspcp.ca/wp-content/uploads/2019/11/CHPCA-and-CSPCP-Statement-on-HPC-and-MAiD-Final.pdf

[32] scoop.co.nz/stories/AK2006/S00673/euthanasia-referendum-threat-to-hospice-movement.htm

[33] toronto.citynews.ca/2020/02/25/b-c-hospice-loses-funding-after-refusing-to-provide-assistance-in-dying/

Isle of Man Hospice Chief Executive Anne Mills and Lead Clinician Dr Benjamin Harris have said that any change would also place medical and nursing staff in an "invidious position":

> "In providing care at the end of life we seek neither to hasten nor delay the time of death. This being the case we would regard it inappropriate for Hospice staff to take part in any assisted dying process, even if that were legalised on the Isle of Man."[34]

We urge MHKs to heed the warnings of Manx Duty of Care, a group of more than 50 Isle of Man-based health and social care workers.[35]

<u>Process (Qs 11, 15 & 17-27)</u>

Regarding <u>Q11</u>, the definition of the term "unable" (to take oral medication) could clearly be reinterpreted: physically incapable, physically difficult, emotionally difficult, nervous… If the principle of physician administration is accepted, it would be hard to justify denying the option to anyone deemed eligible, which would place a still greater demand on doctors. Canada's MAiD regime offers both E&AS, with 99% of participants opting for euthanasia. We are also aware of "combination" deaths in the Netherlands: euthanasia where assisted suicide has failed, a reminder of the complications which can arise.[36]

We note known difficulties with establishing mental capacity for decisions far less momentous than assisted suicide. Given question marks over how "independent" doctors can be from each other in reality, and also concerns over doctor-shopping, we have left <u>Q15</u> blank. In Oregon, doctor-shopping has become commonplace. Oregon Health Authority reports on assisted suicide show patients often being approved by doctors they have only known for a few days.[37] This impairs the ability to understand the patient and their illness, and to detect coercion, which can be subtle. Effectively detecting coercion is not something for which most doctors are trained, and the requirement to do so would increase pressure on service providers.

A survey in England and Wales conducted by the charity SafeLives found that on average, victims at high risk of serious harm or murder live with domestic abuse for 2-3 years before getting help. 85% of victims sought help five times on average from professionals in the year before they got effective help to stop the abuse.[38] How would subtle coercion be effectively detected, particularly in a shorter timeframe when the participating healthcare professionals may not know the patient well?

Regarding <u>Q17</u>, we would argue that *all* applicants should undergo such an assessment. Past-President of the Royal College of Psychiatrists Baroness Hollins has written[39] that assessing mental capacity:

> "isn't like checking the oil or water level in a car… [or] the sort of thing that can be done in a single consultation, especially if the decision in question – as it is in this case – is one with life-or-death consequences."

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[34] manxradio.com/news/isle-of-man-news/mhk-supports-public-conversation-over-assisted-dying/

[35] iomtoday.co.im/news/fifty-medics-get-together-to-say-we-dont-want-euthanasia-587309

[36] www.carenotkilling.org.uk/articles/assisted-dying-inhumane/

[37] carenotkilling.org.uk/articles/oregon-2021-anorexia-hernias-feeling-a-burden/

[38] SafeLives (2015), Insights Idva National Dataset 2013-14. Bristol: SafeLives. Available at: safelives.org.uk/policy-evidence/about-domestic-abuse#top%2010

[39] livinganddyingwell.org.uk/assisted-dying-bill-can-you-really-tell-if-someones-of-sound-and-settled-mind-for-suicide/

> “Researchers have found that some patients who have ended their lives under the terms of Oregon’s assisted suicide law had been suffering from clinical depression. Depression impairs decision-making capacity, it is common in elderly people and it is treatable. But in some cases in Oregon it has not been diagnosed by the doctor who assessed the patient’s capacity and prescribed lethal drugs. Oregon’s law requires referral for psychiatric examination in cases of doubt but in some cases that has not happened.”

There is merit, regarding Q18, in considering whether doctors should be required to see evidence of patients having *experienced* the holistic care that comes with hospice treatment, rather than simply having been “fully informed.”

The question does prompt another question, which featured in the recent consultation in Jersey and with which MHKs must grapple: could healthcare professionals raise the “option” of assisted suicide with patients, including those who had not raised it themselves?

Doctors are expected to inform patients of all available options, even if they have a conscientious objection to taking part, as per the GMC’s guidance[40]. A patient who expresses a wish to die needs a compassionate response and space to explore what that really means, since often it is not a genuine wish to die but an expression of another form of distress. However, a doctor who raises the issue of assisted suicide, may be perceived to be suggesting or recommending that as a course of action. Combined with the inevitable pressures of the cost of treatment and lack of resources, this may well lead to people seeking death by assisted suicide owing to external pressures.

Canada’s law states that no healthcare professional commits an offence “if they provide information to a person on the lawful provision of medical assistance in dying,” paving the way for a 2019 document issued by the Canadian Association of MAID Assessors and Providers which asserts that “physicians and nurse practitioners… involved in care planning and consent processes have a professional obligation to initiate a discussion about MAiD if a patient might be eligible for MAiD.”[41]

If assisted suicide became legal and a mandatory part of healthcare discussions, no person with an eligible illness would be able to avoid considering the “choice” on offer and may well feel a public duty to die in order to avoid being a burden on family, friends and care services. This is increasingly the case in Oregon with over 50% of those having an assisted suicide now regularly citing this reason for seeking death.[42]

How would financial considerations factor into the reality of legalised assisted suicide?

Prior to the expansion of Canada’s MAiD law beyond terminal illnesses, the Parliamentary Budget Office there produced a report which estimated that under the then-law, 6,465 people would die by MAiD in 2021 - 2.2% of all deaths - with net healthcare savings of $86.9m. The PBO expected amending the law to add 1,164 deaths to that figure in the first year alone, leading to increased healthcare savings in 2021 of $149m - almost £87m.

Earlier that same year (2020), the journal *Clinical Ethics* published a controversial paper in which ethicist David Shaw and health economist Alec Morton argued, per *The Times*, “that granting

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[40] gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/good-medical-practice/domain-3---communication-partnership-and-teamwork#paragraph-31

[41] nationalpost.com/news/canada/canada-maid-medical-aid-in-dying-consent-doctors

[42] More than 54% in 2021 oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Pages/ar-index.aspx

terminally-ill patients help to die would save money and potentially release organs for transplant."[43]

Without wishing to indicate reassurance by anything less formal, we have left Q19 (and Q20) blank so as not to endorse legalisation of assisted suicide.

Regarding Q21, we have answered "no" to emphasise that such waiting times are vulnerable to later relaxation of any law: Oregon's Death with Dignity Act was amended in 2019 to allow the waiving of a 15-day waiting period.[44]

Regarding Q22, allowing lethal unregulated doses of drugs to circulate in the community unmonitored and without being certain of the destination would be dangerous; questions arise over conscience rights for pharmacists. Regarding Q23 & Q24, we note that the presence of lethal unregulated doses of drugs in people's homes is dangerous.

We have left Q25, concerning presence at assisted suicide deaths, blank, conscious of the moral, ethical and practical burden this would place on healthcare professionals. MHKs must address the growing body of research on complications in E&AS. Research published in the journal *Anaesthesia* suggested that a relatively high incidence of vomiting, prolongation of death and reawakening from coma could render such deaths "inhumane,"[45] while Dr Joel Zivot, writing in the *Spectator*, has observed that often, "paralytic drugs are used [in euthanasia]. These drugs, given in high enough doses, mean that a patient cannot move a muscle, cannot express any outward or visible sign of pain. But that doesn't mean that he or she is free from suffering."[46]

We have answered "yes" to Q26, and take this opportunity to argue that advocates must not be allowed to leave the details of review procedures and the intended contents of annual reports to later regulations: the plans must be open to scrutiny before *any* further legislative steps are taken.

Where E&AS are legalised, the numbers of deaths tend to rise annually. E&AS accounted for at least 4.5% of Dutch deaths in 2021 (up from 4.1% in 2020[47]), and at least 3.3% of Canadian deaths in 2021 (up from 2.5% in 2020 and 2.0% in 2019[48]). Such laws are necessarily founded on arbitrary limits, which are breached with relative impunity, reinterpreted or expanded.

In 2013 in Belgium, 1.7% of all deaths were of physician-administered euthanasia without the explicit consent of the patient, representing over 1,000 deaths that year.[49] Similarly in 2010 in one survey in Belgium, 50% of nurses involved in administering euthanasia admitted to cases where no consent was obtained.[50]

Regulation of E&AS relies on consistent and independent reporting in order to be meaningful. The European Court of Human Rights' ruling[51] in the case of Tom Mortier illustrates the difficulties of developing a robust system of post-mortem review. Tom's mother was Godelieva de Troyer, a Belgian woman with long-term depression who was euthanised without the support of her

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[43] carenotkilling.org.uk/articles/widening-canadas-euthanasia-law-set-to-save-149m/
[44] oregonlive.com/politics/2019/07/new-law-shortens-death-with-dignity-waiting-period-for-some-patients.html
[45] carenotkilling.org.uk/articles/assisted-dying-inhumane/
[46] spectator.co.uk/article/last-rights-assisted-suicide-is-neither-painless-nor-dignified/
[47] euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2021/maart/31/jaarverslag-2021
[48] canada.ca/en/health-canada/services/medical-assistance-dying/annual-report-2021.html#a3.2
[49] lozierinstitute.org/study-more-than-1000-deaths-hastened-without-patients-explicit-request-in-belgium/
[50] dailymail.co.uk/news/article-1285423/Half-Belgiums-euthanasia-nurses-admit-killing-consent.html
[51] adfinternational.org/tom-mortier-ruling/

psychiatrist by the co-chair of the euthanasia review body, to whose pro-euthanasia organisation she had donated money, with her son only finding out the day after she had died.[52]

Reporting deficiencies are widespread. The Disability Rights Education & Defense Fund tells us that:

> "Oregon's annual reports on their assisted suicide statistics, highly praised by proponents as informative, actually tell us very little. Available data is quite minimal and there is no real oversight, investigation of abuse, enforcement, penalties for non-compliance, nor monitoring."[53]

Worthington, Regnard, Sleeman and Finlay published "the first study to compare the reporting on assisted suicide and euthanasia across all jurisdictions where it is legal" in *BMJ Supportive & Palliative Care* in December 2022. They found that:

> "All of the information included within the reports is self-reported retrospectively by the prescribing clinician. Analyses from Belgium and the Netherlands, where review processes are established, have shown that 48% of assisted deaths in Belgium and one in five of such deaths in the Netherlands are not reported, and in some cases legal requirements are not followed."[54]

The *official* figures cited a few paragraphs ago – E&AS as a proportion of all deaths – should be read with this under-reporting in mind.

Given (Q27) the openness of proponents (as demonstrated by Qs 10 & 11) to E&AS for broader categories of people, it is important to remember the significance of dementia as a terminal illness. The Netherlands permits euthanasia for patients on the basis of mental illness and dementia (115 and 215 deaths respectively in 2021[55]). A Dutch woman with dementia was restrained by her family to allow a doctor to euthanise her in line with an advance directive.[56] When the doctor and the family sought to conduct the euthanasia procedure, the patient resisted and said no three times. The doctor put a sedative in the patient's coffee and she was held down by her son-in-law whilst the doctor administered the lethal drugs to end her life. At a subsequent trial, the doctor was acquitted and later the Supreme Court of the Netherlands confirmed that doctors acting in this way is compatible with the Dutch euthanasia law. The courts ruled that the doctor "did not have to verify the current desire to die."[57]

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[52] adfinternational.org/tom-mortier/

[53] dredf.org/public-policy/assisted-suicide/oregon-so-called-safeguards-and-minimal-data/

[54] Worthington A, Regnard C, Sleeman KE, et alComparison of official reporting on assisted suicide and euthanasia across jurisdictionsBMJ Supportive & Palliative Care Published Online First: 30 December 2022. doi: 10.1136/spcare-2022-003944

[55] euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2021/maart/31/jaarverslag-2021

[56] bbc.co.uk/news/world-europe-52367644

[57] apnews.com/article/europe-health-courts-dementia-euthanasia-1ed45f0819e788708da51d161b48e9f8
apnews.com/article/a041563e55204279bfb8e335a19c2802

Isle of Man Assisted Dying Bill Consultation

1. What is your name?

Name **Professor David Albert Jones**

2. What is your email address?

[Redacted]

3. Are you responding on behalf of an organisation?

[✓ Yes] / No

4. If you answered "yes" to the previous question please state which organisation

Organisation **The Anscombe Bioethics Centre**

5. Are you responding as an individual or a group?

[✓ Individual] / Group

6. Are you resident on the Isle of Man?

Yes / [✓ No]

7. May we publish your response?

[✓ Yes, you can publish my response in full]

Yes, you may publish my response anonymously

No, please do not publish my response

8. In principle, do you agree or disagree that assisted dying should be permitted for terminally ill adults on the Isle of Man?

Agree / [✓ Disagree] / Not Sure

Please explain the reasons for your response

By 'assisted dying' is generally meant either physician-assisted suicide or euthanasia or both, see our briefing paper on definitions https://www.bioethics.org.uk/research/euthanasia-assisted-suicide-papers/defining-the-terms-of-the-debate-euthanasia-and-euphemism-professor-david-albert-jones/ The Parliamentary Office of Science and Technology, in Westminster, has completed a briefing paper which may be of use to the Tynwald. It defines 'assisted dying' as an umbrella term covering both physician-assisted suicide and euthanasia. https://researchbriefings.files.parliament.uk/documents/POST-PB-0047/POST-PB-0047.pdf

Physician-assisted suicide and euthanasia involve intentional ending of life by, or with the assistance of, a doctor. This is fundamentally different from ordinary medical care and from palliative care. It represents a radical departure from the traditional ethic of medicine which allows the taking of risks and acceptance of side effects, and allows treatment to be withdrawn when it is no longer effective or is doing more harm than good, but never allows doctors to aim to kill their patients. Killing is controversial even in warfare and in policing, and while it may be permitted against enemy combatants or violent criminals it is never permitted against the innocent. The World Medical

Association, which represents 116 medical associations world-wide including the British Medical Association, has strongly urged that:

"No physician should be forced to participate in euthanasia or assisted suicide, nor should any physician be obliged to make referral decisions to this end."

https://www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/

If doctors are permitted to end the lives of their patients, or to give patients the means to commit suicide rather than seeking to prevent suicide, then further harms will follow inevitably. Those countries that have legalised physician assisted suicide or euthanasia have seen large increases in assisted deaths. Between 2010 and 2019 officially reported assisted deaths increased in the Netherlands by 103%, in Belgium by 167%, in Oregon by 189% and in Switzerland by 427%. Canada, which only legalised euthanasia in 2016 now has more than 10,000 deaths a year. For sources of these data see the Centre's Evidence Guide

https://www.bioethics.org.uk/research/all-research-papers/euthanasia-and-assisted-suicide-a-guide-to-the-evidence/

The most commonly reason cited for seeking assisted death is not fear of pain or other physical symptoms but loss of the ability to engage in enjoyable activities. In Oregon, a majority (54% in 2021), cite fear of becoming a 'burden on family, friends/caregivers' as a reason for seeking death. In Canada this reason is cited by more than a third and one-in-six cite 'isolation or loneliness'.

There have been four studies published in 2022 on the impact of physician-assisted suicide or euthanasia on rates of self-initiated death and on suicide rates. All show large increases in self-initiated death. Unassisted suicide also increases. Legalisation of euthanasia or assisted suicide is a threat to suicide prevention.

https://www.bioethics.org.uk/research/euthanasia-assisted-suicide-papers/suicide-prevention-does-legalising-assisted-suicide-make-things-better-or-worse-professor-david-albert-jones/

There is also clear evidence that killing without request or consent is widespread in the Netherlands and Belgium with hundreds of such deaths a year. The Irish case of Fleming v. Ireland [2013] (para 104) raised the concern that the number of assisted deaths without explicit request remains 'strikingly high' in the Low Countries. This was cited in as a reason to keep the present law. Since 2013 there has been more evidence of intentional ending of life by doctors even without the consent of the patient. In Belgium, for example, this is increasingly done by 'terminal sedation'. For these and other dangers see

https://www.bioethics.org.uk/research/euthanasia-assisted-suicide-papers/voluntary-euthanasia-physician-assisted-suicide-the-two-slippery-slope-arguments-prof-john-keown/

In summary there is ample evidence that changing the law of assisted suicide and/or on homicide with consent leads to real world harms. The rationale of the practice creates a pressure that pushes towards further expansion: first to those with non-terminal conditions; then to those with mental health conditions; and finally to those who have not asked for death. More people come to seek death because they feel they are a burden to others and more end their lives whether by assisted or unassisted suicide. If such laws are passed then some people will have their lives ended reluctantly or even without their consent and some will die by unassisted suicide who might have lived.

9. Do you think that there should be a limit on their life expectancy?

6 months / 12 months / Longer / Not Sure

Not Answered

10. Do you support the provision of assisted dying for someone who has a condition which causes unbearable suffering that cannot be alleviated by other means but which may not give a terminal diagnosis?

Yes / [✓ No] / Not Sure

11. If they are unable to take oral medication should a health care professionally be permitted to administer medication intravenously to achieve death?

Yes / [✓ No] / Not Sure

12. Do you agree that assisted dying should be available only to people over the age of 18 Years?

Yes / No / Not Sure

Not Answered

13. Should they have to be permanent residents of the Isle of Man?

Yes / No / Not Sure

Not Answered

14. If you agree they should be permanent residents please state for how long.

For over 1 year / For over 5 years / Other

Not Answered

15. Do you agree with the proposal that two different doctors should meet with the person independently and establish they are mentally competent to make an informed decision without pressure or coercion?

Yes / No / Not Sure

Not Answered

16. Should any health professional be able to conscientiously object to being part of an assisted dying programme?

[✓ Yes] / No / Not Sure

17. Do you agree that if either doctor is unsure about the person's capacity to request an assisted death, the person should be referred to a psychiatrist for a further capacity assessment?

Yes / No / Not Sure

Not Answered

18. Do you agree that the two doctors should ensure that the person has been fully informed of palliative, hospice and other treatment and care options?

[✓ Yes] / No / Not Sure

19. Do you support the proposal that the person signs a written declaration of their request, which is witnessed and signed by both doctors?

Yes / No / Not Sure

Not Answered

20. Do you agree that there should be a waiting period of 14 days from this time to the provision of life-ending medication to allow the person to reconsider their decision?

Yes / No / Not Sure

Not Answered

21. Do you feel that this period should be shortened to 7 days if the person is expected to die within 30 days?

Yes / No / Not Sure

Not Answered

22. Should the person themselves or a relative be able to collect the relevant medication from a designated pharmacist?

Yes / [✓ No] / Not Sure

23. Should this be able to be stored securely in the person's home until they decide whether they want to take it or not?

Yes / [✓ No] / Not Sure

24. If they change their mind should the medication be returned to the pharmacy immediately?

Yes / No / Not Sure

Not Answered

25. Should a health care professional be required to be with the patient once they have taken the medication until they are certified to have died?

Yes / No / Not Sure

Not Answered

26. Should an annual report be produced regarding the number of people who have taken advantage of assisted dying, and be published?

Yes / No / Not Sure

Not Answered

27. Should it be possible to include the provision of assisted dying in a "living will" or advanced directive?

Yes / [✓ No] / Not Sure

28. Do you have any comments on the process to provide Assisted Dying which will be included in the draft Bill

Any other comments __________

While the Centre is based in Oxford, and the director is resident in England the Centre covers the British Isles, including England, Wales, Scotland, Northern Ireland, the Republic of Ireland and the Isle of Man.

Many of the ‘Yes/ No’ questions in this consultation have been skipped. This is not because the questions have not been considered but because those questions seem to presuppose that there would be a law, whereas this submission argues that such a law should not be enacted as it would be harmful.

It should not be assumed, however, that the skipping of these questions implies approval for the most dangerous options, for example, for physician-assisted suicide and/or euthanasia for minors (question 12) or for those who might lack of capacity (question 17) or approval for the Isle of Man becoming a centre for suicide tourism (question 13).

If, despite these dangers, legislation moves forward in the House of Keys then Members should seek to limit the danger by restrictions such as age, residence and the nature of the person’s condition. However, the idea that these restrictions constitute ‘safeguards’ is naïve. It first of all ignores the fact that in all jurisdictions with such laws the practice expands beyond the law and doctors are rarely if ever prosecuted. It also ignores the reality that in most if not all jurisdictions with such laws, the laws have already been extended, either by court cases or by tabling amendments. For example in Canada it was at first restricted to the terminally ill but this was extended to those with chronic illness, and in Oregon it was at first restricted to residents but this has been extended to non-residents and in Belgium euthanasia was restricted to adults but now it has been extended to children (without any lower age limit).

Once the major barrier to intentional ending of life is removed, then the minor restrictions put in place are much easier to amend. These restrictions are not based on a long history or a deep and clear principle but are recent provisions based on pragmatic arguments. The proposed restrictions will not prevent future expansion and future abuse. The key question is thus the principle of the legislation and the principle should be judged as though the law had no ‘safeguards’ because the experience of other jurisdictions is that, as soon as they are found to be inconvenient, these restrictions are removed. If euthanasia or physician-assisted dying is legalised then there will be no stopping its expansion. If you blow up the dam then the waters will not be held in place by a few sand bags further down stream.

Consultation: Assisted Dying in the Isle of Man

by email to privatemembersbill@tynwald.org.im

Introduction

1. CARE (Christian Action Research and Education) is a well-established mainstream charity providing resources and Christian insight and experience to matters of public policy and practical caring initiatives. We have supporters resident on the Isle of Man, and give permission for this response to be published in full (Question 7).

Question 8

2. CARE believes the law should not change to allow any 'assisted dying' measures for any patient.

3. CARE's guiding principle is that we affirm the inherent value of every human life – regardless of age; physical, mental or emotional health; or disability. A principle recognised during the pandemic when the elderly and infirm were prioritised for vaccination and protection. This principle is undermined by legislation that permits the terminally ill (or others) to end their lives prematurely.

4. Physician assisted suicide (PAS) and euthanasia are not private acts. They involve a person(s) bringing about the death of another. The societal implications of such a law change have serious implications. We agree with the 1999 Council of Europe Recommendation that "*recognising that a terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person … (and) cannot of itself constitute a legal justification to carry out actions intended to bring about death*".[1]

5. Furthermore, we believe the law should not be changed for at least the following reasons:

The proposal assumes there are no ethical difficulties

6. To allow any form of medical suicide would:
    6.1. Undermine and corrupt the fundamental ethic and principle prohibiting intentional killing or ending of life, sometimes expressed as the *"right not to be intentionally killed (which should be) enjoyed regardless of inability or disability"*[2];
    6.2. endorse the belief that certain lives are no longer worth living; and
    6.3. radically alter the role of doctors by undermining the first "do no harm" principles of both the traditional Hippocratic Oath, the Declaration of Geneva,[3] and the World Medical Association's Declaration on Euthanasia and Physician-Assisted Suicide.[4]

7. CARE believes that medical professionals should not be involved in assisting someone to end their life; nor should anyone else. The current law does not restrict open or honest conversations, it restricts doctors from suggesting to a patient that they may be better off dead, or a patient inferring the same. Those struggling with depression rely on doctors to dissuade them from suicidal thoughts; rather than going to see their doctor with the possibility that their suicidal thoughts may be affirmed.

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[1] Council of Europe Recommendation 1418 (1999), Protection of the human rights and dignity of the terminally ill and the dying. Para 9.3.2 and 9.3.3

[2] Keown J, The Legal Revolution: From "Sanctity of Life" to "Quality of Life" and "Autonomy", *Journal of Contemporary Health Law & Policy*, Vol 14: 2, 1998

[3] Declaration of Geneva, 1948 (Revised most recently in 2017) https://www.wma.net/policies-post/wma-declaration-of-geneva/

[4] WMA Declaration on Euthanasia and Physician-Assisted Suicide, 2019 https://www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/

8. Furthermore, if we enshrine in law the principle that a person should have control over the manner and timing of their death, why should that not be extended to the person suffering from a devastating mental illness? Or someone simply tired of life? If the personal autonomy argument forms the basis for legislative change, it would unavoidably open the door to incremental extension of the law.

The proposal assumes there are no difficulties in prognosis

9. The difficulties of determining prognosis are well documented even for those with specialist knowledge:
    9.1. At the start of the Oregon Act, 1 in 4 doctors were not confident in determining 6-month life expectancy.[5] Those who die from the prescribed drugs in Oregon are judged likely to die within six months. In 2021, the range of days from first request to death was 0 to 1095 days (3 years). Prior to 2020, the range has been 15 to 1503 days (4.12 years). Since the Act was enacted, 4% of participants have outlived their prognosis.[6]
    9.2. A 2022 Australian article said, "*Modern medicine … has not made predicting the life expectancy of an individual any easier…..The reality of such predictions is that it is simply impossible to know with certainty how much longer a complex system like a human can continue to function, but someone has to make the call.*"[7] Another Australian journal article said, "*We predict that many doctors will find it difficult to answer whether they expect individual patients to die within 6 months….Assessing a person's eligibility for VAD is difficult because prognostication is difficult, prognosis is inherently uncertain...*"[8]
    9.3. In July 2013 Lady Neuberger's independent review of the Liverpool Care Pathway underscored the problems of prognoses of death even within 48 hours saying, '*diagnosing imminent death is a far more imprecise science than people realise. And accurate prediction in non-cancer patients is particularly difficult. There are no precise ways of telling accurately when a patient is in the last days of life*'.[9]

10. We are further concerned that there can be no clear definition related to an "incurable physical medical condition" which is leading to "unbearable suffering" since the definition of "unbearable suffering" and what is "deemed tolerable" are exceptionally difficult. The Western Australia Guidance recognises, "*Suffering is a subjective experience.*"[10] Tasmania's law has come into effect and includes expected suffering that *"might arise"*.[11]

11. Canada's law allows assisted dying for non-terminal conditions and there have been multiple articles raising concerns about individuals with non-terminal conditions choosing an assisted death because there are health and social care needs have not been met (as referred to above). In May 2022, the Canadian Human Rights Commission said, "*Medical Assistance in Dying is intended to allow people the ability to die with dignity when science and medicine can offer no better alternative to alleviate unbearable suffering. Leaving people to make this choice because the state is failing to fulfil their fundamental human rights is unacceptable…In an era where we recognize the right to die with dignity, we must do more to guarantee the right to live with dignity.*"[12]

The proposal assumes death will be peaceful

12. Assisted dying is frequently portrayed as a peaceful option amid suffering. However, the evidence is clear that taking these lethal drugs is not always associated with a peaceful, dignified death but can result in complications including regurgitation of the medicine, regaining consciousness and seizures; and that death

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[5] Ganzini L, Nelson HD, Lee MA et al, Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Death with Dignity Act, *Journal of the American Medical Association*, 2001, 285(18), 2363-2369

[6] Oregon Death with Dignity Act Report 2021, Table 1, page 14

[7] Life expectancy: questions to ask yourself, 10 October 2022, Insight Plus.

[8] Nahm, HS, Stockler MR, Keily BE, Voluntary assisted dying: estimating life expectancy to determine eligibility, Med J Aust 2022; 217 (4): 178-179, doi: 10.5694/mja2.51648, Published online 25 July 2022

[9] More Care, Less Pathway, A Review of the Liverpool Care Pathway, 2013, page 19

[10] Western Australian Voluntary Assisted Dying Guidelines, Western Australia, Dept of Health, 2022, para 8.2.5, page 36

[11] Section 14, https://www.legislation.tas.gov.au/view/whole/html/asmade/act-2021-001

[12] MAiD cannot be an answer to systemic inequality, Canadian Human Rights Commission, 10 May 2022

can take a long time, up to 3 or 4 days in some cases.[13] A 2018 journal article reported on the experience of a caregiver who was advised by the patient's doctor to give the patient all the morphine in the house after a delayed death during which time the patient stopped breathing twice and turned purple.[14] One person ingested lethal medication intended for another.[15] Research conducted in the Netherlands showed that in 114 cases of assisted suicide, complications occurred in 7% of cases – such as vomiting the drugs – and problems with completion occurred in 16% of cases (a longer time to death; failure to induce coma or the patient regaining consciousness). [16]

The proposal assumes the law will not be extended beyond the terminally ill

13. Assisted suicide is always proposed, in whatever jurisdiction, in the context of 'rigorous safeguards' to prevent abuses but the international evidence is very clear that where assisted suicide has been available for some time these safeguards are always challenged and usually eroded. The original safeguards in place in Belgium[17] and the Netherlands[18] for example have been substantially eroded.

14. Canada is a Commonwealth country which has demonstrated both changes in scope and pressure on individuals to choose an assisted death.
    14.1. In June 2016 their law came into effect allowing patients to receive "MAID" (Medical Assistance in Dying) when death was "*reasonably foreseeable*".[19]
    14.2. In September 2019 a court deemed this criterion "*too restrictive*";[20] and was supported by the Canadian Government, giving credence to the view that restricting access to a legalised 'right' to assisted suicide only to terminally ill people was discriminatory.[21]
    14.3. In 2021, a further Bill passed which enables people who are not terminally ill to die by MAID and permits administration of lethal drugs to someone incapable of consenting if they had previously been approved for assisted death; as well as provisionally allowing MAID for someone experiencing mental illness[22] (although implementation of this has been delayed).[23]
    14.4. In July 2022, the latest annual report revealed a 32.4% increase in deaths from 2020 (7,603) to 2021 (10,064); 3.3% of all deaths in Canada.[24] In comparison, in California, similar in population size to Canada, 486 people died in 2021 under the PAS legislation for terminal illness.[25]
    14.5. Articles, including from the *Spectator* and the *Lancet*, are reporting that Canadians who meet the medical eligibility for MAID, are choosing MAID because of poverty or lack of support.[26] [27]
    14.6. Campaigners are seeking extension of MAID to "mature minors"[28] and potentially to younger children too.[29]

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[13] Oregon Death with Dignity Annual; Reports 1998-2019, quoting data from 2010, 2007, 2009, 2015-2020, and 2021 pages 14 and 17
Washington Death with Dignity Annual Reports 2009-2018, including 2018 Table 4, page 13. Complications and length of time to death were not reported for 2019 and 2020

[14] Buchbinder M et al, Caregivers' Experiences With Medical Aid-In-Dying in Vermont: A Qualitative Study, Journal of Pain and Symptom Management, December 2018, Vol 56(6), pages 936-943, Tables 2 and 5 and page 940

[15] https://www.jems.com/patient-care/death-with-dignity-when-the-medical-aid-in-dying-cocktail-gets-into-the-wrong-hands/ 29 November 2022

[16] Groenewoud JH et al, Clinical problems with the performance of Euthanasia and Physician –Assisted Suicide in the Netherlands, *New England Journal of Medicine*, Volume 342, Number 8, Feb 2000, Pages 551-556
http://www.nejm.org/doi/pdf/10.1056/NEJM200002243420805

[17] Belgium approves assisted suicide for minors, *Deutsche Welle News*, 13 February 2014 http://www.dw.com/en/belgium-approves-assisted-suicide-for-minors/a-17429423

[18] Jotkowitz A, Glick S, The Groningen Protocol: another perspective, *Journal of Medical Ethics*, Mar 2006, 32(3): 157-8
http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2564470

[19] https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent

[20] The Court's ruling comes into effect on 11 March 2020. Truchon c. Procureur 3eneral du Canada, 2019 QCCS 3792

[21] See also Sleeman K, Chalmers I. Assisted dying: restricting access to people with fewer than six months to live is discriminatory *BMJ* 2019; 367 :l6093 doi:10.1136/bmj.l6093

[22] Bill C-7, An Act to Amend the Criminal Code (Medical Assistance in Dying), Second Session, Forty-third Parliament, 17 March 2021

[23] https://www.theglobeandmail.com/canada/article-maid-expansion-delay-mental-disorders/

[24] Third Annual Report on Medical Assistance in Dying in Canada 2021, July 2022, pages 5 and 18

[25] California End of Life Option Act 2021 Data Report

[26] https://www.spectator.co.uk/article/why-is-canada-euthanising-the-poor- 30 April 2022
Webster P, Worries grow about medically assisted dying in Canada, The Lancet, Vol 400, 10 September 2022, pages 801-2

[27] Alexander Raikin, "No Other Options," The New Atlantis, Number 71, Winter 2023, December 16, 2022

[28] https://www.dyingwithdignity.ca/blog/pr_mature_minors/ 15 Sept 2021

[29] https://nationalpost.com/news/quebec-college-of-physicians-slammed-for-suggesting-maid-for-severely-ill-newborns

15. In the US states where access to PAS only is restricted to terminal illness, Bills are being debated/passed to ensure "*barriers*" (previously termed 'safeguards') are removed, including changing residency requirements, telemedicine, elimination of waiting periods, allowing nurses to prescribe lethal drugs, and changes in the freedom of conscience provisions.[30] [31]

16. In August 2022, in California, the most populous US state and an economy larger than many countries, a new campaign began to allow individuals with non-terminal illnesses to use the end-of-life law.[32] In November 2022, on the anniversary of the New Zealand law coming into effect, the author of the Bill called for the law to be extended beyond individuals with a terminal illness.[33]

The proposal assumes there will be no impact on the disabled

17. Baroness Campbell of Surbiton said "*the distinction between disability and terminal illness is a false one… The disabled person dependant on a ventilator is terminally ill if the ventilator is switched off… I am fearful that any change to the current law prohibiting assisted suicide may adversely affect how I, other disabled friends and the wider community of disabled people are treated in the future*".[34] CARE believes this Bill would be a regressive rather than progressive move which is likely to entrench a negative view of disability and the elderly, as has been demonstrated in Canada.

The proposal assumes there will be no conflict with a suicide prevention focus

18. Introducing a medicalised regime for certain suicides risks dismantling a protective factor against suicides more widely – the wholesale societal rejection of suicide as a tragic act. The timing of this renewed push for policy change is particularly inappropriate given that policies to prevent suicide have been a priority in light of "*broader social implications of the pandemic*".[35] Where "assisted dying" is legal, there is an increase in the total suicide rate (excluding those who might use the legislation), possibly because of "*a reduction in societal taboos associated with suicide*"[36] and "*no evidence that [a change in the law] would be beneficial in relation to suicide prevention overall.*"[37]

The proposal assumes 'choice' will not become an obligation

19. For others struggling to access high quality health or social care, it may seem to be the only choice open to them. There is a huge risk that this lack of choice combined with the provision of a state sanctioned/state regulated assisted dying regime will result in some patients reluctantly opting for an assisted death when they would have preferred to live their life to completion with appropriate symptom management.

    19.1. The Nuffield Trust has stated that "*the cost of hospital care at the end of life is substantial*".[38] The cost of an adult staying in a UK hospital specialist palliative care is estimated at £447 per day.[39] The Sue Ryder website states that inpatient hospice care costs £500 per day and a hospice nurse £3,000 a month.[40] In 2017, the cost of drugs for the Canadian Medical Assistance in Dying (MAID) was

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[30] In Oregon as of 2020, there is an exemption to the requirement to have a cooling off period of 15 days if the patient is expected to live for fewer than 15 days from the time of the first oral request for medication See 127.840 s.3.06. In 2023, there are expected to be changes in residency requirements after a court case dismissed the residency requirement. Written and oral requests; In Washington – debated but not passed SHB 2419 and HB1141. Plans are being made to bring these back in 2023. In California in effect from 1 Jan 2022 Text as amended from Bill SB-380 End of Life; In Vermont in effect from 27 April 2022 from S74; In Hawaii HB1823 not passed. In California, https://broadenchoice.org/our-proposed-changes

[31] Concerns about the balance between safety and access are raised in McDougall R, Pratt B, Too much safety? Safeguards and equal access in the context of voluntary assisted dying legislation, *BMC Med Ethics* 21, 38 (2020)

[32] https://medicalfutility.blogspot.com/2022/08/broadening-end-of-life-choices-in.html; https://broadenchoice.org/our-proposed-changes

[33] https://www.nzherald.co.nz/nz/euthanasia-laws-too-strict-and-should-be-relaxed-act-leader-david-seymour-says/AEC6XMXQRJG35CAAZ42KDU7Y5M/ 6 November 2022

[34] Campbell, J, 'Disabled people like me fear legal assisted suicide: it suggests that some lives are less worth living', British Medical Journal, 6 February 2019

[35] Preventing suicide in England: Fifth progress report of the cross government outcomes strategy to save lives, HM Government, March 2021, para 4.1

[36] Girma S, Paton D, Assisted suicide laws increase suicide rates, especially among women, Vox EU, 29 April 2022

[37] Jones DA, Euthanasia, Assisted Suicide and Suicide Rates in Europe, *Journal of Ethics in Mental Health*, Open Volume 11, February 2022

[38] The Nuffield Trust, 'Exploring the cost of care at the end of life' September 2014, page 17

[39] Curtis, Lesley A. and Burns, Amanda (2020) Unit Costs of Health & Social Care 2020. PSSRU, University of Kent, page 87. Translates to £3,129 per week

[40] https://www.sueryder.org/support-us/make-a-donation/how-we-spend-your-donations Accessed 4 October 2021

estimated to be between CAD$25.40-$326 (£15.57-£199.87).[41] [42] Figures published in Canada in 2020 for the reduction in health care costs under the Canadian MAID regime estimated that for 2021 alone it would equate to CAD$149m (£91.35) and a reduction of 0.08% in health care budgets.[43] [44]

20. CARE believes that the pressure will be subtle but difficult to resist: the choice to die will be seen by some as a duty. Data from Washington and Oregon highlights the number of people who cited being a "burden on family, friends/caregivers" as one of their reasons for choosing to due. In Canada in 2021, 35.7% cited being a burden and 17.3% said isolation or loneliness was a factor in their decision.[45] Research on cancer patients in England *"shows that self-perceived burden affects patients' well-being…associated with hopelessness and depression…in end-of-life care situations has been found to underlie…request for euthanasia"*.[46]

Year	**Oregon**[47]	**Washington**[48]
2019	59%	57.6%
2020	53.1%	58.6%
2021	54.2%	56%

Table: End of life concerns of participants who died: "burden on family, friends/caregivers"

21. Marie Curie reports on another pressure: that "*being diagnosed with a terminal illness and reaching the end of life increases a person's risk of falling below the poverty line. Even those who were previously getting by can be forced into poverty, when they are already at the most vulnerable time in their lives, by the financial impact of a terminal illness.*"[49] This could lead to a person choosing an assisted death for financial reasons.

22. It would be an extraordinarily difficult task for a doctor or tribunal to ensure that someone choosing to end their life would be doing so voluntarily. For this reason, we believe that there is no legal protection, beyond the current law which makes it an offence to assist suicide, that could prevent coercion. Instead, the "*self-perceived burden by patients and its detrimental consequences will need to be addressed by better support for family carers and better home care.*"[50]

The proposal is put forward when there is a short fall in palliative care and other choices

23. The Isle of Man has an ageing population. In fact, the Isle of Man Government's 2020 'Review of Aging Population Report' noted that the population is aging more rapidly than anticipated in previous reports, with the latest data from 2016 showing 20.7% of the population is aged over 64.[51] Of note, whilst identifying the challenges of living with an aging population, the foreword affirms the importance of *"avoid(ing) the pitfalls that debates around ageing populations often fall into, as happened in the past, that our elderly are a burden on our economy. In a range of ways, the opposite is true, with our older people benefiting the Island greatly, from caring for grandchildren so that many of us can go to work, volunteering within our local community or providing care to keep people in their homes for longer."*[52]

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[41] Trachtenberg AJ, Manns B, Cost analysis of medical assistance in dying in Canada, CMAJ, 2017 Jan 23;189(3):E101-E105. Figures referred to are in Table 1 doi: 10.1503/cmaj.160650

[42] Using Financial Times currency conversation rate of 1 CAD=0.6131 GBP of as 11 January 2023

[43] Cost Estimate for Bill C-7 "Medical Assistance In Dying", Office of the Parliamentary Budge Officer, 20 October 2020, Tables 1 and 2, pages 1 and 2

[44] Based on 2021 data, the population of Canada is less than two thirds of the population of England and Wales see data from the ONS (mid-year population for England and Wales was 59,641,829) and Statistics Canada as of July 1 2022 was 38,226,498.

[45] Third Annual Report, *Op Cit,* Chart 4.3, page 26

[46] Bausewein et al, 'Burden to others' as a public concern in advanced cancer: a comparative study in seven European countries BMC Cancer 2013, 13:105 http://www.bIsle of Manedcentral.com/content/pdf/1471-2407-13-105.pdf

[47] Oregon Death with Dignity Act Annual Reports

[48] Washington Death with Dignity Act Annual Reports, Table 3 for 2019 and 2020, Table 2 for 2021 (Note: there are two Table 1 in 2021)

[49] Dying in poverty, Exploring poverty at the end of life in the UK, Marie Curie, May 2022, page 4

[50] Bausewein et al, 'Burden to others' as a public concern in advanced cancer, *Op Cit*

[51] Review of Aging Population Report, Economic Affairs (Cabinet Office), Isle of Man Government, October 2020, page 4

[52] Review of Aging Population Report, *Op Cit*, page 2

24. Health and social care policy must provide appropriate care and not leave people in limbo, ill-health and feeling devalued.[53] We note the recent statement on '*Protecting the rights of older people to health and social care'* by the British Geriatrics Society.[54]

25. NHS England defines palliative care, *"as an approach that improves the quality of life of patients…and their families who are facing problems associated with life-limiting illness, usually progressive. It prevents and relieves suffering through the early identification, correct assessment and treatment of pain and other problems whether physical, psychosocial or spiritual."* Palliative care is one element of the care needed at the end of life but,[55] is there enough, provided at the right time and how good is it at resolving pain and other problems?

26. There is a need to continue investment in access to uniformly excellent palliative care in the Isle of Man and the rest of the UK:
    - 26.1. Hospice Isle of Man's 2018-2023 Strategy notes that *"Approximately 76% of all deaths on Island might benefit from end of life care, we currently care for 41%."*[56]
    - 26.2. A Needs Assessment published in February 2020 by the Strategic Partnership Steering Group led by Hospice Isle of Man in conjunction with the Department for Health and Social Care and Third Sector partners, noted that *"Since 2016, when Hospice Isle of Man extended its services to those without cancer, referrals to Hospice have increased by 24%. This rise will continue and we also do not know how many more people might benefit from specialist palliative or end of life care and are not receiving it."*[57]
    - 26.3. The subsequent joint report 'From Vision to Reality: Island Plan for Integrated Palliative and End of Life Care', published by the Isle of Man Government, Isle of Man Council of Voluntary Organisations and Hospice Isle of Man notes that *"palliative and end of life care has proven value, is a human rights, public health and equalities issue, and the need for it is growing in a society that is ageing."*[58]
    - 26.4. Hospice Isle of Man note in their 2021 Annual Review and Accounts the continued challenge of *"managing a relatively high fixed cost base against wildly fluctuating and unpredictable income streams whilst maintaining top quality service levels."*[59] This is typical of the sector.
    - 26.5. The situation on the Island is mirrored, in general terms, across the rest of the UK, with various estimates suggesting:
        - 26.5.1. one in four people are not able to access palliative/end of life care services/support.[60]
        - 26.5.2. 215,000 people a year miss out on end-of-life care and that without intervention this could rise to 300,000 within 20 years,[61] (half of all deaths).
        - 26.5.3. 1 in 5 hospices are at risk of closure, whilst facing an expected 55% increase in demand over the next decade.[62]
    - 26.6. A European review showed the UK was one of seven countries that decreased specialised palliative care services between 2009-2019.[63] [64]

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[53] Long-term funding of adult social care, Levelling Up, Housing and Communities Select Committee, HC19, 4 August 2022.

[54] Statement on Protecting the rights of older people to health and social care, British Geriatrics Society, 10 January 2023

[55] https://www.england.nhs.uk/eolc/

[56] 'Much more than a building': 2018-2023 Strategy, Hospice Isle of Man

[57] Needs Assessment: Integrated Palliative and End of Life Care for the Isle of Man, February 2020, page 2

[58] From Vision to Reality: Island Plan for Integrated Palliative and End of Life Care 2018-2023, Isle of Man Government, CVO, Hospice ISLE OF MAN, page 3

[59] Annual Review & Accounts 2021, Hospice Isle of Man, page 5

[60] Equality in hospice and end of life care: challenges and change, *Hospice UK*, 2021, page 6

[61] Press release 3 March 2022, New UK legal right to palliative care - Cicely Saunders International
Etkind SN et al, How many people will need palliative care in 2040? Past trends, future projections and implications for services, BMC Med 15, 102 (2017), https://doi.org/10.1186/s12916-017-0860-2

[62] Hanging by a thread - Sue Ryder responds to the Government Budget, Sue Ryder, 27 October 2021

[63] Arias-Carias N et al, Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years, Palliat Med, 2020 Sep;34(8):1044-1056. doi: 10.1177/0269216320931341

[64] 'It's time to end the hospice funding crisis', Sue Ryder, 8 March 2021

27. In 2015, the Westminster Parliamentary and Health Service Ombudsman said, "*End of life care is, sadly, a recurring and consistent theme in our casework*" saying, "*with good care it is unusual for pain not to be controlled acceptably*" and that "*harrowing results*" could be avoided, by taking steps such as improving clinician confidence with established good practice, the skilled use of morphine, and providing out of hours specialist services.[65]

28. In this context the following observation by UN experts about assisted suicide is of real concern. *"Even when access to medical assistance in dying is restricted to those at the end of life or with a terminal illness, people with disabilities, older persons…may feel subtly pressured to end their lives prematurely due to attitudinal barriers as well as the lack of appropriate services and support.*[66] This is a crucial issue for the Isle of Man to grapple with.

29. It is essential that with an ageing population, all those who need it can access physical and mental healthcare, including palliative care, social care and support. Services should be signposted and readily available. However, palliative care and so-called assisted dying are not complementary in nature. Palliative care is about holistically enhancing the quality of life of a patient. Assisted dying involves extinguishing a life.

The implementation of an assisted dying law in the Isle of Man

30. CARE's opposition to the proposed changes in the Isle of Man includes the concern that no safeguard will prevent undue pressure for someone to 'choose' assisted dying.

31. CARE disagrees that the law should be changed at all under any circumstances, but we pass brief comment on the following points:
    31.1. No law should be extended beyond terminal illness; indeed the subjective nature of the term "unbearable suffering" only underscores the entirely arbitrary nature of any provision initially deemed only for the terminally ill (Question 10) (see paragraph 10 above for further detail on this point).
    31.2. There should not be any ability for a physician to administer lethal medication; "unable" as referenced in the question is open to very broad interpretation, and it is also important to emphasise that once the principle of physician involvement is ceded, there is no clear demarcated line to which to withdraw which would prevent further extension of the law, or indeed greater involvement of physicians. This is particularly pertinent when considering the situation in Canada. Since the legalisation of euthanasia and assisted suicide in 2015, more than 30,000 'medically assisted deaths' have been recorded in Canada.[67] Nearly all (99%) were euthanasia deaths, in which a physician or nurse practitioner directly administered lethal drugs (Question 11). [68]
    31.3. We are firmly opposed to the legalisation of any form of assisted suicide or euthanasia, for either adults, children or 'mature minors', as Canada is considering.[69] For some, the Isle of Man is known as a tax haven; it would be tragic for the Isle of Man to become known as a 'haven' of an entirely different and corrupted kind were 'suicide tourism' enabled as part of any change to the law. It should be noted that, even with purportedly tight safeguards, residency requirements can and will be challenged. In Oregon in March 2022, in resolution of a federal lawsuit, state health authorities agreed to stop enforcing the residency requirement and to ask the legislature to remove it from the law (Questions 12 and 13).[70]

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[65] Dying without Dignity: Investigations by the Parliamentary and Health Service Ombudsman into complaints about end of life care, Parliamentary and Health Ombudsman, May 2015, pages 6 and 24

[66] Disability is not a reason to sanction medically assisted dying – UN experts, 25 January 2021

[67] Third Annual Report on Medical Assistance in Dying in Canada 2021, July 2022, pages 5 and 18

[68] *Ibid*, page 18

[69] Dying with Dignity, 15 Sept 2021, *Op Cit.*

[70] Oregon Ends Residency Requirement for Medically Assisted Deaths, The New York Times, 29 March 2022

31.4. Medical professionals (including pharmacists), hospices, care homes, and hospitals should have a robust right to conscience (Question 16).

31.4.1. We firmly believe that doctors should not have to provide supporting assessments or provide their professional opinion in cases where a medical professional wishes to exercise their right to conscience. CARE also believes that institutions like care homes and hospices should not be required to allow assisted deaths if that is against their policy.

31.4.2. However, even if the right to conscience was initially protected, evidence suggests that there will be pressure for change to ensure that access to assisted dying is not restricted.[71] California's 2015 legislations initially ensured that no doctor would be "*required to take any action in support of an individual's decision*". The doctor was under no threat of penalty for not giving a patient information nor referring to another doctor. [72] In October 2021, this position significantly changed. Provision of information is no longer included under protection of conscience and doctors must record the first request.[73] In requiring the doctor to document the first request, they become part of the process. In September 2022, a court ruled *"The ultimate outcome of this requirement is that non-participating providers are compelled to participate in the Act through this documentation requirement, despite their objections to assisted suicide."* The court also ordered that California should not enforce the requirement.[74]

31.4.3. Medical professionals must not be able to initiate discussions on assisted dying with patients and no explicit requirement should be placed on professionals to discuss assisted dying either.

31.5. Were the law to change, an expert assessment of capacity <u>and</u> judgement is essential for determination of eligibility and just before death.[75] [76] Lord Falconer's Commission said, "*in the context of such a serious decision as requesting an assisted death…a formal assessment would be needed to ensure that the person concerned had capacity.*"[77] Studies have shown 30% of people with terminal illnesses display psychiatric illnesses (particularly depression).[78] (Question 17)

31.6. There should be open transparency about the impact of the law with a full annual report with reporting of prescriptions, deaths, complications and reasons for an assisted death as a minimum including assisted death being reported as the cause of death and a post-death administrative review (Question 26).

31.7. It should not be possible to include the provision of assisted dying in a "living will" or advanced directive. It is essential that if dementia is to be included as a physical condition considered to be in scope that the person has capacity and judgement to make a decision for assisted death and should not be able to make an advanced decision. There should be no option for a waiver of final consent as there is too much ambiguity about the wishes of the individual if not consenting is to be judged by "sounds or gestures" as is allowed in Victoria.[79] We also believe that there should be clear verbal communication for the first request and for confirmation of capacity and that gestures are insufficient. (Question 27)

[Contact details redacted]

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[71] Concerns about the balance between safety and access are raised in McDougall R, Pratt B, Too much safety? Safeguards and equal access in the context of voluntary assisted dying legislation, *BMC Med Ethics* 21, 38 (2020)

[72] Section 443.14(e)(1) and (2) of the California Health and Safety Code, as passed in 2015

[73] Section 443.14(e)(1) and (2)and 443.15(3)(B), Health and Safety Code of California. Text as amended from Bill SB-380 End of Life

[74] Court Ruling, 2 September 2022, pages 20-21 and page 26

[75] Response to the Assisted Dying for the Terminally Ill Bill, 24 April 2006, Statement from the Royal College of Psychiatrists on Physician Assisted Suicide

[76] This option was recommended for consideration by the House of Lords Select Committee on the Assisted Dying for the Terminally Bill, April 2005, Paper 86-I, paras 252-254

[77] Commission on Assisted Dying, *Op Cit*, pages 28-29

[78] Lloyd Williams M., Screening for depression in patients with advanced cancer, European Journal of Cancer Care, 2001, 10:31-35
Bowers L., Boyle D.A., Depression in patients with advanced cancer, Clinical Journal of Oncological Nursing, 2003, 7:281-288
Stiefel et al, Depression in palliative care: a pragmatic report from the Expert Working Group of the European Association for Palliative Care, Support Cancer Care 2001, 9:477-488

[79] Section 4(1)(d), https://content.legislation.vic.gov.au/sites/default/files/2021-06/17-61aa005%20authorised.pdf

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Forch, 25 January 2023

Assisted dying Isle of Man public consultation

Responses to the questions in the consultation / survey
Submission by DIGNITAS – To live with dignity – To die with dignity
Forch, Switzerland

for and on behalf of the 7 Isle of Man and 1,433 UK members
of DIGNITAS – To live with dignity – To die with dignity
submitted in electronic format to privatemembersbill@tynwald.org.im

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1) Introduction

This submission answers the 28 questions of and comments on the consultation / survey regarding Assisted Dying on the Isle of Man[1]. In this, it also provides information for the discussion on introducing assisted dying legislation on the Isle of Man. It does not claim to, and it cannot cover the issue in all details.

The Swiss non-profit membership association "DIGNITAS – To live with dignity – To die with dignity" (hereafter abbreviated "DIGNITAS" for easier reading and writing) provides this submission based on its work of 24 years which includes know-how and experience from conducting over 3,400 cases of assisted dying (assisted / accompanied suicides, PSAS)[2] in line with Swiss law. The reason for providing this submission is obvious from the aims and further information available on the website of DIGNITAS[3]:

DIGNITAS has, besides other work, focussed on implementing and safeguarding the human right of individuals to decide on time and manner of their own end in life and to have access to professional help to put this into practice in a legal and safe way at their home. DIGNITAS does this so that these individuals (and their loved ones) do not have to carry the burden of going abroad with all the negative consequences thereof. Alongside this, DIGNITAS and the country of Switzerland would not then have to take care of an issue which should be resolved by the states where these individuals travel from.

The aim of DIGNITAS is that the "medical tourism of assisted dying" stops and DIGNITAS becomes obsolete for these people[4]. DIGNITAS will serve as an information provider and "emergency exit" only as long as many countries' governments and legal systems disrespect their citizens' basic human right to self-determination and choice in life and life's end, ban the topic with a taboo, and force them either to turn to lonely risky do-it-yourself suicide attempts or to travel abroad instead.

DIGNITAS finds that the proposed assisted dying Bill for the Isle of Man is an important step forward to resolve several problems of the present legal situation which, in regard of assisted dying, is now inadequate and incoherent, as it (still) is all over the UK[5], despite recent developments which give rise to hope for a change. Therefore, DIGNITAS is fully supportive of the proposed assisted dying Bill despite raising criticism in some points as explained hereafter.

DIGNITAS is happy to give further evidence, personal, oral and written, if members of Tynwald and/or others involved in the consultation would wish so, as DIGNITAS already did in earlier consultation processes. They are also welcome to visit DIGNITAS.

2) Assisted Dying: a human right, freedom and choice

All European states – with the exception of the Vatican, Belarus and Kosovo – have adhered to the European Convention on Human Rights (ECHR)[6]. In specific cases, set legal situations

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[1] https://consult.gov.im/private-members/assisted-dying

[2] See subheading 4 of this submission.

[3] E.g. "The basic information at a glance and a 'click" on http://www.dignitas.ch/index.php?lang=en

[4] See "The goal of DIGNITAS", page 19 herein: http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-dansketnomedicalsociety-31082022.pdf

[5] See the report by The Commission on Assisted Dying https://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_I_web_single-NEW_.pdf?1328113363

[6] The Convention: http://www.echr.coe.int/Documents/Convention_ENG.pdf ; Member States: http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/005/signatures

may be questioned whether they would be in line with the basic human rights and liberties enshrined in the ECHR. The European Court of Human Rights (ECtHR)[7] has developed an important jurisdiction on basic human rights, including the issue of the right to choose a voluntary death. According to its preamble, this international treaty is not only a fixed instrument, "securing the universal and effective recognition and observance of the rights therein declared" but also aiming at "the achievement of greater unity between its members and that one of the methods by which that aim is to be pursued is the maintenance and further realisation of human rights and fundamental freedoms"[8]. The ECHR text and case law are relevant in discussing an assisted dying Bill for the Isle of Man[9], which is why DIGNITAS herewith outlines aspects of a selection of the ECtHR judgments, and further court judgments in relation to a self-determined and self-enacted end of suffering and life.

In the judgment of the ECtHR in the case of DIANE PRETTY v. the United Kingdom dated 29 April 2002[10], at the end of paragraph 61, the Court expressed:

> "Although no previous case has established as such any right to self-determination as being contained in Article 8 of the Convention, the Court considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees."

Furthermore, in paragraph 65 of this judgment, the Court expressed:

> "The very essence of the Convention is respect for human dignity and human freedom. Without in any way negating the principle of sanctity of life protected under the Convention, the Court considers that it is under Article 8 that notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity."

On 3 November 2006, the Swiss Federal Supreme Court recognized that someone's decision to determine the way of ending his or her own life is part of the right to self-determination protected by article 8 § 1 of the ECHR, stating:

> "The right to self-determination within the meaning of Article 8 § 1 [of the Convention] includes the right of an individual to decide at what point and in what manner he or she will die, at least where he or she is capable of freely reaching a decision in that respect and of acting accordingly."[11]

In that decision, the Swiss Federal Supreme Court had to deal with the case of a man suffering not from a physical but a psychiatric / mental ailment. It further recognized:

> "It must not be forgotten that a serious, incurable and chronic mental illness may, in the same way as a somatic illness, cause suffering such that, over time, the patient concludes that his or her life is no longer worth living. The most recent ethical, legal and medical opinions indicate that in such cases also the prescription of sodium pentobarbital is not

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[7] https://www.echr.coe.int

[8] http://www.echr.coe.int/Documents/Convention_ENG.pdf page 5.

[9] The ECHR came into force in the UK on 3 September 1953.

[10] Application no. 2346/02; Judgment of a Chamber of the Fourth Section http://hudoc.echr.coe.int/eng?i=001-60448

[11] BGE 133 I 58, page 67, consideration 6.1 (translated) http://bit.ly/BGE133I58

> necessarily precluded or to be excluded on the ground that it would represent a breach of the doctor's duty of care. […] Where the wish to die is based on an autonomous and all-embracing decision, it is not prohibited to prescribe sodium pentobarbital to a person suffering from a psychiatric illness and, consequently, to assist him or her in suicide. […] The question of whether the conditions have been met in a given case cannot be examined without recourse to specialised medical – and particularly psychiatric – knowledge and is difficult in practice; the respective assessment requires an in-depth psychiatric appraisal…"

Based on this judgment, the applicant made efforts to obtain an appropriate assessment, writing to 170 psychiatrists – yet he failed to succeed. Seeing that the Swiss Federal Supreme Court had obviously set up a condition which in practice could not be fulfilled, he took the issue to the ECtHR.

On 20 January 2011, the ECtHR rendered the judgement Haas v. Switzerland[12] and stated in paragraph 51:

> "In the light of this case-law, the Court considers that an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention."

In this, the ECtHR adhered to the Swiss Federal Supreme Court and acknowledged that the freedom to choose the time and manner of one's own end in life is a basic human right protected by the ECHR.

In a further case, Ulrich Koch against Germany, the applicant's wife, suffering from total quadriplegia after an accident, demanded that she should have been granted authorisation to obtain 15 grams of pentobarbital of sodium, a lethal dose of medication that would have enabled her to end her ordeal by choosing suicide at her home. In its decision of 19 July 2012, the ECtHR declared the applicant's complaint about a violation of his wife's Convention rights inadmissible, however, the Court held that there had been a violation of Article 8 of the Convention in that the [German] domestic courts had refused to examine the merits of the applicant's own rights he claimed[13]. The case had to be dealt with by the German domestic courts again. Finally, the German Federal Administrative Court corrected the lower courts judgments: The general right to personality article 2,1 (right to life) in connection with article 1,1 (protection of human dignity) of the Basic (Constitutional) Law of Germany comprises the right of a severely and incurably ill patient to decide how and at what time his or her life shall end, provided that he or she is in a position to make up his or her own mind in that respect and act accordingly. The Court found, even though it was generally not possible to allow the purchase of a narcotic substance for the purpose of suicide, there had to be exceptions[14].

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[12] Application no. 31322/07; Judgment of a Chamber of the First Section: http://hudoc.echr.coe.int/eng?i=001-102940

[13] Application no. 479/09, Judgment of the Former Fifth Section: http://hudoc.echr.coe.int/eng?i=001-105112

[14] See the respective press release by Dignitas http://www.dignitas.ch/images/stories/pdf/medienmitteilung-08032017.pdf (in English); link to the judgment by the Federal Administrative Court of Germany: http://www.bverwg.de/entscheidungen/entscheidung.php?ent=020317U3C19.15.0 (in German).

In the case of GROSS v. Switzerland, the ECtHR further developed its jurisdiction. The case concerned a Swiss woman born in 1931, who, for many years, had expressed the wish to end her life, as she felt that she was becoming increasingly frail, and she was unwilling to continue suffering the decline of her physical and mental faculties. After a failed suicide attempt followed by inpatient treatment for six months in a psychiatric hospital which did not alter her wish to die, she tried to obtain a prescription for sodium pentobarbital by Swiss medical practitioners. However, they all rejected her wish; one felt prevented by the Swiss code of professional medical conduct as the woman was not suffering from any life-threatening illness, another was afraid of being drawn into lengthy judicial proceedings. Attempts by the applicant to obtain the medication to end her life from the Health Board were also to no avail.

In its judgment of 14 May 2013[15], the ECtHR held in paragraph 66:

> "The Court considers that the uncertainty as to the outcome of her request in a situation concerning a particularly important aspect of her life must have caused the applicant a considerable degree of anguish. The Court concludes that the applicant must have found herself in a state of anguish and uncertainty regarding the extent of her right to end her life which would not have occurred if there had been clear, State-approved guidelines defining the circumstances under which medical practitioners are authorised to issue the requested prescription in cases where an individual has come to a serious decision, in the exercise of his or her free will, to end his or her life, but where death is not imminent as a result of a specific medical condition. The Court acknowledges that there may be difficulties in finding the necessary political consensus on such controversial questions with a profound ethical and moral impact. However, these difficulties are inherent in any democratic process and cannot absolve the authorities from fulfilling their task therein."

In conclusion, the Court held that Swiss law, while providing the possibility of obtaining a lethal dose of sodium pentobarbital on medical prescription, did not provide sufficient guidelines ensuring clarity as to the extent of this right and that there had been a violation of article 8 of the Convention. However, the case was referred to the Grand Chamber of the ECtHR by the Swiss government as, prior to a public hearing on the case, it became known that the applicant had passed away in the meantime. This led to the case not being pursued.

Another important judgment was rendered on 26 February 2020 by the Federal Constitutional Court of Germany[16]: The court declared unconstitutional and void § 217 of the German Criminal Code ("geschäftsmässige Förderung der Selbsttötung"), a statuary provision that had criminalised repeated – and thus professional – advisory work and assistance for a self-determined ending of one's own life[17]. The Court held:

> "As an expression of personal autonomy, the general right of personality (Art. 2(1) in conjunction with Art. 1(1) of the Basic Law) encompasses a right to a self-determined death. The right to a self-determined death includes the freedom to take one's own life. Where an individual decides to end their own life, having reached this decision based on how they personally define quality of life and a meaningful existence, their decision must, in principle, be respected by state and society as an act of personal autonomy and

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[15] Application no. 67810/10; Judgment of a Chamber of the Second Section: http://hudoc.echr.coe.int/eng?i=001-119703

[16] https://www.bundesverfassungsgericht.de/SharedDocs/Entscheidungen/EN/2020/02/rs20200226_2bvr234715en.html

[17] See: http://www.dignitas.ch/images/stories/pdf/medienmitteilung-26022020-e.pdf

> self-determination. The freedom to take one's own life also encompasses the freedom to seek and, if offered, make use of assistance provided by third parties for this purpose. […] The right to a self-determined death, as an expression of personal freedom, is not limited to situations defined by external causes. The right to determine one's own life, which forms part of the innermost domain of an individual's self-determination, is in particular not limited to serious or incurable illness, nor does it apply only in certain stages of life or illness. […] The right to a self-determined death is rooted in the guarantee of human dignity enshrined in Art. 1(1) GG; this implies that the decision to end one's own life, taken on the basis of personal responsibility, does not require any explanation or justification. […] What is decisive is the will of the holder of fundamental rights, which eludes any appraisal on the basis of general values, religious precepts, societal norms for dealing with life and death, or considerations of objective rationality […]."

On 11 December 2020, the Austrian Constitutional Court[18] rendered its judgment on a constitutional complaint against the prohibition of assistance in suicide and voluntary euthanasia. § 78 "participation in self-murder" (sic!) of the Austrian criminal code, which was set up in the Austro-fascist 1930s, said: "Any person who incites another to commit suicide [literally: 'kill himself'], or provides help in this, is liable to a custodial sentence of six months to five years." The Court found the second fact of § 78 ("or provides help in this") unconstitutional, with effect from 1 January 2022. In essence the Court held:

> "A right to free self-determination is to be derived from several constitutional guarantees, in particular the right to private life, the right to life, as well as the principle of equality. This right also extends to the freedom to end one's own life. Where a person decides to end his or her own life, this decision must be respected by the State provided that it is based on the free will of the individual concerned. The right to end one's own life also includes the freedom to seek and, where offered, make use of assistance provided by third parties for that purpose. […] From a fundamental rights perspective there is no difference between a patient that refuses life-prolonging or life-maintaining medical measures within his or her sovereignty over treatment or by exercising his or her right to self-determination within his or her living will, and a person willing to commit assisted suicide as part of his or her right to self-determination in order to die in dignity. In both cases, the decisive aspect is that the decision is taken on the basis of free self-determination."

In this context the so-called Artico-jurisdiction based on the ECtHR judgment of 13 May 1980, series A no. 37, no. 6694/74, paragraph 33[19] needs to be remembered:

> "The Court recalls that the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective; …"

Dignity and freedom of humans mainly consists of acknowledging the right and freedom of someone who does not lack capacity to decide even on existential questions for him- or herself, without outside interference. Everything else would be paternalism compromising

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[18] Abstract in English provided by the Court: https://www.vfgh.gv.at/downloads/Bulletin_2020_3_AUT-2020-3-004_G_139_2019.pdf ; respective press release by Dignitas: http://www.dignitas.ch/images/stories/pdf/medienmitteilung-11122020-e.pdf

[19] http://hudoc.echr.coe.int/eng?i=001-57424

dignity and freedom of choice. In the judgment PRETTY v. the United Kingdom mentioned before, the Court correctly recognized that this issue will present itself increasingly – not only within the Convention's jurisdiction, but internationally – due to demographic developments and progress of medical science.

It also presents itself increasingly because a growing part of the public wishes to have the freedom and right to choose the course of their own life *and* their end in life[20]. Yet sometimes it can be observed that politics and linked administrative authorities take another stand and block or delay assisted dying legislation, despite a majority of the public being in favour of such choice being legalised. The public opinion is relevant from an ECHR perspective: in the judgment OLIARI AND OTHERS v. Italy dated 21 July 2015, the ECtHR observed a reflection of the sentiments of a majority of the (in this case Italian) population as shown through official surveys[21].

3) Responses to the questions of the consultation / survey

Questions (Q.) 1 – 6 regarding name, address, etc.

Answer (A.): See page 1 of this submission.

Q. 7 May we publish your response?

A. Yes, in full.

Q. 8 In principal, do you agree or disagree that assisted dying should be permitted for terminally ill adults on the Isle of Man?

A. Agree.

Assisted dying should be permitted not only for the terminally ill, but for everyone who "is capable of freely reaching a decision on this question and acting in consequence" as found by the ECtHR[22]. It is an individual's human right and freedom to decide on the time and manner of their own end in life, as outlined in subheading 2 of this submission. Several polls have shown that a majority of the people in the UK and the Isles wish for assisted dying to be legalised, which is also the case for the Isle of Man according to an Island Global Research opinion survey carried out in May 2021 mentioned in the overview on this public consultation. Permitting assisted dying is to protect lives: premature deaths can be avoided because individuals would not, or at least less likely, (need to) travel abroad to DIGNITAS or to take to risky do-it-yourself (DIY) suicide attempts to end their suffering. And, permitting assisted dying is to improve health, in the words of Julian Gardner, Chairperson of the Voluntary Assisted Dying Review Board of the state of Victoria, Australia[23]: "Having some control of the dying process may lift psychological and general health. For many people, having access to medication gives them the option to exercise their autonomy and die on their own terms. Some of those people choose not to have the medicine dispensed and some have the medication and choose not to take it. We know from feedback they do receive comfort from that[24]."

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[20] As to the Isle of Man, see for example the result of the Island Global Research opinion survey mentioned in the Overview https://consult.gov.im/private-members/assisted-dying/#pasted-question-16699768286-74352-16699768296-65456

[21] https://hudoc.echr.coe.int/eng?i=001-156265 paragraph 181 / 144.

[22] Judgment in the case of HAAS v. Switzerland, paragraph 51, mentioned in subheading 2 of this submission.

[23] https://www.safercare.vic.gov.au/about/vadrb/members

[24] In the article "Why some people with euthanasia drugs do not take the fatal dose", in "The Age", 8 January 2023.

To only allow access to assisted dying for individuals who face a terminal illness, that is, “diagnosed them as having a progressive disease, which can reasonably be expected to cause their death”, is to discriminate against individuals who suffer from other health conditions which severely impair their quality of life. In fact, prohibiting access to assisted dying on the grounds of the individual being part of a certain group, especially a minority group, constitutes a discrimination against such an individual and group. For example, individuals such as the late Paul Lamb, who was paralysed from the neck downwards after an accident, and who fought in the UK courts to obtain access to assisted dying[25].

Those denied access to and help in assisted dying are left to illegal and/or risky approaches and methods, for example, unguided do-it-yourself (DIY)-suicide attempts of which the majority fail with dire consequences for the individual, their loved ones and society in general[26]. Not permitting access can violate the human right to (the protection of) life and/or constitute an inhumane or degrading treatment, besides the right to respect for private and family life. All are aspects of the ECHR.

Furthermore, individuals with severe psychiatric ailments are discriminated against – whilst in fact the very claimant before the ECtHR, Mr. Haas, who brought about the judgment acknowledging the human right/freedom to decide on the time and manner of one’s own end in life, was suffering from a psychiatric ailment but not a physical and/or terminal disease[27]. A psychiatric illness may impact a person’s capacity to make decisions, but it need not. Sometimes it can be observed, especially amongst opponents of assisted dying working in the fields of psychiatry and psychology, that it is insinuated that individuals requesting assisted dying would up-front not have capacity. This approach not only tries to turn upside down the legal basis that a person is presumed to have decision-making capacity (in relation to assisted dying) unless the person is shown not to have that capacity, as stated in the consultation report para 21. But it labels and stigmatises people who contemplate end-of-life choices – with the negative effects of entrenching the taboo on suicide, on (assisted) dying and on death, and potentially leading these people to not talk to doctors, therapists and their loved ones but “to take matters in their own hands”[28].

Q. 9 Do you think that there should be a limit on their life expectancy?

A. No.

The eligibility criterion of any life expectancy limit should be done away with. No one, not even the most expert medical professional, is able to predict the future and to *know* whether a patient is still alive in a set time such as 6 or 12 months or any other number of months or days. There may be life expectancy *estimates* based on experience, depending on the

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[25] The case of Paul Lamb (and Tony Nicklinson) was finally referred to the ECtHR, yet the ECtHR declared Lamb’s complaint inadmissible because the rule of exhaustion of domestic remedies had not been observed. https://hudoc.echr.coe.int/eng?i=001-156476
Cf. the findings of Prof. Ben Colburn, University of Glasgow, and further references in the section “Disability” in the Overview of the Assisted Dying Consultation of the Isle of Man: https://consult.gov.im/private-members/assisted-dying

[26] Cf. page 13, subheading 7 “The protection of life and the general problem of suicide” in Dignitas’ submission to the Joint Committee on End of Life Choices South Australia: http://www.dignitas.ch/images/stories/pdf/diginpublic/stellungnahme-submission-end-of-life-choices-south-australia-31072019.pdf

[27] Case of Haas v. Switzerland, application no. 31322/07, https://hudoc.echr.coe.int/eng?i=001-102940 ; see also subheading 2 of this submission.

[28] See the TEDx talk “Cracking the taboo on suicide is the best means to prevent suicide attempts and deaths by suicide” http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-tedxzurich-08072021.pdf

diagnosis; however, there is also the experience of exceptions. In result, the criterion of a certain limited life expectancy is a hypothetical, and it leads to arbitrariness and inequality: one medical professional may hold the opinion that the patient is going to die in a set time span, but another may estimate this to be different. Depending on the opinions of the two separate doctors foreseen in the process for assisted dying patients meet in the process, they may be judged differently.

What is the purpose of a limited life expectancy criterion in relation to assisted dying law-making anyway? Some claim it to be a "safeguard". The opposite is the case. Patients who do not meet this eligibility criterion, in their despair might try an unguided (DIY) suicide, or they will turn to DIGNITAS. Both outcomes are undesirable. The limited life expectancy criterion is a copy-paste from the now 20-year-old and outdated Death with Dignity Act of the state of Oregon USA. Most European assisted dying laws, i.e. Belgium, the Netherlands, Luxembourg, Switzerland (with the longest-standing professionally-medically assisted dying practice (PSAS) of over 35 years) and Germany, do not have such restrictive criterion.

Making use of any form of assisted dying – whether by PSAS or voluntary euthanasia or discontinuing treatment ("passive euthanasia"; e.g. based on a legally effective advance directive) – is a personal choice in the frame of every individual's right to self-determination; no matter whether (or not) such individual is in fact or assumed to be a member of a certain group defined by medical diagnosis or life expectancy.

DIGNITAS suggests that the Isle of Man Assisted Dying legislation adopts eligibility criteria that do not give precedence to what some doctors judge about life expectancy of their patient, but rather to focus on the personal experience / point of view of the individual / patient.

Besides, permitting access to assisted dying for only those with a limited life expectancy appears illogical in the light of the fact that life itself is a "diagnosis" that is expected to cause death, whether or not a medical practitioner diagnoses a terminal illness or other and estimates a certain life expectancy.

Note: the online survey does not provide and allow for ticking "No" with question 9, which may be due to a pre-decision not to look into this aspect (again), but that some limit on an individual's life expectancy as an eligibility criterion is firm, unfortunately.

Q. 10 Do you support the provision of assisted dying for someone who has a condition which causes unbearable suffering that cannot be alleviated by other means but which may not give a terminal diagnosis?

A. Yes.

However, the criterion of "unbearable suffering that cannot be alleviated by other means" should be done away with. A medical condition which impairs an individual's quality of life is itself sufficient grounds to permit access to assisted dying. Besides, only the individual is capable of determining whether their suffering is "unbearable"; it would be an entirely subjective criterion.

Q. 11 If they are unable to take oral medication should a health care professionally be permitted to administer medication intravenously to achieve death?

A. Yes.

This provides an important element of relief for a suffering person, especially those with a diagnosis that is likely to rob them of their ability to ingest the medication themselves and orally.

Q. 12 Do you agree that assisted dying should be available only to people over the age of 18 Years?

A. No.

This, even though it is to be expected that requests for assisted dying on the Isle of Man will come forward mainly from individuals aged over 18. To compare: in Switzerland, according to the Federal Office of Statistics analysing the years 2010-14, most assisted dying cases (PSAS) took place in the age group 75-84, and overall 94% of the persons concerned were over 55 years old[29]. Yet, there may be cases of younger than 18-year-old individuals with an illness which impairs their quality of life grievously to the point of them possibly wishing to have the option of assisted dying. The assisted dying laws of Belgium and the Netherlands adhere to this and allow for under-18 to access assisted dying under specific circumstances[30]. The Isle of Man should take this as an example. A 17-year-old young may well have capacity to understand the consequences of a diagnosis of a severe illness, may it be terminal cancer or any other, and what assisted dying implies. Furthermore, if a 17-year-old is permitted to set up and/or have respected an advance directive to refuse treatment, which will hasten death if applied (passive euthanasia), it does not make sense to bar such young person from assisted dying which leads to the same result[31].

Q. 13 Should they have to be permanent residents of the Isle of Man?

A. No.

All discrimination related to the place of residency should be avoided. The issue of potential “assisted dying tourism”, i.e. people from other parts of the UK or even beyond (trying to) access assisted dying on the Isle of Man, should not be solved with setting up discriminating criteria, but with engaging in the decriminalisation of assisted dying in legislations around the Isle of Man, so that such people would not need to consider at all turning to the Isle of Man (and elsewhere). In this context it is also to be noted that the residency criterion of the US State of Oregon was challenged to be unconstitutional in the Gideonse v. Brown, et al. court case, which on 18 March 2022 led to a settlement in which the Oregon Health Authority, Oregon Medical Board, and the Multnomah County District Attorney have all agreed to “not apply or otherwise enforce the residency requirement” in the Oregon Death with Dignity Act, and the Oregon Health Authority agreed “to submit a legislative concept that would repeal the residency requirement”[32].

Q. 14 If you agree they should be permanent residents please state for how long.

A. See Q. / A. 13

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[29] https://www.bfs.admin.ch/bfs/en/home/statistics/catalogues-databases/publications.assetdetail.3902308.html

[30] https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request

[31] Cf. judgment by the Austrian Constitutional Court of 11 December 2020 mentioned in subheading 2 of this submission.

[32] https://compassionandchoices.org/docs/default-source/legal/rec-doc-20-1-exhibit-wm.pdf?sfvrsn=6041423c_1 and https://compassionandchoices.org/legal-advocacy/recent-cases/gideonse-v-brown-et-al

Q. 15 Do you agree with the proposal that two different doctors should meet with the person independently and establish they are mentally competent to make an informed decision without pressure or coercion?

A. No.

Whilst Dignitas acknowledges that involving two separate doctors in the process of assessing and possibly supporting an individual's request for assisted dying may be seen as a safeguard, it adds an unnecessary hurdle that consumes time which a rapidly declining individual may have little left of, and it prolongs the suffering.

In the Swiss legal system of PSAS, one doctor is seen as sufficient[33]. This doctor may choose to reach out to one or several colleagues if, for example, the individual's situation and request for assisted dying appears complex and the doctor wishes for support and second opinion(s). This has proved to work well for over 35 years, and Dignitas suggests this approach.

In the analysis and discussion following the consultation, the question should be discussed whether *at all* doctors should be involved as "gatekeepers" for assisted dying. In the light of the human rights and constitutional court judgments mentioned in subheading 2 of this submission, it can be noted that the prerequisite of a medical condition, even more so one that is diagnosed as being "terminal" as foreseen in the proposed Bill, violates the very human right to decide on the time and manner of one's own end in life (and for this to reach out to voluntary help from others). A different assessment procedure should be discussed, in which doctors do not (need to) pass judgement on whether or not someone has a certain medical diagnosis, whether or not it causes unbearable suffering and whether or not it is expected to cause death. Rather, they should put centre stage what the individual considers to be quality of life. The role of doctors would then be to focus on establishing that the individual requesting assisted dying:

- understands the information relevant to the decision relating to access to assisted dying and the effect of the decision; and
- has reached a voluntary decision without coercion or duress; and
- is informed as to palliative, hospice and other care options – this should include information as to the potential negative effects of unguided DIY-suicide attempts; and
- is able to communicate the decision and their views and needs as to the decision in some way, including by speech, gestures or other means, and also able to administer the life-ending medication themselves; and
- has discussed the matter with their loved ones with the aim of avoiding a negative "surprise effect" and impact for these loved ones.

This approach would also alleviate any pressure that doctors may feel about making predictions about whether a suffering is "unbearable" and «cannot be alleviated by other means" (cf. Q. / A. 10) and/or whether or not the illness "can reasonably be expected to cause death". All these are criteria of opinion, which by nature is subjective. The patient's view should be taken seriously with respect to their own suffering, just as the doctors' word is to be taken with respect as to the diagnosis and treatments and medication possible.

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[33] Cf. http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-dansketnomedicalsociety-31082022.pdf pages 11, 13 and 31.

Q. 16 Should any health professional be able to conscientiously object to being part of an assisted dying programme?

A. Yes.

Assisted dying is about the right and freedom to choose; this concept of free choice should apply for the individual who wishes to make use of assisted dying just as much as for those directly co-decisive: medical professionals.

Q. 17 Do you agree that if either doctor is unsure about the person's capacity to request an assisted death, the person should be referred to a psychiatrist for a further capacity assessment?

A. Yes.

Still though, it needs to be remembered that, in principle, people who are of age are assumed to be mentally competent unless there are indications that their mental capacity is limited or no longer present. This is the basis in common law which recognises – as a "long cherished" right – that all adults must be presumed to have capacity until the contrary is proved[34].

Q. 18 Do you agree that the two doctors should ensure that the person has been fully informed of palliative, hospice and other treatment and care options?

A. Yes.

Q. 19 Do you support the proposal that the person signs a written declaration of their request, which is witnessed and signed by both doctors?

A. No.

The person should sign a written declaration of their request, but to have this witnessed and signed by one or more doctors is not necessary. In the assisted dying law proposal for the Isle of Man two doctors will anyway interact with the individual requesting assisted dying and therefore can verify the written request. In the Swiss legal system of PSAS there is no such mandatory witnessing and signing provision, and it does not appear to have posed a problem in 35 years of this being practice.

Q. 20 Do you agree that there should be a waiting period of 14 days from this time to the provision of life ending medication to allow the person to reconsider their decision?

A. No.

Assisted dying on the Isle of Man should adhere to the approach of Canada, Belgium, the Netherlands, New Zealand, Switzerland and Germany which have no such waiting period in law[35]. The experience of DIGNITAS derived from having conducted over 3,400 PSAS is that, generally, people who contemplate end-of-life-choices make up their mind as part of their

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[34] This approach is also found, for example, in the Assisted Dying in Jersey Consultation Report, page 100: "In line with existing capacity legislation, the person is presumed to have decision-making capacity in relation to assisted dying unless the person is shown not to have that capacity" https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/Assisted%20Dying%20Consultation%20Report.pdf . Also Swiss law bases on the assumption that everybody is assumed to have capacity of judgment; this, unless there are clear signs that such is not the case, see article 16 of the Swiss Civil Code https://www.admin.ch/opc/en/classified-compilation/19070042/index.html#a16

[35] Cf. the Assisted Dying in Jersey Consultation Report, page 33, para 76.a. https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/Assisted%20Dying%20Consultation%20Report.pdf

"personal life philosophy" long before they would face a health situation in which they would get in touch with DIGNITAS to request PSAS.

Any imposed minimum timeframe for a waiting period appears arbitrary and paternalistic, and leads to possibly prolonging the suffering. The assessment procedure as foreseen in the proposed Bill for the Isle of Man already takes time.

Q. 21 Do you feel that this period should be shortened to 7 days if the person is expected to die within 30 days?

A. See Q. / A. 20

Q. 22 Should the person themselves or a relative be able to collect the relevant medication from a designated pharmacist?

A. Yes. But it should be foreseen that if the person cannot do so for health reasons and if there is no relative, someone else should be able to collect it.

Q. 23 Should this be able to be stored securely in the person's home until they decide whether they want to take it or not?

A. Yes.

Q. 24 If they change their mind should the medication be returned to the pharmacy immediately?

A. Yes.

Q. 25 Should a health care professional be required to be with the patient once they have taken the medication until they are certified to have died?

A. Yes.

Q. 26 Should an annual report be produced regarding the number of people who have taken advantage of assisted dying, and be published?

A. Yes.

Q. 27 Should it be possible to include the provision of assisted dying in a "living will" or advanced directive?

A. Yes.

This provides an important element of emotional relief for a severely suffering person, especially those with a diagnosis that is likely to rob them of their capacity of judgment e.g. a brain tumour or dementia.

Q. 28 Do you have any comments on the process to provide Assisted Dying which will be included in the draft Bill

See Q. / A. 15

4) Terms and abbreviations used in this submission

Assisted dying: an umbrella term including PSAS and/or voluntary euthanasia with the support of and/or carried out by doctors / physicians. In this submission, depending on the context, it is used as defined in the consultation report.

Assisted/accompanied suicide and physician-supported accompanied suicide (abbreviation: **PSAS**): this is what is made possible for members of DIGNITAS in the frame of Swiss law. A person wishing to put an end to their suffering and their life chooses a well-considered, carefully prepared self-administration of a lethal substance provided by a (Swiss) physician usually at their home. The physician has assessed the person's request and medical file, the person is accompanied by professionals all through the process until the end, and next-of-kin and friends are involved.

Voluntary euthanasia: a person wishing to end his/her suffering and life requests and permits a third person to put an end to his/her life, for example by injection of a lethal medication. This is prohibited in Switzerland, yet legal under certain circumstances in some countries such as Belgium, Luxembourg and the Netherlands.

Passive euthanasia: (termination of treatment, "to let die"): ending or not starting life-maintaining and life-prolonging therapies, renouncing treatments, waiving food and drink.

Palliative care: an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (as defined by the World Health Organisation WHO).

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This response to the consultation report is submitted by e-mail. DIGNITAS confirms to have read and understood the Privacy Policy in the Online Survey and that this submission may be published in full.

Yours sincerely,
DIGNITAS
To live with dignity - To die with dignity

[Signatures redacted]

Ludwig A. Minelli Silvan Luley

[Contact details redacted]

25 January 2023

Assisted Dying Bill Consultation
c/o Clerk of Tynwald Office
Legislative Buildings
Finch Road
Douglas
IM1 3PW

Public Consultation
Section 8
Do you agree or disagree that Assisted Dying should be permitted for terminally ill adults on the Isle of Man

We disagree that Assisted Dying should be permitted for terminally adults on the Isle of Man.

1. There have been incidents in the past where a terminal diagnosis has been incorrect.

2. There may be pressure from relatives to recommend Assisted Dying for someone who is not well but is also known to have financial assets which could then be released.

3. A diagnosis may appear terminal because it has been aggravated by another condition such as depression.

What is the definition of a Health care professional?
The person concerned in this context should be medically qualified either a general medical practitioner or of consultant status.

Section 11

What are the qualifications and experience of the “Health Care Professional” who would be appointed to administer the intravenous medication to achieve death? There is a significant danger of the person/persons concerned being stereotyped. Is this person one of the two medical practitioners who have confirmed a terminal diagnosis. If not, then administering a lethal dose by another practitioner could be construed under some circumstances as manslaughter or worse.

We enclose a copy of an article by Madeline Grant on page 15 of The Daily Telegraph dated 25 January 2023 which amplifies our causes for concern.

John Ormrod Lee Retired Consultant Surgeon, Nobles Hospital [Signatures redacted]

Anne Maureen Lee Retired Paediatrician, Nobles Hospital

It's reckless to trust the NHS with assisted dying

he evidence from the US, anada and Europe shows hat legalising euthanasia eally is a slippery slope

ADELINE GRANT

The Very Clever People often employ a line of argument that goes something like this. The lippery slope is not a valid response to n argument for change; simply a fear ctic used by the dim-witted when ey've run out of reasonable points to ake. Slippery-slope arguments are ommonly considered the height of nsophistication; the rhetorical quivalent of having a "live, laugh, ve" poster on your wall. The rown-Ups™ do not use it in their igh-calibre discussions, and nor, erefore, should anyone else.

Except of course, the slippery slope emains as well-lubricated as ever. Far om being a moron's fallacy, again and gain it provides an accurate analysis human nature, and our tendency to row ourselves down hills, political d personal – visible in everything om income tax to lockdown policy to at family-sized bar of chocolate you id would last you a week. This may ot be how we'd like to conduct politics, since it goes against our idealistic view of ourselves. But, time and again, it has been vindicated.

The Scottish Parliament will shortly debate a new assisted suicide bill. But analysing the experience of euthanasia around the world sets off deafening alarm bells. The assisted dying lobby is adamant that the law can contain sufficient safeguards to protect the vulnerable. History, however, shows that safeguards initially introduced are invariably removed, as happened in Belgium and the Netherlands, both of which have expanded their remit to include the euthanasia of children.

In Oregon, one of the US states where assisted dying is legal, the law first applied only to patients with terminal diagnoses and months to live. Yet a recent data report found examples of patients being granted assisted dying not because they were terminally ill, but suffering from conditions of old age, such as arthritis or complications from a fall.

In ultra-permissive Canada, the situation is less slippery slope, more the north face of the Eiger. Canadian law has endlessly expanded the remit and reach of its euthanasia programme ever since its inception. In 2021, the rules were amended to remove the requirement for a natural death to be "reasonably foreseeable". That year, 10,064 people used MAiD (Medical Assistance in Dying) provisions to end their lives, accounting for 3.3 per cent of all deaths in Canada – a 32.4 per cent increase from 2020.

In March, the criteria will expand again to include those suffering from mental health problems as their sole condition, despite the inherent difficulty of ascertaining whether mentally ill individuals are always capable of giving informed consent.

Harrowing tales have surfaced of disabled people, those in financial straits or simply tired of life, choosing to end their lives. Last month, a study from the *American Journal of Transplantation* revealed that Canada leads the world in organ donation from assisted dying.

Those in favour of evidence-based policy need to have an answer to the chilling experience of Canada, where lawmakers appear to have graduated from mass euthanasia to organ harvesting. Ethical questions shouldn't just focus on those suffering excruciating pain in their final days; they should also consider whether it is even possible to legislate so as only to do the right thing and never err.

How confident can we be that this will not happen in Britain? Everything points to strong incentives for an equally nightmarish experience; an overstretched health service, an ageing population, a social care crisis, the fact that many households are cash-poor yet asset-rich, with their "inheritance" tied up in the bricks and mortar of the family home.

There is a coldly utilitarian approach to life in other ways. It is not uncommon to hear that certain people should be denied medical treatment; polls suggest that over half of the population believe the NHS should not fund treatment if a patient's illness is a direct consequence of smoking.

Then there is our uniquely dysfunctional relationship with the health service. During lockdown, British citizens proved adept at "protecting" the NHS. The stay-at-home messaging landed rather too well, leading to numerous avoidable deaths as fearful individuals failed to present at A&E. That same wish "not to be a bother" persists, especially among the elderly, and could surely be abused by opportunistic relatives. How do we know this? According to a Health Canada survey, more than 35 per cent of Canadians who died by MAiD in 2021 felt they were "a burden on family, friends or caregivers".

When assisted dying was debated in the House of Lords, it drew thoughtful contributions from both sides. Yet the Scottish Parliament is a unicameral legislature, with no "House of Review" to scrutinise laws. Judging by its handling of the botched Offensive Behaviour at Football Act, and, more recently, the Gender Recognition Reform Bill, it is not at all clear that this would be the best place for a measured and sober discussion of the risks.

The Archbishop of Canterbury put it well when he outlined his reservations at the Lords' debate. "The sad truth is that not all people are perfect, not all families are happy, not everyone is kind and compassionate. No amount of regulation can make a relative kinder or a doctor infallible. No amount of safeguards can perfect the human heart." Amen to that.