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Code of Practice

Capacity Act 2023

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Contents

Introduction

The Capacity Act 2023 ("the Act") provides a statutory framework for people in the Isle of Man who lack capacity to make decisions for themselves, or who have capacity but wish to prepare for a time when they may lack capacity. The Act received Royal Assent on 25 April 2023 and will come into force via a staged commencement with the first stage taking effect in April 2027.

Section 44 of the Act (Codes of Practice) requires the Department of Health and Social Care ("the Department") to issue a Code of Practice (the "Code") that provides essential guidance to support the legal framework set out under the Act and explain how the provisions in the Act are to operate in practice.

The Code is not law, but it does have statutory force. This means that certain categories of people have a legal duty to have regard to it when working with or caring for individuals who may lack capacity to make decisions for themselves. The Act does not impose a legal duty to "comply" with the Code. However, if the relevant guidance in the Code has been ignored the reasons for this departure must be clearly justified and recorded.

As the Act and the Code emphasise, the best interests of the person who lacks capacity must always be considered.

Once the Act is fully in force, the Categories of people that are required to have regard to the Code include anyone who is:

- an attorney under a Lasting Power of attorney
- persons assessing whether another person has capacity in relation to any matter
- persons acting in connection with the care or treatment of another person (including those being paid for acts for or in relation to a person who lacks capacity)
- persons carrying out research in reliance on any provision made under the Act, and
- persons appointed as receivers under Part 7 of the Mental Health Act 1998.

Those assessing someone's capacity, or acting in connection with the care and treatment of another person, in a professional manner may include:

- healthcare professionals
- social care professionals, and
- others who may, from time to time, be involved in the care of individuals who lack capacity to make the decision in question.

People who are being paid to carry out actions for or in relation to a person who lacks capacity may include:

- care assistants in care homes
- care workers providing domiciliary care services
- personal assistants and support workers, and
- others who may have been contracted to provide a service to people who lack capacity to consent to that service, for example staff at a day care centre or at an activity group.

The Act also applies more generally to anyone who provides care for, or support to, a person who lacks capacity to make specific decisions. Although such individuals may not be under a legal duty to have regard to the Code, they should, so far as they are aware of it, follow the guidance it contains. Doing so will assist them in understanding and applying the Act correctly and appropriately.

The above mentioned does not negate or amend the rights of an individual (data subject) or the responsibilities of others (processors and / or controllers) as set out in the Data Protection Act 2018 or its underlying Orders or Regulations. These rights and responsibilities can be found in the Data Protection (Application of GDPR) Order 2018 and shall be referenced throughout this document as 'the Applied GDPR'.

What does the Code provide guidance on?

The Code explains the Act and its key provisions.

Chapter 1 introduces the Capacity Act 2023.

Chapter 2 sets out the seven statutory principles behind the Act and the way they affect how it is put in practice.

Chapter 3 explains how the Act makes sure that people are supported to make their own decisions as far as possible.

Chapter 4 explains how the Act defines 'a person who lacks capacity to make a decision' and sets out a clear test for assessing whether a person lacks capacity to make a specific decision at the time it needs to be made.

Chapter 5 explains what the Act means by acting in the best interests of someone lacking capacity to make a decision for themselves, and describes the checklist set out in the Act for working out what is in someone's best interests.

Chapter 6 explains how the Act protects people who provide care or treatment for someone who lacks the capacity to consent to the action or decision being taken.

Chapter 7 explains those parts of the Act which can apply to children and young people and how these relate to other laws affecting them.

Chapter 8 describes the role of the court in making decisions or declarations in cases where there is no other way of resolving a matter affecting a person who lacks capacity to make the decision in question.

Chapter 9 explains how the Act relates to the Mental Health Act 1998.

Chapter 10 explains the new offences of ill-treatment and deliberate neglect under the Act, and the protections in place for individuals who are unable to make decisions for themselves.

Chapter 11 examines the various ways that disagreements and disputes over decisions made under the Act or otherwise affecting people who lack capacity to make relevant decisions can be resolved.

Chapter 12 summarises how the laws about data protection and freedom of information relate to the provision of the Act.

Areas of the Act not covered by the Code and pending implementation

It is acknowledged that certain provisions of the Act, including Advance Decisions to Refuse Treatment (ADRT), Lasting Powers of Attorney (LPA), supervisory functions, safeguards relating to

research, and formal processes concerning restrictions on a person's liberty, are not yet in force. As such, the Code does not provide guidance on these areas at this stage. Instead, it focuses on the currently implemented aspects of the legislation, while recognising that further guidance will be developed and introduced as these provisions are enacted through the phased implementation programme. In the interim all users of the Code must continue to operate within existing legal and policy frameworks when addressing matters related to these areas.

Using the Code

Throughout the Code of Practice, the Capacity Act 2023 is referred to as "the Act", and all section references relate to that Act unless otherwise stated. References to sections of the Act are given in the form section 4(1), with subsection numbers shown in brackets.

Where provisions from other legislation are referred to, the full title of the relevant Act will be used (for example, "the Mental Health Act 1998"), unless otherwise indicated.

The Code of Practice is referred to as "the Code".

Scenarios used in the Code

The Code includes many example scenarios, using imaginary characters and situations. These are intended to help illustrate and provide guidance as to what is meant in the main text of the Code. The scenarios should not in any way be taken as templates for decisions that need to be made in similar situations.

What does it mean when we talk about a person who 'lacks capacity'?

Whenever the term 'a person who lacks capacity' is used, it means a person who lacks capacity to make a specific decision or take a specific action for themselves at the time it needs to be taken. This reflects the fact that people may lack capacity to make some decisions for themselves but will have capacity to make other decisions. For example, they may have capacity to make small decisions about day-to-day issues such as what to wear or what to eat but lack capacity to make more complex decisions about financial matters.

It also reflects the fact that a person who lacks capacity to make a decision for themselves at the time it needs to be taken may be able to make that decision at a later date. For example, they may have an illness or condition that means their capacity changes. Alternatively, it may be because at the time the decision needs to be made, they are unconscious or barely conscious, whether due to an accident or being under anaesthetic, or their ability to make a decision may be affected by the influence of alcohol or drugs.

Finally, it reflects the fact that while some people may always lack capacity to make some types of decisions, for example due to a condition or severe learning disability that has affected them from birth. Others may learn new skills that enable them to gain or regain capacity to make decisions for themselves. Chapter 4 provides a full definition of what is meant by 'lacks capacity'.

What is the legal status of the Code? Where does it apply?

The Code has statutory force in the Isle of Man. This means that certain categories of people are under a legal duty to have regard to it when acting under the Act, including when making decisions or taking actions on behalf of individuals who may lack capacity.

Its application is not limited to formal care or treatment settings but extends to any situation where the Act is engaged.

What happens if people don't comply with the Code?

A failure to follow the Code may be relied on as evidence in civil or criminal proceedings where the court or tribunal considers it relevant. If a court or tribunal finds that a person making decisions for someone who lacks, or may lack, capacity has not acted in that person's best interests, it can take their non-compliance with the Code into account as evidence. For this reason, anyone involved in caring for or making decisions on behalf of a person who lacks, or may lack, capacity should be familiar with the Code.

Where can I find out more?

The Code is not an exhaustive guide or complete statement of the law. Under the Act the Department may revise the Code from time to time and may also issue more than one Code of Practice to provide guidance on specific capacity matters. Many organisations provide guidance on capacity related matters.

Some organisations produce materials to help people who need support to make decisions and for those who support them. Some of this material is designed to help people with specific conditions, such as Alzheimer's disease or a learning disability.

Alternative formats

The Code can be made available in other formats on request.

FAQ

Who must follow the Code?

Anyone acting in a professional or formal capacity under the Act must follow the Code. This may include:

- health professionals, for example consultants, doctors, nurses, allied health professionals
- social care professionals, for example social workers, safeguarding leads, safeguarding teams, community care staff
- care providers, for example care home managers, care home staff, domiciliary/home care workers, supported living staff
- emergency and front-line services, for example police officers, paramedics, ambulance staff, emergency responders dealing with vulnerable people
- public body staff, for example government workers, regulatory bodies such as Registration and Inspection, Department of Health and Social Care
- court and legal system, for example legal professionals, court officers or
- anyone with legal authority to act on behalf of the person in relation to financial or property matters, for example attorneys acting under an Enduring Powers of Attorney, court appointed receivers and appointees.

Family and informal carers are not legally required to follow the Code in the same way but are expected to have regard to it when making decisions.

How is capacity assessed?

Capacity Act 2023, section 4 and 5.

Capacity is assessed using the legal test as set out in the Act:

A person is considered to lack capacity if, at the time a decision needs to be made, they are unable to make that specific decision because of an impairment or disturbance in the functioning of their mind or brain.

A person may have capacity for some decisions (e.g. daily choices) while lacking capacity for more complex ones (e.g. financial or medical decisions).

What are the seven statutory principles?

Capacity Act 2023, section 3.

The following seven principles underpin all actions and decisions made under the Act:

1. Assume capacity unless established otherwise.
2. Do not assume lack of capacity because of age, appearance, condition or behaviour.
3. Take all practicable steps to help the person decide.
4. People may make unwise decisions, that does not mean they lack capacity.
5. Actions taken on behalf people lacking capacity must be in their best interests.
6. Decisions taken on behalf people lacking capacity must be in their best interests.
7. Choose the least restrictive option that still meets the purpose.

The Code explains how these principles must be applied in real life.

Can someone's capacity change?

Capacity Act 2023, section 4(2) and 6(5).

Yes. An impairment or disturbance in the functioning of the mind or brain may be temporary or permanent. This means a person's capacity may fluctuate due to:

- illness
- medication
- mental health conditions
- brain injury
- intoxication
- recovery or rehabilitation.

Support must be adapted accordingly, and decisions postponed when possible if the person is likely to regain capacity.

Does the Code apply to children and young people?

Capacity Act 2023, section 4(4) and Chapter 7 of the Code.

The Act relates primarily to people aged 16 and over. The Code provides dedicated guidance on how the Act interacts with children and young people, and other legal frameworks within Chapter 8.

What decisions can never be made on someone's behalf?

Capacity Act 2023, section 38 to 40.

Some decisions remain so personal that no one can make them for a person lacking capacity, including:

- consenting to marriage or civil partnership
- consenting to sexual relations
- consenting to end a marriage or civil partnership
- consenting to adoption
- decisions governed by mental health legislation
- voting in elections.

What does "best interests" mean?

Capacity Act 2023, section 6 and Chapter 5 of the Code.

When a person lacks capacity, any action done or decision made must be in their best interests. This requires the decision-maker to:

- consider the person's past and present wishes, feelings, beliefs, values
- involve them as much as possible
- consult with those who know the person well
- consider less restrictive alternatives
- weigh all relevant circumstances.

Best interests is not about what the decision-maker would do, but what is right for that individual.

Who makes the best interests decision?

The decision-maker is the person responsible for making a particular decision at the time it needs to be made depending on the type of decision and the situation.

Examples:

- a doctor might make decisions about treatment, prescribing medication or surgery
- a social worker may make decisions about care arrangements, such as a care package or where a person should live.

The decision-maker will vary depending on the specific decision being made.

What support must be provided to help someone make a decision?

Capacity Act 2023, section 3(4) to 5(2).

All practicable steps must be taken to support a person to make their own decision. Support should be tailored to the needs of the individual and may include:

- using clear language or visual aids
- choosing the best time and location
- involving trusted people
- treating medical issues affecting cognition
- allowing extra time or breaking decisions into parts, and
- using alternative communication (e.g. signs, technology, Makaton).

Can restraint ever be used on someone who lacks capacity?

Capacity Act 2023, section 9(1-2) and Chapter 6 of the Code.

If there is reasonable belief that the person lacks capacity, restraint can only be used if:

- it is necessary to prevent harm to the person, and it is proportionate to the likelihood and seriousness of that harm and
- it is the least restrictive option and used for the shortest possible time.

How does the Act interact with the Mental Health Act 1998?

Chapter 9 of the Code.

If a person is detained under the Mental Health Act 1998 ("MHA") for treatment of a mental disorder, the MHA takes priority for treating mental disorder, but the Capacity Act may still apply to other decisions such as physical healthcare.

Protecting those who lack capacity

Chapter 10 of the Code.

Key protections include:

- assumption of capacity
- support to make decisions
- best interests requirement
- least restrictive option

- safeguards against abuse or poor practice through the introduction of two new criminal offences
- clear rules on restraint, and
- court involvement for complex or disputed cases.

What if there is disagreement about a person's capacity or best interests?

Chapter 11 of the Code.

Options include:

- asking for a second opinion
- holding a best interests meeting
- mediation
- the organisation's complaints process, and
- applying to the court for a decision if the dispute cannot be resolved.

Glossary

the Act	Capacity Act 2023.
Adult	For the purposes of the Act and the Code, references to age apply to persons who are aged 16 years or over.
Adult at Risk Vulnerable Adult	The term "vulnerable adult" is used in the Safeguarding Act 2018, however in practice the term Adult at Risk may also be used to describe a person aged 18 or over who: • has care and support needs • is experiencing or at risk of abuse or neglect • is unable to protect themselves because of those needs
Advance Directive	For the Code a term used to describe where a person has made an advance decision when they had capacity to refuse a specified medical treatment in defined future circumstances. Though not legally binding, where they exist, they should be used to help find out what someone's wishes and feelings might be, as part of working out their best interests.
Advocate (Legal)	A legal practitioner authorised to practise as an advocate in the Isle of Man, including advising on Manx law and representing clients before the Isle of Man courts.
Advocacy (Health & social care) Independent Advocacy Services	Independent advocacy is a service that ensures individuals are supported to have their voices heard, their wishes and feelings represented, and their rights upheld in decisions affecting their lives, by an advocate who operates wholly independent of care providers, decision-makers, and commissioning authorities, and whose sole duty is to the individual, free from conflicts of interest. Under the Act this is not a statutory function.
Appointee	An individual appointed under social security legislation to act as an appointee, enabling them to claim and manage State benefits on behalf of a person who lacks capacity to manage their own claim. However, an appointee's authority is strictly limited to benefit-related income and does not extend to other assets, savings or property.
Approved social worker ASW	Within the Mental Health Act 1998, an Approved Social Worker (ASW) is a professionally qualified and authorised social worker who carries out specific statutory functions under the Mental Health Act 1998. They are specially trained and experienced in mental disorder and mental health law. Functions include coordinating assessments that may lead to them making an application for compulsory detention or guardianship, consider the least restrictive options available, and acting as a safeguard for service users' rights by ensuring that compulsory powers are used lawfully, proportionately, and only when necessary. They also consult with the nearest relative and other professionals.
Assessor	A suitably skilled and competent person, appropriate to the decision, who undertakes a capacity assessment by applying the

	statutory principles and functional test to determine whether a person can make a specific decision. This role is not formally defined by the Capacity Act 2023.
Best interests	Is the legal requirement under the Act that any decision or action made on behalf of a person who lacks capacity must be made for their overall benefit, taking into account all relevant circumstances, including their wishes and feelings, beliefs and values, the views of others, and the least restrictive option available.
Capacity	The ability to make a decision about a particular matter at the time the decision needs to be made. The legal definition of a person who lacks capacity is set out in section 4 of the Act (Lack of capacity).
Carer	The role of the carer is different from the role of a professional care worker. A carer is someone who provides, or intends to provide, unpaid care and support to someone whose health, wellbeing or daily functioning would be adversely affected without that help.
Care worker	Someone employed to provide care and support. They could be employed by the person themselves, by someone acting on the person's behalf or by a care agency.
the Code	Capacity Act 2023 Code of Practice.
Complaint	An expression of dissatisfaction about a service, action, decision, behaviour, conduct, delay, communication or the way a process has been carried out. A complaint can be made formally or informally.
Consent	A person's voluntary and informed agreement to an act or decision.
Court	In the chapters throughout the Code 'court' refers to the Isle of Man Courts of Justice.
Covert treatment	The administration of medication or other treatment to a person without their knowledge, usually by disguising it in food or drink.
Data Protection Act 2018	An Act to enable provision to be made to adequately protect personal data; to regulate the control and processing of personal data; and for connected purposes.
Data subject	The individual to whom personal data relates.
Decision-maker	The person responsible for making the decision on behalf of someone who lacks capacity. This role is not formally defined by the Capacity Act 2023.
Deliberate neglect (Offence) Wilful neglect	Section 42 of the Act (Ill-treatment or neglect) introduces a criminal offence of deliberate neglect of a person who lacks capacity (otherwise known as wilful neglect.) An intentional or deliberate omission or failure to carry out an act of care by

	someone who has care of a person who lacks (or whom the person reasonably believes lacks) capacity to care for themselves.
the Department	Department of Health and Social Care.
Dispute	A sustained or formal disagreement where early or informal resolution has not been possible and escalation is required.
European Convention on Human Rights ECHR	An international treaty protecting fundamental human rights and freedoms.
Enduring Power of Attorney EPA	A document created under the Powers of Attorney Act 1987 appointing one or more people to manage the donor's property and financial affairs if the doner later loses capacity to do so themselves.
Executive function	Mental skills that enable a person to plan, organise, regulate behaviour, consider consequences and follow through on decisions.
Fluctuating capacity	A person's ability to make a decision that changes over time, meaning they may have capacity at some times but not at others. This may occur, for example, due to conditions such as dementia or schizophrenia, or due to the effects of drugs or alcohol.
GDPR The Applied GDPR	General Data Protection Regulation (EU)2016/679 as applied on the Isle of Man, taking the meanings given in the Data Protection (Application of GDPR) Order 2018.
Guardian ad litem	A person appointed by the court, independently of the Act, to represent and protect the best interests of a child during legal proceedings. They do not act for the parents or any other party; their sole role is to help the court understand what outcome is best for the child's welfare.
Guardianship	Under the Mental Health Act 1998, a guardian is appointed to help manage the care, welfare, and living arrangements of a person with a mental disorder who needs support in the community but does not require detention in hospital.
Harm	In accordance with the Act, harm includes physical, psychological, financial or other harm, and what constitutes harm will vary depending on the circumstances.
Health and Social Care Ombudsmen Board	The HSCOB is a statutory body set up to review unresolved complaints made about health and social care services which have been provided by Manx Care or services commissioned by Manx Care.
Ill-treatment (Offence)	Section 42 of the Act (Ill-treatment or neglect) introduces a criminal offence of ill-treatment of a person who lacks capacity. For a person to be found guilty of ill-treatment, they must either have deliberately ill-treated the person or be reckless as to whether they were ill-treating the person or not.

Impairment or disturbance of the mind or brain	A condition or effect that affects how the mind or brain functions, whether temporary or permanent, and which may affect a person's ability to make a decision.
the Individual the person, 'P'	Unless otherwise stated, references in the Code to "the individual" mean the person who is at the centre of the decision-making process under the Capacity Act 2023 i.e. the person who lacks, or may lack, capacity to make the specific decision at the relevant time. For ease of reading, the Code uses a range of terms to identify the individual (for example "the person" or "the patient"), these are not intended to indicate different legal statuses or different people unless expressly stated.
Information Commissioner's Office ICO	An independent authority responsible for upholding the public's information rights and promoting and enforcing compliance with the Island's information rights legislation.
Least restrictive option	The requirement to consider whether the purpose of an act or decision can be achieved in a way that is less restrictive of the person's rights and freedoms.
Legal Authority	Those who are legally allowed to act, on behalf of a person who lacks capacity, in relation to specified matters. In the Code, this refers to a person acting under Enduring Power of Attorney or a Receiver appointed under the Mental Health Act 1998, and only within the scope of the authority they have been given.
Life-sustaining treatment	The Act states this is treatment that, in the view of a person providing health care for the person concerned, is necessary to sustain life.
Litigation friend	A person appointed by the court to conduct legal proceedings on behalf of, and in the name of, someone who lacks capacity to conduct the litigation or to instruct a legal advocate themselves. This is set out 3.13 of the Rule of the High Court.
Makaton	Makaton is a unique language programme that uses symbols, signs and speech to enable people to communicate.
Mediation	A process for resolving disagreement in which an impartial and independent third party (the mediator) helps to find a mutually acceptable resolution.
MHA	Mental Health Act 1998.
MHA Code	Mental Health Act Code of Practice.
Multi-disciplinary team	A team of professionals with different skills that contribute to a person's care.
Nearest relative	A legally defined role determined under the Mental Health Act 1998, with a fixed statutory hierarchy (e.g. spouse/partner, then children, then parents, then siblings etc.).

Next of kin	There is no statutory definition of "next of kin". It generally means a person's identified close contact for communication and support. It confers no automatic legal rights or decision-making authority, including no automatic authority to consent to treatment or access confidential information. This is distinct from the "nearest relative" under the Mental Health Act 1998.
Patient	Generally, a patient is any person receiving healthcare services, whether public (Manx Care) or private, including GP patients, hospital inpatients, outpatients, and community patients. Under the Mental Health Act 1998, a patient is a person who is suffering from (or believed to be suffering from) a mental disorder and who is admitted, detained, treated, assessed, or placed under Guardianship as set out in the Mental Health Act 1998.
Practicable	Practicable actions are reasonable, proportionate, appropriate and realistic given the circumstances.
Protection from liability	Legal protection, granted to anyone who has acted or made decisions in line with the Act's principles.
Property	As defined by the Act, this includes anything a person owns or has rights over, such as land, possessions, money, financial assets, and legal rights (for example, the right to make a claim or enforce a payment).
Rights and freedoms	The individual's legal and human rights, including autonomy, dignity, liberty, and freedom from unnecessary restriction or interference.
Reasonable belief	A belief based on proper steps (as set out in the Act), relevant information and sound reasoning - not guesswork or assumptions - that leads the decision-maker to conclude that what they are doing is in the person's best interests.
Receiver	A Receiver is a person appointed by the court under section 103 of the Mental Health Act 1998 to manage the property and affairs of a person who is incapable, by reason of mental disorder, of managing those matters for themselves.
Restraint	Actions that involve using or threatening force, or limiting a person's freedom of movement, whether or not they are resisting.
Statutory principles	The seven legal principles set out in section 3 of the Act (The principles) that must be followed when making decisions or taking actions for a person who lacks capacity. They underpin all decisions made under the Act.
Treatment	As defined by the Act, this includes care, medical intervention, and procedures used to diagnose a condition.

Unwise decision	A decision that others may consider risky, ill-judged or contrary to advice, but which does not of itself indicate that a person lacks capacity to make the decision.
Vulnerable Adult Adult at Risk	See "adult at risk".
Written statements of wishes and feelings	For the purposes of the Code, a person might have made statements before losing capacity about their wishes and feelings regarding issues such as the type of medical treatment they would want in the case of future illness, where they would prefer to live, or how they wish to be cared for. Where they exist, they should be used to help find out what someone's wishes and feelings might be, as part of working out their best interests.

Chapter 1
Capacity Act 2023

Key Points

- The underlying philosophy of the Act is to empower people to make their own decisions where possible.
- The Act provides the legal framework for making decisions and taking actions on behalf of people who lack the capacity to make specific decisions for themselves.
- It applies whenever someone is working with, treating, supporting or caring a person who may lack capacity.
- The Act covers a wide range of decisions made, these can be decisions about day-to-day matters or for major life-changing events.
- Certain decisions can never be made on someone's behalf.
- The Capacity Act sits alongside other legislation (e.g. Mental Health Act 1998, Human Rights Act 2001) which may also apply.
- Anyone required to follow the Act should use the Code as guidance to inform their actions and decisions.

Key Terms

The Act The Capacity Act 2023, which provides the statutory framework for decision making and actions taken on behalf of people who lack capacity.

Assessor The person responsible for assessing whether an individual has the capacity to make a specific decision.

Assumption of capacity The starting point that a person is assumed to have capacity unless it is established otherwise.

Capacity The ability to make a decision about a particular matter at the time the decision needs to be made.

The Capacity Act 2023 (the Act) establishes the legal framework for making decisions and taking actions on behalf of individuals who are unable to decide for themselves. Everyone working with, treating, supporting or caring for an individual who may lack capacity must comply with the Act when supporting or making a decision for that person. The same rules apply whether the decision is regarding a life changing event or a day-to-day situation.

Overview of the Act

1.1 The Act's starting point is that it should be assumed that a person (aged 16 or over) has legal capacity to make a decision for themselves (the right to autonomy) unless it is established that they do not have capacity. A person will lack capacity if an assessment shows that they do not have capacity to make a decision at the time it needs to be made. This is known as the assumption of capacity.

1.2 The Act also states that people must be given all practicable help and support to enable them to make their own decisions or to maximise their participation in any decision-making process.

1.3 The underlying philosophy of the Act is to empower people to make their own decisions where possible and to ensure that any decision made, or action taken, on behalf of someone who lacks the capacity to make the decision or act for themselves is made in their best interests.

1.4 The Act is intended to assist and support people who may lack capacity and to discourage anyone who is involved in caring for someone who lacks capacity from being overly restrictive or controlling. But the Act also aims to balance an individual's right to make decisions for themselves with their right to be safeguarded from harm if they lack capacity to make decisions to protect themselves.

1.5 The Act sets out core principles and framework for making decisions and carrying out actions in relation to a wide range of matters relating to personal welfare, health or social care affecting people who may lack capacity to make specific decisions about these matters for themselves.

1.6 Many of the provisions in the Act are based upon best practice that has been established on the Island, gives regard to the UK's legislation and existing common law principles (i.e. principles that have been established through decisions made by courts in individual cases). The Act clarifies and improves upon these principles and builds on current good practice.

The Act and decisions made, or actions taken

1.7 The Act covers a wide range of decisions made, or actions taken, on behalf of people who may lack capacity to make specific decisions for themselves. These can be decisions about:

- day-to-day decisions, such as what to wear, when to get up, what to buy when shopping or whether to go to the doctor when feeling ill, or
- major life-changing events, such as deciding where to live or undergoing major surgery.

1.8 There are certain decisions which can never be made on behalf of a person who lacks capacity. This is because these decisions are either highly personal to the individual concerned or are governed by other legislation.

Decisions made or actions taken that can never be made under the Act

1.9 Sections 38 (Family matters), 39 (Mental Health Act matters) and 40 (Voting rights), of the Act set out the specific decisions which can never be made or carried out on behalf of another person under the Act; these are summarised below. While the Act does not permit anyone to make a decision about these matters for a person who lacks capacity (for example, consenting to have sexual relations), this does not prevent action being taken to protect a person at risk of abuse or exploitation.

Decisions concerning family matters

1.10 Nothing in the Act permits a decision to be made on someone else's behalf on any of the following matters:

- consenting to marriage or a civil partnership
- giving consent, and remaining consenting, to have sexual relations
- consenting to a divorce order under the Matrimonial Proceedings Act 2003
- consenting to a dissolution order being made in relation to a civil partnership on the basis of two years' separation
- consenting to a child being placed for adoption or the making of an adoption order, or
- discharging parental responsibility for a child in matters not relating to a child's property.

Mental Health Act matters

1.11 Where a person who lacks capacity to consent is currently detained and being treated under Part 4 of the Mental Health Act 1998, nothing in the Act authorises anyone to:

- give the person treatment for mental disorder, or
- consent to the person being given medical treatment for mental disorder.

"Medical treatment", "mental disorder" and "patient" are defined by the Mental Health Act 1998.

Voting rights

1.12 Nothing in the Act permits a decision on voting, at an election for any public office or at a referendum, to be made on behalf of a person who lacks capacity to vote.

Other pieces of legislation that relate to the Act

1.13 The Act operates alongside other legislation that applies to individuals who may lack capacity in relation to specific matters.

1.14 This means that those acting under the Act should also be aware of their obligations under other legislation, including (but not limited to):

- Children and Young Person Act 2001
- Data Protection Act 2018 and the Applied GDPR
- Equality Act 2017
- Fraud Act 2017
- Freedom of Information Act 2015
- Human Rights Act 2001
- Human Tissue and Organ Donation Act 2021
- Mental Health Act 1998
- National Health Service Act 2001
- Powers of Attorney Act 1987
- Regulation of Care Act 2013
- Social Services Act 2011

1.15 Nothing in the Act alters or affects the operation of Manx criminal law. Actions that would amount to offences (including murder, manslaughter, or the abetment of suicide), remain offences irrespective of any question of capacity.

The Act and the Code

1.16 Section 44 of the Act (Codes of Practice) sets out the purpose of the Code, which is to provide guidance for specific people in specific circumstances. Section 45 of the Act (Codes of Practice: procedure), explains the procedures that had to be followed in firstly preparing a code or code(s). This includes consulting on its contents and necessitating that the Code is laid before Tynwald. Section 44(5) (Codes of Practice) sets out the categories of people who are placed under a legal duty to 'have regard to' the Code and gives further information about the status of the Code.

Chapter 2
Statutory Principles

Key Points

- There are seven statutory principles which underpin all decision-making and actions taken under the Act.
- Every person has the right to make their own decisions if they have the capacity to do so. Family carers and health or social care staff must assume that a person has the capacity to make decisions, unless it is established that the person does not have capacity.
- Before concluding that an individual lacks capacity to make a particular decision, all practicable steps must have been taken to help them make their own decision.
- A person who makes a decision that others think is unwise should not automatically be considered as lacking the capacity to make the decision.
- Any act done for, or any decision made on behalf of, someone who lacks capacity must be in their best interests and should be an option that is the least restrictive of their basic rights and freedoms, as long as it is still in their best interests.

Key Terms

Adult For the purposes of the Act and the Code, references to age apply to persons who are aged 16 years or over.

Practicable steps Practicable actions are reasonable, proportionate, appropriate and realistic given the circumstances.

Rights and freedoms The individual's legal and human rights, including autonomy, dignity, liberty, and freedom from unnecessary restriction or interference.

Unwise decision A decision that others may consider risky, ill-judged or contrary to advice, but which does not of itself indicate that a person lacks capacity to make the decision.

Least restrictive option The requirement to consider whether the purpose of an act or decision can be achieved in a way that is less restrictive of the person's rights and freedoms.

2.1 In this chapter, as throughout the Code, a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made. Section 3 of the Act (The principles) sets out seven statutory principles, the values that underpin the legal requirements in the Act. This chapter provides guidance on how people should interpret and apply the principles.

2.2 The Act is intended to be enabling and supportive of people who lack capacity, not restricting or controlling of their lives. The Act is intended to protect people who lack capacity to make specific decisions, while also maximising their ability to make decisions and supporting their participation in the decision-making process as far as possible.

The seven Statutory Principles

2.3

The seven statutory principles	
Principle 1	A person must be assumed to have capacity unless it is established that the person lacks capacity.
Principle 2	A person is not to be assumed to lack capacity because of that person's: (a) age; (b) appearance; (c) condition (whether permanent or temporary); (d) behaviour (or an aspect of that behaviour).
Principle 3	A person is not to be treated as unable to make a decision unless all practicable steps to help that person to do so have been taken without success.
Principle 4	A person is not to be treated as unable to make a decision merely because that person makes or may make an unwise decision.
Principle 5	An act done under the Act for or on behalf of a person who lacks capacity must be done in that person's best interests.
Principle 6	A decision made under the Act for or on behalf of a person who lacks capacity must be made in that person's best interests.
Principle 7	Before an act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

Following the principles and applying them to the Act's framework for decision-making will help to ensure that appropriate actions are taken in individual cases and provide guidance for difficult or uncertain situations.

The role of the statutory principles

2.4 The statutory principles aim to:

- empower people and encourage them to make their own decisions where possible, with support if needed, and not to restrict or control their lives
- protect the rights and interests of people who lack capacity, and
- help people take part, as much as practicable, in decisions that affect them.

2.5 The principles reinforce that decisions made about a person align as much as possible, within the law, with that person's wishes and feelings (whether expressed orally, in writing or by behaviour), beliefs and values (that would be likely to influence the person's decision if they had capacity). Failure to observe the principles may leave organisations vulnerable to legal challenge.

Applying the statutory principles

Principle 1 Section 3 (2)	A person must be assumed to have capacity unless it is established that person lacks capacity –

2.6 This principle states that every person has the right to make their own decisions – unless it is established that they lack the capacity to make a particular decision when it needs to be made. This has been a fundamental principle of best practice for many years, and it is now mandated in legislation.

2.7 It is important to balance a person's:

- right to make a decision with
- their right to safety and protection, where they lack capacity to make decisions needed to protect themselves.

2.8 The starting point must always be to assume that an individual has capacity, unless and until an assessment determines otherwise.

2.9 Chapter 4 explains the Act's definition of 'lack of capacity' and the processes involved in assessing capacity.

2.10 The presumption of capacity should not be used as a reason to avoid carrying out an assessment. Where there is doubt about a person's ability to make a decision, a proper assessment must always be undertaken.

2.11 The responsibility lies with the person proposing to take the intervention to demonstrate that the individual lacks capacity; it is not for the individual to prove that they have capacity.

Principle 2 Section 3 (3)	A person is not to be assumed to lack capacity because of that person's, — (a) age; (b) appearance; (c) condition (whether permanent or temporary); (d) behaviour (or an aspect of that behaviour).

2.12 This principle emphasises that an assessment of someone's capacity should not be based on factor such as age, appearance, condition or the way a person is behaving.

2.13 'Appearance' covers all aspects of the way people look. This could include:

- skin colour
- tattoos
- piercings
- the way people dress including religious dress
- physical characteristics of certain medical conditions such as scars, muscle spasms caused by a neurological conditions or features associated with a genetic disorder.

2.14 'Condition' includes:

- physical disabilities
- learning difficulties and disabilities
- mental illness
- dementia
- conditions affecting the brain
- illness related to age
- temporary conditions for example, drunkenness or unconsciousness.

2.15 Aspects of 'behaviour' might include:

- highly expressive (e.g. shouting or gesticulating)
- withdrawn for example, (e.g. talking to oneself or avoiding eye contact)
- changes in behaviour, including regarding decision-making
- related to the person's cultural background.

Principle 3 Section 3(4)	A person is not to be treated as unable to make a decision unless all practicable steps to help that person to do so have been taken without success.

2.16 It is important to take all practicable steps to support a person in making a decision for themselves before concluding that they lack capacity. Individuals with an illness or disability that affects their ability to decide should be given appropriate support to enable them to make as many decisions as possible.

2.17 This principle aims to stop people being wrongly labelled as lacking capacity to make particular decisions, without evidence. Because it encourages individuals to make decisions for themselves, it also helps prevent unnecessary interference in their lives.

2.18 The kind of support people might need to help them make a decision varies. It depends on personal circumstances, the kind of decision that has to be made and the time available to make the decision. It might include:

- using a different form of communication (for example, non-verbal communication)
- providing information in a more accessible form (for example, photographs, drawings, or films)
- considering where and when a decision is made – for some people it may be better that they make a decision at a particular time of day, or in a familiar setting
- treating a medical condition that may be affecting the person's capacity
- using a structured programme to improve a person's capacity to make particular decisions (for example, helping a person with a learning disability to acquire new skills)
- involving an independent advocate or trusted friend (who can advise, or support the person) or
- ensuring the person is spoken to or given written information in their preferred language.

Chapter 3 gives more information on ways to help people make decisions for themselves.

2.19 Anyone supporting a person who may lack capacity should not use excessive persuasion or allow their support to become pressure. This might include behaving in a manner which is overbearing or dominating, or seeking to influence the person's decision, and could push a person into making a decision they might not otherwise have made. It is important, however, to provide appropriate advice and information, outlining the choices a person has and the implications of making or not making a decision.

2.20 In some situations decisions cannot be delayed while a person gets support to make a decision. This can happen in emergencies or when an urgent decision is required (for example, immediate medical treatment). In such situations, the only practical and appropriate step may be to keep the person informed about what is happening and the reasons for it.

Principle 4 Section 3(5)	A person is not to be treated as unable to make a decision merely because he makes an unwise decision.

2.21 Everyone has their own beliefs, values, preferences, and attitudes. A person should not be assumed to lack capacity simply because others consider their decision to be unwise, even where family members, friends, or health and social care professionals disagree. The Act is concerned with a person's ability to make a decision, not the outcome of that decision. This principle reflects and upholds a person's fundamental right to make their own choices and to determine their own life.

2.22 There may be cause for concern if somebody:

- repeatedly makes unwise decisions that put them at significant risk of harm or exploitation
- makes a particular unwise decision that is obviously irrational or out of character.

2.23 These circumstances do not necessarily mean that somebody lacks capacity. Individuals have a right to make decisions that others may feel are unwise, however, there might be a need for further investigation taking into account:

- the person's past decisions and choices
- whether the person has developed a medical condition or disorder that is affecting their capacity to make particular decisions?
- whether the person may be subject to undue pressure or influence, and
- whether the person needs more information or support to help them understand the consequences of the decision they are facing?

2.24 Where there is a reasonable basis to doubt that a person has capacity to make a decision, their capacity must be assessed in accordance with the test set out in the Act.

Scenario

Decisions that cause concern

Mr R has an acquired brain injury following a car accident. Before the accident, he managed his finances well and believes he retains this ability. However, those close to him are concerned, as he appears unable to keep within a budget.

A capacity assessor asks Mr R what a budget is, and he explains that it is a set amount of money available to spend over a period or on particular items. When asked about the risks of overspending, he demonstrates a clear understanding of debt and its consequences.

The assessor notes that Mr R regularly exceeds his monthly allowance of £2,000 and asks him about this. Mr R responds that the amount is insufficient for his needs. He explains that he spends £350 per month on trainers and around £750 taking friends out to dinner, which he considers reasonable.

Although Mr R's spending decisions may appear unwise and give rise to concern, this alone does not mean he lacks capacity. The Act requires an assessment of his ability to make the decision, not a judgment about the outcome of that decision.

Principle 5

Section 3(6) An act done under this Act for or on behalf of a person who lacks capacity must be done in that person's best interests.

2.25 The principle of acting in the best interests is well established best practice for anyone working with, treating, supporting or caring for a person who lacks capacity.

2.26 When an act is carried out on behalf of a person who lacks capacity, it must be done in their best interests. This requires careful consideration of the person's wishes and feeling, including those expressed previously. Their usual behaviour, cultural background and any factors that are important to them should be taken into account. As far as practicable, the person should be involved and consulted before any action is taken. Best interests are not determined by general societal standards; they must reflect what matters to the individual. Wherever appropriate, those involved in the person's care, or others with an interest in their welfare, should also be consulted, and their views considered as part of the decision-making process.

Principle 6
Section 3(7)

A decision made under this Act for or on behalf of a person who lacks capacity must be made in that person's best interests.

2.27 Best interests decisions should consider the issues from the person's own point of view, taking into account their wishes and feelings, involving them in the decision wherever possible, and including wider considerations than their 'medical' or 'financial' interests. As with principle 5, decision-makers must reasonably consult others involved in caring for the person or with an interest in their welfare and take into account their view.

2.28 If the individual has capacity to make a decision, a best interests decision cannot be made for them even if someone believes they have a 'duty of care' towards the person.

Principle 7
Section 3(8)

Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

2.29 Before somebody makes a decision or acts on behalf of a person who lacks capacity to make that decision or consent to the act, they must always question if they can do something else that would interfere less with the person's basic rights and freedoms.

2.30 Where there is more than one option, it is important to explore ways that would be less restrictive or allow the most freedom for a person who lacks capacity to make the decision in question. However, the final decision must always allow the original purpose of the decision or act to be achieved.

2.31 Any decision or action must still be in the best interests of the person who lacks capacity. So sometimes it may be necessary to choose an option that is not the least restrictive alternative if that option is in the person's best interests. In practice, the process of choosing a less restrictive option and deciding what is in the person's best interests will be combined and applied each time a decision or action may be taken on behalf of a person who lacks capacity to make the relevant decision.

Scenario

Least restrictive alternative

Ms J is in a rehabilitation hospital six months after experiencing a traumatic brain injury. She has some movement in her left hand and very little other movement. A friend has bought her a soft cuddly toy with a long tail which she is just about able to grip.

Ms J has no language yet and little purposeful activity. She enjoys holding the toy moving it across her face for stimulation.

When her parents arrive to visit her one morning, they find she is wearing a boxing glove on her left hand. This prevents her from making any movement. The nurses' rationale is that this is in her best interests as they feared her putting the toy in her mouth and possibly choking.

Ms J's parents point out that a less restrictive option would be to remove the soft toy when she is not monitored, which would keep her safe but would not restrict the only physical movement she has.

Chapter 3
Helping People To Make Their Own Decisions

Key Points

- The Act requires that all practicable steps are taken to support a person to make their own decisions before concluding that they lack capacity.
- The type and level of support required will depend on the nature and significance of the decision, and the person's individual circumstances.
- Support may include:
    - providing information in accessible formats,
    - using appropriate communication methods,
    - choosing suitable timing and settings, or
    - involving trusted people where appropriate.
- Support must not amount to coercion or undue influence.
- In urgent or emergency situations, decisions may need to be made without full support, but the person should still be involved as far as practicable.

Key Terms

Appropriate communication
Communication that is tailored to the person's needs, abilities, and preferences, including the use of alternative or non-verbal methods where necessary.

Practicable Actions that are reasonable, proportionate, appropriate and realistic given the circumstances.

Support to make a decision Actions taken to help a person understand, consider, and communicate a decision, without directing or controlling the outcome.

Trusted person Someone known to the individual who may assist with communication or reassurance, provided their involvement does not compromise the person's autonomy.

Undue influence Pressure or behaviour that overrides or distorts a person's ability to make a free decision, whether intentional or unintentional.

Before deciding that someone lacks capacity to make a particular decision, it is important to take all practicable steps to enable them to make that decision for themselves (statutory principle 3, see Chapter 2, statutory principles). In addition, as section 5(2) of the Act (Inability to make decisions) underlines, these steps (such as helping individuals to communicate) must be taken in a way which reflects the person's individual circumstances and meets their particular needs. This chapter provides practical guidance on how to support people to make decisions for themselves or participate as much as possible in the decision-making process.

How to help someone make a decision

3.1 There are several ways in which a person can be helped and supported to enable them to make a decision for themselves. These will vary depending on the decision to be made, the time-scale for making the decision and the individual circumstances of the person making it.

3.2 To help someone make a decision for themselves, consider the following points:

- providing relevant information
- communicating in an appropriate way
- making the person feel at ease, and
- offering appropriate support.

3.3 The Act applies to a wide range of people with different conditions that may affect their capacity to make particular decisions. The appropriate steps to take will therefore depend on:

- the person's individual circumstances (e.g. somebody with learning disabilities may need a different approach to somebody with dementia)
- the nature of the decision to be made, and
- the time available to make the decision.

3.4 Significant, one-off decisions (such as moving house) will require different considerations from day-to-day decisions about a person's care and welfare. However, the same general processes should apply to each decision.

3.5 The purpose of providing support is to enable the person to make their own decision. While the person offering support may have a view about what decision is best, they must not pressure the individual into making that choice. This is particularly important where the person's life experiences mean they have had limited opportunities to make decisions for themselves. Providing appropriate help and support with decision-making should form a core part of a person-centred approach to the care and support planning process.

Emergency situations

3.6 In emergency situations (e.g. where a person collapses and is brought unconscious into a hospital), urgent decisions will have to be made and immediate action taken in the person's best interests. In these situations, it may not be practicable or appropriate to delay the decision while trying to help the person make their own decisions or to consult those involved in their care or interested in their welfare. However, even in emergency situations, health and social care staff should make reasonable efforts to ascertain the person's wishes, feelings, beliefs, and values (seeking input from others where necessary). They should also communicate with the person and, at a minimum, keep them informed about what is happening.

Informing and communicating effectively

3.7 It is important to provide information that will help the person to make decisions and to tailor that information to the individual's needs and abilities. Information must also be in the easiest and most appropriate form of communication for the person concerned. For example, some people respond better when given information verbally, others may like to read a leaflet before they decide. Some may also require support from a carer or friend who may know how best to communicate with the person, or their preferred way to receive information.

3.8 What information should be provided to the person will depend on the nature of the decision. For example, if the decision concerns medical treatment, the doctor must explain the purpose and effect of the course of treatment and the likely consequences of accepting or refusing treatment.

3.9 Anyone helping someone to make a decision for themselves should follow these steps:

1. Take time to explain anything that might help the person make a decision. It is important that they have access to all the information they need to make an informed decision, including the nature of the decision and why it needs to be made.

2. Try not to give more detail than the person needs as this might confuse them but ensure to include all important relevant information.

3. Explain the risks and benefits. Describe any foreseeable consequences of making the decision, and of not making any decision now or at all.

4. Explain the effects the decision might have on the person and those close to them – including anyone involved in their care.

5 If they have a choice, give them the information for each of the options, in a balanced way.

6 For some types of decisions, it may be important to give access to advice from elsewhere. This may be independent or specialist advice (for example, from a medical practitioner or a financial or legal adviser), but it might simply be advice from trusted friends or relatives.

7 It may be helpful to make a record of the information provided and the steps taken to communicate it.

Communication: General guidance

3.10 To help someone make a decision for themselves, all possible and appropriate means of communication should be tried.

3.11 Consider the following:

- The first step should be to ask the person if they would like any help, or if there is anyone who they would like to be there with them, for example, relatives, friends, a GP, social worker or religious community member.
- Ask people who know the person well about the best form of communication. This may be relatives, friends, carers or other support workers. They may also know somebody the person can communicate with easily, or the time when it is best to communicate with them.
- Use clear language or other aids, for example pictures, objects or illustrations to demonstrate ideas.
- Speak at the right volume and speed, with appropriate words and sentence structure. It may be helpful to pause to check understanding, to ask open questions that check understanding, or show that a choice is available.
- Break down difficult information into smaller points that are easy to understand. Allow the person time to consider and understand each point before continuing.
- It may be necessary to repeat information or go back over a point several times, in order to enable the individual to retain the information long enough to make an effective decision.
- Be aware of cultural, ethnic or religious factors that may influence a person's way of thinking, behaviour or communication. For example, some people may be accustomed to involving members of their community in decision-making. Someone's religious beliefs may influence their approach to medical treatment decisions. Awareness of cultural considerations should be balanced with awareness

of other relevant considerations such as undue pressure or coercion, and safeguarding duties.

Helping people with specific communication or cognitive problems

3.12 Where people have specific communication or cognitive problems, it is important to identify their preferred method of communicating:

- find out how the person is used to communicating. Do they use picture boards or Makaton (signs and symbols for people with communication difficulties) or do they have a way of communicating that is only known to those close to them?
- if the person has hearing difficulties establish their preference (e.g. British Sign Language, visual aids or written messages)
- use a qualified interpreter where appropriate
- consider whether assistive communication technology such as voice synthesisers, keyboards or other computer equipment is available to help the person communicate
- allow more time where the person does not use verbal communication
- recognise that, for people who use non-verbal methods of communication, their behaviour (in particular, changes in behaviour or distress) can provide indications of their feelings
- others may communicate most effectively using computers or other communication technologies. This is particularly true for those with autistic spectrum disorders
- seek advice or support from an appropriate professional where the person has specific communication difficulties such as a speech and language therapist or an expert in clinical neuropsychology.

Scenario:

Making the most of technology

Mr A has a mild learning disability and cerebral palsy. He uses very little verbal communication and relies on assistive technology to communicate effectively. He was admitted to hospital and a surgical intervention was proposed by the medical team. Mr A's communication difficulties and learning disability raised concerns about his capacity to consent to this procedure.

The speech and language team, along with other members of hospital staff, spent time with Mr A explaining the intervention to him in a way that he could understand after liaising with his family and community speech and language therapist. Easy read written information is provided for him to peruse in his own time. The speech and language therapists involved in Mr A's care create a plan to help him communicate his wishes during the capacity assessment.

Mr A's assistive technology device is brought to the hospital, and he is supported to practise using this, but alternative methods of communication are also planned in case he does not feel confident using it as due to his illness he has not used it in some time. Flashcards with "Yes" and "No" are

used as a supplementary communication tool. The capacity assessment was also broken down into parts that could be answered using "yes" and "no" answers.

Using a mixture of the above, the hospital team demonstrates that Mr A has capacity to consent to the medical investigation. He communicates his wishes regarding his health and wellbeing.

The medical procedure was undertaken successfully. Similar steps are taken to discuss with Mr A how to manage the findings of the procedure.

Putting a person at ease

3.13 To help put someone at ease and so improve their ability to make a decision, careful consideration should be given to both location and timing.

Location

3.14 Consider the following:

- where possible, choose a location where the person feels most at ease. For example, people are usually more comfortable in their own home than at a doctor's surgery
- would the person find it easier to make their decision in a relevant location? For example, could you help them decide about medical treatment by taking them to hospital to see what is involved?
- choose a quiet location where the discussion will not be easily interrupted.
- try to eliminate any background noise or distractions (for example, the television or radio, or people talking)
- choose a location where the person's privacy and dignity can be properly respected, and the person is free from influence so they can make their own decision.

Timing

3.15 Consider the following:

- choose where possible, a time of day when the person is most receptive, recognising that some people are better in the mornings, others are more alert in the afternoon or early evening. It may be necessary to meet several times before a decision can be made
- if the person's capacity is likely to improve in the foreseeable future, wait until it has done so – if practicable and appropriate. For example, this might be the case after treatment for depression or a psychotic episode. This may not be practicable and appropriate if the decision is urgent

- some medication can affect a person's capacity (for example, medication which causes drowsiness or affects memory). Can the decision be delayed until side effects have subsided?
- take one decision at a time – be careful to avoid making the person tired or confused
- don't rush – allow the person time to think things over or ask for clarification, where that is possible and appropriate, and
- avoid or challenge time limits that are unnecessary if the decision is not urgent. Delaying the decision may enable further steps to be taken to assist people to make the decision for themselves.

Scenario:

Putting someone at ease

Ms K has moderate learning disabilities and needs a diagnostic scan. She finds hospital environments daunting and says that she sometimes doesn't understand verbal instructions and finds visual information easier than spoken and written information.

She meets with her consultant, support worker and Learning Disabilities Clinical Nurse Specialist to consider the scan. The medical team want to ensure she has capacity to consent to the procedure if possible. The consultant explains the risks and benefits of the procedure to her, in clear language, allowing time for her to process the information. Ms K is also offered a tour of the scanning department.

In this way Ms K is able to understand and retain the information and communicate this to the consultant. She says she is happy to have the scan and signs the consent form.

During the procedure Ms K is supported by a member of the Learning Disabilities team. She completes the scan successfully.

Support from other people

3.16 In many cases, ensuring that a person has someone else there to support them will enable them to make their own decision (and therefore supports principle 3). This may be because this will put them at their ease and reduce anxiety. It may also be because the person can help interpret the way in which they communicate. Often the person can provide information on who would help them make a decision (or, in some cases, who would not help them). Such information from the person must be taken seriously and given appropriate weight.

3.17 It is important to make sure that the person is happy to receive support and that they trust the person who is supporting them. All practicable steps should be taken to avoid the risk of coercion or undue influence.

3.18 If there are no significant trusted people, or no-one willing or available to provide support then it may be appropriate to engage a relevant and independent third party to assist the person who may lack capacity (independent advocate).

3.19 A professional who has to decide whether the person has the capacity to make the decision in question should watch the interaction between the individual and the person providing them with support. If the professional feels that the supporter is not seeking to enable the person to make their own decision or is trying to get the person to make the decision that the supporter wishes, they may have to ask the supporter to leave. The risk of undue influence is great when decisions involve vulnerable people, anyone with concerns about this should raise this through appropriate channels. Chapter 10 provides more information on this topic.

3.20 Professionals who are involving others should be aware of the confidentiality requirements and responsibilities under their professional duty of confidentiality and as set out in the Data Protection Act 2018 and its associated regulations (see Chapter 12: Access to information about a person who lacks capacity). This limits what can be shared with others. If the person has capacity in relation to information sharing, no confidential information can be shared without their consent unless there is an overriding lawful reason to disclose.

Other ways to enable decision-making

3.21 There are many other ways to help someone make a decision for themselves. It is important to exhaust as many options as is reasonable in order to help someone make a decision for themselves.

- Many people find it helpful to talk things over with people they trust or people who have been in a similar situation or faced similar dilemmas. For example, people with learning disabilities may benefit from the help of a designated support worker or being part of a support network.
- It may be reasonable to delay a decision so that the person can receive necessary treatment or support. Reasons to delay may include physical illness or infection, long-standing problems that affect someone's ability to understand an issue, or if someone is very distressed (for example, following a death of someone close).
- Some organisations produce materials to help people who need support to make decisions and for those who support them. Some of this material is designed to help people with specific conditions, such as Alzheimer's disease or a learning disability.
- In some situations – for example, when considering sexual relationships or online safety - tailored training courses may help to the person to understand what they need to in order to make a decision.

Chapter 4
What Capacity Means And How To Assess It

Key Points

- There is an assumption that people have the capacity to make their own decisions. If there is a proper reason to doubt that the person has capacity to make the decision, it is necessary to assess their capacity.
- Before acting for someone, carers and professionals must take reasonable steps to support decision-making and have a reasonable belief about whether the person lacks capacity.
- For day-to-day decisions, the person involved in providing care or support at the time may assess capacity. For more serious or complex decisions, a more formal assessment and professional input may be needed.
- A person's capacity must be assessed specifically in terms of their capacity to make a particular decision at the time it needs to be made. It is important to take all possible steps to try to help people to make a decision for themselves.
- The legal test asks: (1) Is there an impairment of or disturbance in the functioning of the mind or brain? (2) Does that impairment mean the person is unable to make the specific decision when required?
- Someone is unable to make a decision if they cannot understand the information relevant to the decision, retain that information for an appropriate period, use or weigh that information as part of the process of making the decision, or communicate their decision.

Key Terms

Assessor The person responsible for assessing whether an individual has the capacity to make a specific decision.

Capacity The ability to make a decision about a particular matter at the time the decision needs to be made.

Executive function Mental skills that enable a person to plan, organise, regulate behaviour, consider consequences and follow through on decisions.

Reasonable belief A belief formed on the basis of relevant information, proper consideration and sound reasoning, rather than assumption.

Understanding capacity

4.1 Capacity can be described as a person's decision- making ability when a decision needs to be made, with support as necessary. This includes:

- day-to-day decisions, such as what to wear, when to get up, what to buy when shopping or whether to go to the doctor when feeling ill
- more serious or significant decisions that may have legal or life-changing consequences for the person or others, such as deciding where to live or undergoing major surgery.

4.2 Assessing capacity correctly is vitally important to everyone affected by the Act. Someone who is incorrectly assessed as lacking capacity may be denied their right to make a specific decision – particularly if others think that the decision would not be in their best interests or could cause harm. If, however, a person lacks the capacity to make specific decisions, that person might make a decision they do not really understand, which in itself could cause harm or put the person at risk.

4.3 It can be particularly difficult for people caring for the person if they consider their decision to be unwise. However, the Act says that a person is not to be treated as lacking capacity merely because they make an unwise decision (section 3(5) of the Act). Where there is doubt about a person's capacity to make the decision, an assessment should be carried out to establish whether they have capacity. The assessment must focus on the person's ability to make the decision, not on whether others consider the decision to be unwise.

4.4 Some people may need help to be able to make or communicate a decision (see Chapter 3: Helping people to make their own decisions). This does not necessarily mean that they lack capacity to do so. What matters is their ability to carry out the processes involved in making the decision rather than the outcome.

4.5 Many organisations provide specific professional guidance on assessing capacity for members of their profession.

When to consider capacity

4.6 The starting point must always be to assume that a person has the capacity to make a specific decision.

4.7 However, there are occasions where it may be necessary to consider whether someone has the capacity to make a certain decision. Examples of these occasions may include, but not limited to:

- the decision the person is proposing to take is significantly out of character

- the decision the person is proposing to take appears to be unwise, especially if they are putting themselves or others at risk
- it has already been shown that the person lacks capacity to make other decisions in their life as a result of an impairment or disturbance that affects the way their mind or brain works, or
- where it is known that a person has an underlying condition such as dementia that may impair their decision making even though their level of capacity is not immediately evident.

4.8 Considering a person's capacity is not the same as assessing their capacity. It is asking whether there is a proper reason to doubt that the person has the capacity to make the decision in question. Failing to take this into account can be just as harmful to the person as prematurely concluding that they lack capacity.

4.9 When considering a person's capacity, it is important that steps are taken to try and support the person to make their own decision. This is discussed in depth in Chapter 3.

4.10 Questions to ask someone to aid them in decision-making:

- Does the person have all the relevant information they need to make the decision?
- If they are making a decision that involves choosing between alternatives, do they have information on all the different options?
- Would the person have a better understanding if information was explained or presented in another way?
- Are there times of day when the person's understanding is better?
- Are there locations where they may feel more at ease?
- Can the decision be put off until the circumstances are different and the person concerned may be able to make the decision?
- Can anyone else help the person to make choices or express a view, for example, a family member or carer, or someone to help with communication?

When to assess capacity

4.11 If there is a proper reason to doubt that the person has capacity to make the decision, it is necessary to assess their capacity by applying the test in the Act. An assessment is not the same as a conclusion that the person lacks capacity to make the decision. When provided with appropriate support (see Chapter 3: Helping people to make their own decisions), the conclusion of a capacity assessment may be that the person does have capacity to make the decision.

4.12 Capacity assessments should be reviewed if circumstances which may affect the person's decision-making capacity change.

Record keeping

4.13 When there has been reason to assess a person's capacity, the assessment should be retained in the appropriate records. It can be just as important to record a conclusion that the person does have capacity to make a decision as it is to record that they do not, particularly if:

- concluding that the person has capacity is likely to expose them to particular risks, or
- the person has fluctuating decision-making capacity and there may be doubt in future about whether they had the capacity at that time to make a decision, such as granting a power of attorney.

What does the Act mean by 'lack of capacity'?

4.14 Section 4 (1) of the Act (Lack of Capacity) states:

'For the purposes of this Act, a person lacks capacity in relation to a matter if at the material time that person is unable to make a decision for themselves in relation to the matter because of an impairment of, or a disturbance in the functioning of, the mind or brain.'

4.15 Although the Act outlines the assessment of Capacity as a two-stage test, in practice this statutory test requires consideration of three key questions:

- Firstly, is the person able to functionally arrive at a decision, with support if required? For example, are they able to understand, retain, use or weigh relevant information and communicate their decision, as set out in 4.24 of the Code?
- Secondly, if they cannot, is there an impairment or disturbance in the functioning of their mind or brain?
- Finally, is the person's inability to make the decision because of that impairment or disturbance?

4.16 An assessment of a person's capacity must be based on their ability to make a specific decision at the time it needs to be made (with support if necessary), and not their ability to make decisions in general. A person may be able to make decisions about some issues but not about others. For example, a person may be able to manage a small financial allowance that covers their day-to-day expenditure but not be able to make more complex decisions about their financial affairs.

Scenario
Assessing capacity is decision-specific

Ms A has diabetes and a learning disability. Her local authority needs to determine whether she can make decisions regarding her health and welfare. She manages her diabetes independently without difficulty.

Historically she has put herself at risk by allowing strangers into her home which they have used as a base to sell drugs from. Ms A does not understand the risk associated with inviting these strangers into her home.

If a capacity assessor were to assess Ms A generally regarding 'health and welfare' she would fail because of her inability to understand the risk associated with inviting the strangers into her home.

However, a capacity assessment about the specific health and welfare decisions regarding managing her diabetes demonstrates she has capacity to make these decisions.

4.17 Section 4(2) of the Act (Lack of Capacity) states that the impairment or disturbance of the mind or brain does not have to be permanent. A person can lack capacity to make a decision at the time it needs to be made even if:

The loss of capacity is temporary, for example if the person is/has:

- drunk or abusing drugs
- affected by prescribed medication drugs
- delirium from acute infections, for example septicaemia, pneumonia, or urinary tract infection
- infections without irreversible damage to the brain
- conditions such as stroke which have the potential to recover, or
- head injury without irreversible damage to the brain.

Their capacity changes over time (fluctuating capacity), for example a person with:

- early-stage dementia
- clinical depression, or
- schizophrenia.

Assessing capacity: Safeguards

4.18 Section 3(3) of the Act (The Principles) sets out the core principle:

A person is not to be assumed to lack capacity because of that person's, -

(a) age

(b) appearance

(c) condition (whether permanent or temporary)

(d) behaviour (or an aspect of that behaviour).

4.19 This principle is intentionally wide ranging to avoid bias when in contact with a person who may or may not lack capacity. It emphasises that an assessment of someone's capacity should not be based on any factors such as age, appearance, condition or the way a person is behaving. As show in paragraphs 2.10 – 2.12, this includes:

4.20 'Appearance' which covers all aspects of the way people look. This could include:

- skin colour
- tattoos
- piercings
- the way people dress including religious dress, and
- physical characteristics of certain medical conditions such as scars, muscle spasms caused by a neurological conditions or features associated with a genetic disorder.

4.21 'Condition' which covers:

- physical disabilities
- learning difficulties and disabilities
- mental illness
- dementia
- conditions affecting the brain
- illness related to age, and
- temporary conditions for example, drunkenness or unconsciousness.

4.22 Aspects of 'behaviour' which might include:

- highly expressive behaviours for example, shouting or gesticulating
- withdrawn behaviours, for example, talking to oneself or avoiding eye contact
- changes in behaviour, including regarding decision-making, and
- behaviours related to the person's cultural background.

Scenario
Not making assumptions about someone's ability to make a decision

Mr F has a diagnosis of paranoid schizophrenia. He wants to make a Will.

Despite some delusional beliefs, for instance that his neighbours listen to him through the electrical sockets in his home, Mr F demonstrates that he is able to understand the nature and purpose of a Will, what he has to give away and the value of the same, those that might expect to inherit, as well

as who he wants to give his estate to and how he wishes to divide it up. Mr F's diagnosis does not influence how Mr F opts to dispose of his property in his Will.

Despite his delusional beliefs, Mr F meets the criteria for capacity to make a Will.

Proof of lack of capacity

4.23 Anyone who is required to demonstrate in court that an individual lacked capacity to make a decision at the relevant time must establish this on the balance of probabilities (section 4(3) of the Act – Lack of Capacity). Strictly speaking, this standard does not apply in all other contexts where the Act requires consideration of capacity. For example, a person providing day-to-day care or treatment need only have a reasonable belief that the individual lacks capacity. Where appropriate steps have been taken to assess capacity, a belief that it is more likely than not that the person lacks capacity will generally be considered reasonable.

The test of capacity

4.24 Although the Act outlines the assessment of Capacity as a two-stage test, in practice this statutory test requires consideration of three key questions:

- Firstly, is the person able to functionally arrive at a decision, with support if required? Are they able to understand, retain, use or weigh relevant information and communicate their decision, as set out in 4.24 of the Code?
- Secondly, if they cannot, is there an impairment or disturbance in the functioning of their mind or brain?
- Finally, is the person's inability to make the decision because of that impairment or disturbance?

4.25 A conclusion that a person lacks capacity to make a particular decision must be based upon this test, and not on any alternative test used by health or social care professionals for other purposes. For instance:

- a doctor may feel a person lacks insight into their condition, but this does not in itself mean the person lacks capacity to make a specific decision, and
- a formal standardised cognitive assessment (e.g. the Montreal Cognitive Assessment (MoCA)) may aid in assessing whether a person has cognitive impairment due to a condition such as dementia, but a particular score does not in of itself mean that the person has or lacks capacity to make a specific decision.

Scenario

Assessing an impairment or disturbance

Mrs C has had a stroke. This has weakened the left-hand side of her body. She is living in a house that has been the family home for years. Her son wants her to sell her house and live with him. Mrs C likes the idea, but her daughter does not. She thinks her mother will lose independence and her condition will get worse. She talks to her mother's consultant to get information that will help stop the sale.

The consultant says that although Mrs C is anxious about the physical effects the stroke has had on her body, and despite the fact that the stroke has affected part of her brain, it has not caused any mental impairment or affected her ability to process the relevant information regarding her circumstances, so she still has capacity to make her own decision about selling her house.

Inability to make a decision

4.26 Section 5(1) of the Act (Inability to make decisions) describes that a person is unable to make a decision if they cannot:

1. understand the information relevant to the decision
2. retain that information for an appropriate period
3. use or weigh that information as part of the process of making the decision
4. communicate their decision whether by talking, using sign language or any other means.

4.27 The first three points above should be applied together. If a person cannot do one or more of the three things, they will be assessed as unable to make the decision. The fourth point only applies in situations where people cannot communicate their decision in any way. These four points are explained in more detail below.

Understanding information about the decision to be made

4.28 It is important not to assess someone's understanding before they have been given relevant information about a decision. Every effort must be made to provide information in a way that is most appropriate to help the person to understand. Quick or partial explanations are not acceptable unless the situation is urgent (see Chapter 3: Helping people to make their own decisions).

4.29 Relevant information includes:

- the nature of the decision
- the reason why the decision is needed, and
- the likely effects of deciding one way or another or making no decision at all.

4.30 Section 5(2) of the Act (Inability to make decisions) outlines the need to present information in a way that is appropriate to meet the individual's needs and circumstances. It also stresses the importance of explaining information using the most effective form of communication for that person (such as clear language, sign language, visual representations, computer support or any other means). It may be appropriate to seek advice or support from a speech and language therapist or other relevant professionals.

4.31 Presenting information in an appropriate way will look different for each individual. For instance:

- A person with a learning disability may need somebody to read written information to them. They might also need illustrations to help them to understand, or they might stop the reader to ask what things mean.
- A person with anxiety or depression may find it difficult to reach a decision about treatment in a group meeting with professionals. They may prefer to read the relevant documents in private. This way they can come to a conclusion alone, asking for help if necessary.
- Someone who has an acquired brain injury might need to be given information several times. It will be necessary to check that the person understands the information. If they have difficulty understanding, it might be useful to present the information in a different way, for example using different forms of words, pictures or diagrams. Written information, voice recordings, videos and posters can help people remember important facts.
- A person's family structure or cultural background may mean that a particular decision would normally be made by, or with the agreement of, their family or community, but it should not be assumed that the person's background means they will make a decision in a particular way.

Further advice on how to effectively communicate with the individual can be found in Chapter 3

4.32 Information relevant to a decision must include what the likely consequences of a decision would be (the possible effects of deciding one way or another) – and also the likely consequences of making no decision at all (section 5(3) of the Act – Inability to make decisions). In some cases, it may be enough to give a broad explanation using clear language. A person might need more detailed information or access to advice, depending on the decision that needs to be made.

4.33 It is vital to ask questions to check that the person has understood the information. If a decision could have serious consequences, it is even more important that a person understands the information relevant to that decision.

4.34 The person should be able to give some form of explanation of the information that has been explained to demonstrate that they have understood.

Scenario

Providing Relevant Information in an appropriate format

Mr L has learning disabilities and has developed an irregular heartbeat. He has been prescribed medication for this but is anxious about having regular blood tests to check his medication levels. His doctor gives him a leaflet to explain:

1. the reason for the tests,
2. what a blood test involves,
3. the risks in having or not having the tests, and
4. that he has the right to decide whether or not to have the test.

The leaflet uses clear language and photographs to explain these things. Mr L's carer helps him read the leaflet over the next few days, and checks that he understands it. Mr L goes back to tell the doctor that, even though he is scared of needles, he will agree to the blood tests so that he can get the right medication. He is able to pick out the equipment needed to do the blood test. The doctor concludes that Mr L can understand, retain and use the relevant information and therefore has the capacity to make the decision to have the test.

Retaining information

4.35 Section 5(1)(b) the Act (Inability to make decisions) defines what it means for a person to be unable to make a decision. To be able to make a decision under this section, a person must be capable of retaining information for what is described as "an appropriate period".

4.36 Section 5(4) of the Act (Inability to make decisions) defines that a period of time is "appropriate", regardless of its length, if it:

- is of sufficient duration to enable the person to make a decision
- is apt in the circumstances in which it is given, and
- is appropriate for the purpose for which it is given, taking into account whether that purpose relates to a single event or state of affairs, or a continuing one.

4.37 People who can only retain information for a short while must not automatically be assumed to lack the capacity to decide, it depends on what is necessary for the decision in question.

However, the person must be able to hold the information in their mind long enough to use it to make an effective decision.

4.38 It will also depend on the context and nature of the decision the person is being asked to decide upon. A simple day-to-day decision may only require a person to retain the information for a few minutes whereas a decision regarding healthcare will require a person to understand the reasons for the procedure and the risks associated with having or not having the procedure. Given the nature of this decision a person would need to evidence understanding and retention of information, alongside consistency in reasoning for a longer period of time.

4.39 Every practicable effort should be made to help a person record and retain information. Items such as notebooks, computers, photographs, posters, videos and voice recorders can help people record and retain information. It may be helpful at the end of the decision-making process to check that the person has retained the information they need.

Using or weighing information in decision-making

4.40 Weighing information is the ability to assess the likely consequences and outcomes of making a decision compared to those of not making it, by considering relevant facts, evaluating their significance and balancing them to reach a reasoned conclusion. For a person to have capacity, they must be able to use or weigh relevant information. However, a person is not to be treated as unable to weigh information merely because they assign different importance to factors or make a decision that others regard as unwise or irrational. It is only where an impairment or disturbance of the mind or brain prevents the person from using or weighing information that they will lack capacity.

4.41 For example:

- A person with the eating disorder anorexia nervosa may understand information about the consequences of not eating. But their compulsion not to eat might be too strong for them to ignore. Being able to use information means being able to apply it in practice.
- Some people who have a brain injury might make impulsive decisions regardless of the information they have been given or their understanding of it, which may indicate that they are not able to use or weigh the information.

4.42 Another common area of difficulty arises where a person who has a condition affecting their cognitive function (e.g. an acquired brain injury or dementia) is able to give coherent answers to questions, but their actions suggest they are unable to put those decisions into effect. This is sometimes described as an impairment of executive function.

Scenario

Executive functioning impairment

Ms L suffered a brain injury three years ago. She has impulsivity arising from this injury and finds it hard to control issues relating to basic needs such as food and sex. She is overweight and this is beginning to affect her mobility and general health.

During any discussion with her carer she is competent and gives measured answers to questions about why it is important that she follows a restricted diet. However shortly afterwards she purchases and eats multiple bars of chocolate from a vending machine or shop.

In a capacity assessment interview around the question of control of her diet Ms L is able to understand all the information she is given. She also appears to be able to use and weigh that information.

However, the capacity assessment goes broader than the interview, establishing that when Ms L is in the presence of food that she should not eat, there is a pattern of her impulsivity taking over so that she invariably eats the food. Immediately after each incident Ms L is able to describe why she shouldn't have eaten it.

The capacity assessment demonstrates a repeated mismatch between what Ms L says and what she does when she encounters food, and that she lacks the capacity to make decisions about her diet.

4.43 Where a person is unable to understand, or to use and weigh, the discrepancy between what they say and what they do when required to act, they may lack capacity to make the decision in question. However, such a conclusion should only be reached where there is clear evidence of a consistent mismatch between the person's expressed intentions and their actions. In practice, this means it is unlikely that a lack of capacity can be established on this basis from a single assessment alone.

4.44 A person who makes a decision which others consider to be unwise should not be assumed to lack capacity. However, a series of unwise decisions may indicate an inability to use or weigh information.

Scenario

Using and weighing information

Ms W has a learning disability and experienced trauma in her childhood resulting in what is described as 'an emerging personality disorder' She has known attachment issues and can latch on to men and become convinced they are going to marry her. She is desperate for a baby.

Recently Ms W's internet use has become extremely worrying. She lives with her mother, who now feels unable to support her. Ms W is making contact with numerous men, including known sex offenders, and is being sexually explicit in text and photographs online.

A social worker assesses Ms W's capacity for internet usage. At first, he feels that she has capacity as she gives a good account of the risks and internet safety and appears to understand everything, he talks to her about. Ms W is less clear in demonstrating her understanding that someone may not be

who they say they are, but she still says that people might say they are your friend when they aren't, or their online photograph may be of another person.

Ms W tells the social worker that her boyfriend is coming to collect her tonight. He is buying her a ring and a puppy, and they are going to get married. The social worker asks her about her boyfriend, and she shows him some of their conversations, and says she met her boyfriend a week ago on a dating site, has sent very explicit photographs and has agreed to have sex with his sons when he collects her.

The social worker tries to discuss how Ms W knows her boyfriend is genuine and whether it is safe to run away with him so soon. All that Ms W says is that he is going to marry her and buy her a ring and a puppy.

The social worker concludes that Ms W's learning disability and the impact on that of an attachment disorder and a personality disorder mean that she is unable to use and weigh the necessary information to keep safe on the internet.

Inability to communicate a decision in any way

4.45 Occasionally, it may not be possible for a person to communicate at all. This will apply to a small number of people, but it does include:

- people who are unconscious or in a coma, or
- those with the very rare condition known as 'locked-in syndrome', where a person is conscious but cannot speak or move at all.

4.46 Section 5 of the Act (Inability to make decisions) states that if a person cannot communicate their decision in any way at all, they should be treated as if they are unable to make that decision.

4.47 Before concluding that someone falls into this category it is important to make all practicable and appropriate efforts to help them to communicate. For instance, this might require the involvement of speech and language therapists, specialists in non-verbal communication or other professionals (see Chapter 3: Helping people to make their own decisions, for more information).

4.48 Communication by simple muscle movements can show that somebody can communicate and may have capacity to make a decision. For example, a person might blink an eye or squeeze a hand to say 'yes' or 'no'. In these cases, assessment must use the first three points listed in paragraph 4.26.

4.49 Very few people have capacity to make a decision but not be able to communicate it to anyone else. If other people consider that the person cannot do one of the things required to make a decision (i.e. to understand, retain, use and weigh the relevant information) but they are trying to communicate something, any record of the consideration of the person's

capacity should not say that they are unable to communicate their decision. This is because they have not made a decision that they can communicate. The record should show what the person is communicating, for the purpose of working out their best interests.

Impairment or disturbance in the functioning of the mind or brain

4.50 If it is established that a person is unable to make a particular decision, it is then necessary to show that the person has an impairment or the mind or brain, or some sort of disturbance that affects the way their mind or brain works, and that this has caused them to be unable to make the decision. When documenting assessments, it is important to record the person's inability to make the decision is because of that impairment or disturbance.

If the person does not have an impairment or disturbance in the functioning of the person's mind or brain, then they cannot lack decision-making capacity for the purposes of the Act.

4.51 Examples of an impairment or disturbance in the functioning of the mind or brain may include the following:

- conditions associated with some forms of mental illness
- dementia
- significant learning disabilities
- the long-term effects of an acquired brain injury
- physical or medical conditions that cause confusion, drowsiness or loss of consciousness
- delirium
- concussion following a head injury, and
- the symptoms of alcohol or drug use.

4.52 It is easier to establish that a person has an impairment or disturbance in the functioning of their mind or brain if they have a formal diagnosis of a particular condition. However, a formal diagnosis is not necessary for the purposes of the Act. It is also not necessary for the impairment or disturbance to fit into a recognised clinical diagnosis (for example in a psychiatric manual). The person claiming that an individual lacks capacity must be able to show a proper basis for considering that they have an impairment or disturbance.

Is the person's inability to make the decision caused by the impairment or disturbance in the functioning of their mind or brain?

4.53 In all cases, it is necessary to ask whether the inability of the person to make the decision is because of the impairment or disturbance in the functioning of their mind or brain. This will mean explaining (for instance) how a person's dementia means that they cannot use and

weigh the information relevant to the decision in question. The impairment or disturbance must not merely impair their ability to make the decision but render them unable to make the decision.

4.54 There will be some cases where it is not easy to identify whether a person is unable to make their own decisions because of an impairment or disturbance or because of the influence of a third party. So long as the impairment or disturbance can be demonstrated to be a cause of the person's inability to make the decision, then they will lack capacity for purposes of the Act.

4.55 However, if the reason a person cannot make a decision is not because of an impairment or disturbance in the functioning of their mind or brain then they do not lack capacity for the purposes of the Act. It may be that the real reason is the influence of someone else, threat, coercion or fear of the consequences of a decision. If this is the case and there are concerns about the person's safety or wellbeing, then safeguarding procedures should be followed. In some circumstances it may be appropriate for an application to be made to the High Court to consider the matter under its inherent jurisdiction.

Fluctuating capacity or a temporary incapacity

4.56 It is important to recognise that an assessment that a person lacks capacity to make a particular decision at a particular time does not mean that they lack capacity for all decisions at all times. Some people's ability to make decisions fluctuates because of the nature of a condition that they have. This fluctuation can take place either over a matter of days or weeks (for instance where a person has bipolar disorder) or over the course of the day (for instance a person with dementia, whose cognitive abilities may be significantly less impaired at the start of the day than they are towards the end). Temporary factors, such as acute illness, severe pain, a urinary tract infection, medication or bereavement may also affect someone's ability to make decisions. How to approach the situation will depend upon the nature of the decision.

4.57 Where a person has fluctuating capacity, consideration should be given to whether, during periods when their capacity is sufficiently restored, they are able to understand, retain, use and weigh the relevant information, including the risks associated with fluctuations in their capacity, in order to make an informed decision.

Scenario

Fluctuating capacity

Mr J has long term complex alcohol misuse and mental health issues, living in a care setting.

Mr J has a history of exceeding his agreed daily alcohol intake, becoming intoxicated. On these occasions, he forgets to eat and has accessed a shared computer at the service to participate in online gambling, which has resulted in him losing substantial amounts of money.

Where there are instances of Mr J appearing to be intoxicated which could result in him having impaired judgement, staff carry out a capacity assessment to understand whether he has the capacity to make a decision to pay large sums of money in the hope of a jackpot win.

Staff assess whether he can weigh up the risks versus benefits of continuing to gamble and make a decision about whether to go on spending the money. Where he is unable to weigh up the risks, his access to the shared computer is restricted using a best interests decision, as agreed as part of his care planning.

Isolated decisions

4.58 If it is an isolated decision that needs to be made, it may be possible to delay the decision until the person has the capacity to make it for themselves. The person's decision should then be clearly recorded, and evidence recorded to show that they had capacity to make it at that time.

4.59 It may also be helpful to discuss and record what the person would want if they lost capacity to make similar decisions in future. This means that, if further decisions then need to be taken in their best interests, the decision-maker can take the person's wishes and feelings into consideration (see Chapter 5: Best interests).

4.60 If it is not possible to delay the decision, the minimum action necessary should be taken until the person regains decision-making capacity.

Repeated decisions

4.61 Some decisions are not one-off and need to be repeated over a period of time, for example the day-to-day management of a person's finances, or management of a condition such as diabetes. While capacity is time-specific, for repeated decisions it may be appropriate to consider the broader time over which the decisions need to be made. If a person is only able to make the decisions at limited periods of the time over which they need to be made, it may be appropriate to proceed on the basis that they lack capacity. This is especially so if the consequences of the decisions are serious and the person only has capacity to make them for a very small part of the time.

4.62 It will be necessary to keep the person's capacity under review and reassess their capacity if it becomes apparent that they have the capacity to make the decisions more often than not.

On-going conditions that may affect capacity

4.63 Generally, capacity assessments should be related to a specific decision. But there may be people with an ongoing condition that affects their ability to make certain decisions or that may affect other decisions in their life. One decision on its own may make sense, but may give cause for concern when considered alongside others.

4.64 It is important that assessments are reviewed from time to time. People can improve their decision-making capabilities. For instance, people with learning disabilities may learn and develop skills over their lifetime, improving their capacity to make some, if not all, decisions.

4.65 Conversely, some people (for example people with dementia) may become less able to make decisions as time passes and their condition progresses.

4.66 Capacity should always be reviewed:

- when a care plan is being developed or reviewed
- during relevant stages of the care planning process, and
- if new decisions need to be made.

4.67 It is important to acknowledge the clear difference between unwise decisions (which, as the Act states, a person is allowed to make) and decisions that are based on a lack of understanding of risks or inability to weigh up the information about a decision.

Who should assess capacity?

4.68 Different individuals may be involved in assessing a person's capacity for different decisions. The assessor is usually the individual directly concerned with the person at the time the decision needs to be made.

4.69 For most day-to-day decisions, this will be the person caring for them at the time a decision must be made. For example, a care worker might need to assess if the person can agree to being bathed, a district nurse might assess if the person can consent to have a dressing changed.

4.70 For acts in connection with care or treatment (see Chapter 6: Protection for people providing care and treatment), the assessor must take 'reasonable steps' to establish whether the person lacks capacity and have a 'reasonable belief' that the person lacks capacity to agree to the action or decision to be taken before making a decision or taking an action in their best interests.

4.71 If a healthcare professional proposes or is delivering a course of action (for example, treatment or an examination), they must be alert to signs that the person may lack capacity

to consent and give them all reasonable help and support to make a decision. Assessment of capacity is a core clinical skill. In settings such as a hospital, assessment of capacity may involve the multi-disciplinary team. But ultimately, it is for the professional responsible for the person's treatment to make sure that capacity has been assessed.

4.72 If a person chooses to instruct a legal advocate for a legal transaction (for example selling a house), the legal advocate must be satisfied that the person has capacity to instruct them. They should also consider whether the client has the capacity to satisfy any relevant legal test for the transaction. If the legal advocate believes their client lacks capacity, they should advise them of their concerns and of the implications if they are found to lack capacity. It may be necessary to advise the client that an opinion on their capacity should be obtained from a professional with the relevant expertise.

4.73 More complex decisions are likely to need more formal assessments. A professional opinion on the person's capacity might be necessary. This could be, for example, from a psychiatrist, psychologist, a speech and language therapist, occupational therapist or social worker. Ultimately, the final decision about a person's capacity must be made by the person intending to make the decision or carry out the action on behalf of the person who lacks capacity – not the professional, who is there to advise.

4.74 Any assessor should have the skills and ability to communicate effectively with the person (see Chapter 3: Helping people to make their own decisions). If necessary, the assessor should seek professional help to assist them with communicating with the person. In all cases, the person carrying out the assessment must be careful not to allow their own view of the decision to bias their assessment.

"Reasonable belief" of lack of capacity

4.75 Carers (whether family carers or other carers) and care workers do not have to be experts in assessing capacity in relation to day-to-day decisions. But to have protection from liability when providing care or treatment (see Chapter 6: Protection for people providing care or treatment), they must have a 'reasonable belief' that the person they care for lacks capacity to make relevant decisions about their care or treatment (section 8 (1)(b) of the Act- Acts in connection with care or treatment).

4.76 To rely on a reasonable belief, the person must have taken reasonable steps to establish whether the individual lacks capacity to make the decision or give consent at the time it is required. This includes taking appropriate steps to support the person to make their own decision. They must also establish that the act or decision is in the person's best interests and hold a reasonable belief to that effect.

4.77 Day-to-day decisions do not usually need to follow formal processes, such as involving a professional to make an assessment. However, if somebody challenges their assessment, the carer must be able to describe the steps they have taken. They must also have objective reasons for believing the person lacks capacity to make the decision in question. Record keeping of decisions and the reasons behind them is advisable at each step.

4.78 The steps that are accepted as 'reasonable' will depend on individual circumstances and the urgency of the decision. Professionals who are qualified in their particular field, are normally expected to undertake a fuller assessment, reflecting their higher degree of knowledge and experience than family members or other carers with no formal qualifications.

4.79 See paragraph 4.88 for a list of points to consider when assessing someone's capacity.

The following may also be helpful:

- Start by assuming the person has capacity to make the specific decision. Is there anything to suggest otherwise?
- Are there any relevant cultural considerations about how the person usually makes specific decisions, for instance collectively as part of a family unit? Be alert to any signs of coercion or undue pressure.
- Does the person have a previous diagnosis of disability or mental disorder? Would that condition now affect their capacity to make this decision? If there has been no previous diagnosis, it may be best to get a medical opinion.
- Make every effort to communicate with the person to explain what is happening.
- Make every effort to try to help the person make the decision in question.
- See if there is a way to explain or present information about the decision in a way that makes it easier to understand. If the person has a choice, do they have information about all the options?
- Can the decision be delayed to allow time to help the person make the decision, or to give the person time to regain the capacity to make the decision for themselves?
- Does the person understand what decision they need to make and why they need to make it?
- Can they understand information about the decision? Can they retain it, use it and weigh it to make the decision?
- Be aware that the fact that a person agrees with you or assents to what is proposed does not necessarily mean that they have capacity to make the decision.

When should professionals get involved?

4.80 Anyone assessing someone's capacity may need to get a professional opinion when assessing a person's capacity to make complex or major decisions. In some cases this may involve contacting the person's doctor. If the person has a particular condition or disorder, it may be appropriate to contact a specialist (for example, consultant psychiatrist, psychologist or other professional with experience of caring for patients with that condition). A speech and language therapist might be able to help if there are communication difficulties. Other professionals such as nurses, social workers, occupational therapists and others may be able to provide the professional skills necessary. In some cases, a multi-disciplinary approach is best, or it may be necessary to seek an experienced capacity assessor.

4.81 Professionals should never express an opinion without carrying out a proper examination and assessment of the person's capacity to make the decision. They must apply the appropriate test of capacity. In some cases, they will need to meet the person more than once, particularly if the person has communication difficulties. Professionals can request background information from a person's family and carers. But the personal views of these people about what they want for the person who lacks capacity must not influence the outcome of that assessment.

4.82 Professionals might need to be involved if:

- the decision that needs to be made is complicated or has serious consequences
- an assessor concludes a person lacks capacity, and the person challenges the finding
- family members, carers and/or professionals disagree about a person's capacity
- there is a conflict of interest between the assessor and the person being assessed
- the person being assessed is expressing different views to different people – they may be trying to please everyone or telling people what they think they want to hear
- somebody might challenge the person's capacity to make the decision – either at the time of the decision or later, for example where a family member might challenge a will after a person has died on the basis that the person lacked capacity when they made the will
- somebody has been accused of abusing a person who may lack capacity to make decisions that protect them, or
- a person repeatedly makes decisions that put them at risk or could result in suffering or harm.

4.83 In some cases, it may be a legal requirement, or good professional practice, to undertake a formal assessment of capacity. These cases include:

- where a person's capacity to sign a legal document, for example, a will, could later be challenged
- where there is doubt about whether a person who might be involved in a legal case has capacity to instruct a legal advocate or take part in the case, and whether they may need assistance of a legal advocate, guardian ad litem or other litigation friend (somebody to represent their views to a court and give instructions to their legal representative)
- whenever the court has to decide if a person lacks capacity in a certain matter
- where the courts are required to make a decision about a person's capacity in other legal proceedings
- where there may be legal consequences of a finding of capacity, for example when deciding on financial compensation following a claim for personal injury.

Other legal tests of capacity

4.84 The Act makes clear that the definition of 'lack of capacity' and the test for capacity are 'for the purposes of that Act'. This means that the definition and test are to be used in situations covered by the Act. In certain areas, the Act's test of capacity is not the sole or determining standard.

4.85 While the Act provides a general framework for assessing capacity, some decisions continue to be governed by established legal principles derived from common law. In these cases, specific tests developed through the courts may apply in preference to, or alongside, the Act's test. Decision-makers and professionals must therefore be aware that the appropriate test of capacity may vary depending on the nature of the decision.

Assessing capacity: The steps to take

4.86 Capacity assessments should be criteria-focussed, evidence-based, person-centred and non-judgemental. Chapter 3 describes steps which should be taken to support the person to make their own decision. This should not stop when the person's capacity is being assessed. Indeed, trying to support the person to make their own decision will also help the assessor in gathering information to be able to assess whether the person has the capacity to make the decision.

4.87 Anyone assessing someone's capacity will need to decide which of the steps listed below are relevant to their situation.

4.88 Steps to help when assessing capacity:

- Ensure all practicable steps have been taken and continue to be taken to try to support the person to make the decision for themselves.

- Be sure the person understands the nature and effect of the decision.
- Access to relevant documents and background information may be needed to support the assessment. See Chapter 12: Access to information about people who lack capacity.
- Family members and close friends may be a vital resource for background information, for example the person's past behaviour and types of decisions they can currently make. Their personal views and wishes about what they want for the person must not influence an assessment.
- Ensure they are assessing the person when they are in the best state to make the decision, if possible. Many of the practical steps suggested in Chapter 3 will help to create the best environment for assessing capacity.
- Explain to the person all the information relevant to the decision. The explanation must be in the most appropriate and effective form of communication for that person.
- Check the person's understanding after a few minutes. The person should be able to give a rough explanation of the information that was explained. There are different methods for people who use non-verbal means of communication, for example observing behaviour or their ability to recognise objects or pictures.
- Avoid questions that need only a 'yes' or 'no' answer, for example, do you understand what I just said? These questions are not enough to assess the person's capacity to make a decision. There may be no alternative in cases where there is major communication difficulties, and in these cases, check the response by asking questions again in a different way.
- Repeating these steps can help confirm the result.
- Skills and behaviour do not necessarily reflect the person's capacity to make specific decisions. The fact that someone has developed social or language skills, polite behaviour or good manners doesn't necessarily mean they understand the information or are able to weigh it up.

4.89 Capacity assessments should take place with the person – it is not normally appropriate to make assessments based on papers or reports (see paragraph 4.96 regarding action where an assessment is not possible). Where justified in some circumstances, it may be appropriate to carry out an assessment remotely via video conference if:

- it is not possible to visit the person and there is reason to doubt their capacity, or
- doing so is a practicable step to support the person's capacity, perhaps due to the nature of their condition or situation.

4.90 An explanation of why it has not been possible to carry out the assessment in person should be recorded.

4.91 It is important for the assessor to recognise that people may make decisions in different ways. For example, in some cultures decisions are typically made by individuals, whereas in others they may be made collectively with family or community members. A person's preference to defer decisions to others may therefore be wrongly interpreted as a lack of capacity, when in fact it reflects their usual decision-making approach.

4.92 It is also therefore important for the assessor to use the information they have gathered as part of the assessment to develop a good understanding of the person, including how they make decisions usually, to help them consider and assess whether that individual has capacity.

Assessing capacity: Confidentiality

4.93 People involved in assessing capacity will need to share information about a person's circumstances. But there are ethical codes and laws that require professionals to keep personal information confidential. As a general rule, professionals must ask their patients or clients if they can reveal information to somebody else – even close relatives. However, sometimes information may be disclosed without the consent of the person who the information concerns (e.g. to protect the person or prevent harm to other people).

4.94 People involved in assessing capacity may need to share information about the person to carry out the assessment properly. However, professionals must respect confidentiality and follow legal and professional rules about keeping information private. In most cases, they should ask the person for permission before sharing information, even with family members. They should explain clearly why the information needs to be shared, what it will be used for, and what could happen if it is shared or not shared. In some situations, information can be shared without consent where there is a lawful, necessary and justified reason (e.g. if it is necessary to protect the person or others from harm).

4.95 To assess capacity properly, professionals need accurate and relevant information about the person and the decision being made. They should make sure that appropriate information is available to support the assessment. Wherever possible, they should seek the person's consent before sharing this information and explain why it is needed. If the person is not able to give permission, relevant information may still be shared where it is necessary to carry out a capacity assessment. Further guidance on accessing and sharing information can be found in Chapter 12.

Assessing capacity: When assessment is not possible

4.96 Where it is not possible to carry out a capacity assessment, it is important to consider and record the reasons why, and to determine what steps should be taken next. If there are reasonable grounds to doubt the person's capacity, the reasons for this and any supporting evidence should be documented. In some cases, it may be appropriate to make an application to the court to determine the person's capacity to make the decision in question.

4.97 There may be circumstances in which a person whose capacity is in doubt does not engage with an assessor or refuses to undergo a capacity assessment or examination by a relevant professional. In such cases, it may be helpful to explain the purpose of the assessment and the likely consequences of not taking part. Consideration should also be given to what additional steps could be taken to support the person to participate. It is not acceptable to use force or to threaten the person in order to secure their agreement to an assessment.

4.98 If the person lacks capacity to agree or refuse, the assessment can normally proceed, as long as the person does not object to the assessment, and it is in their best interests (see Chapter 5: Best interests).

4.99 No one can be compelled to undergo a capacity assessment. For example, if a person refuses to open the door to their home, entry cannot be forced for that purpose. A warrant may only be issued where there are significant concerns about the person's mental health, and the statutory criteria under section 131 of the Mental Health Act 1998 are met. A refusal to participate in a capacity assessment, in itself, is not sufficient grounds to justify action under the Mental Health Act 1998 (see Chapter 9: The Act and the Mental Health Act 1998).

4.100 If there are concerns that a refusal is the result of coercion by another person, it may be possible to seek an order from the High Court requiring that the individual be allowed to speak with a professional in private.

Assessing capacity: Who should and when to keep a record of assessments?

4.101 Assessments of capacity to take day-to-day decisions or consent to care require no formal procedures or recorded documentation. See paragraphs 4.75-4.79 above that explain the steps to take to reach a "reasonable belief" that someone lacks capacity to make a particular decision. It is good practice for paid care workers to keep a record of the steps they take when caring for the person concerned, including steps to establish capacity.

Professionals and record keeping

4.102 It is good practice for professionals to carry out a proper assessment of a person's capacity to make particular decisions and to record the process of the capacity assessment in the

relevant professional records to demonstrate how the conclusion that the person has or does not have capacity was reached.

- Doctors or healthcare professionals when proposing treatment should perform an assessment of the person's capacity to consent and record it in the person's clinical notes.
- Legal advocates should assess a client's capacity to give instructions or carry out a legal transaction, obtaining a medical or other professional opinion if necessary and record the assessment on the client's file.

4.103 An assessment of a person's capacity to consent or agree to the provision of services will be part of the care planning processes for health and social care needs and should be recorded in the relevant documentation.

Formal records of capacity

4.104 In some cases, a more detailed report of capacity may be required. Regulations, Rules or Orders made under the Act or other statutes may require findings to be recorded in a specific way.

Assessing capacity: How to challenge a finding of lack of capacity?

4.105 There are likely to be occasions when someone may wish to challenge the results of an assessment of capacity. The first step is to raise the matter with the person who carried out the assessment. If the challenge comes from the individual who is said to lack capacity, they might need support from family, friends or an independent advocate. Ask the assessor to:

- give reasons why they believe the person lacks capacity to make the decision, and
- provide objective evidence to support that belief.

4.106 The assessor must show they have applied the principles of the Act and will also need to show that they have also followed guidance in this chapter.

4.107 It might be possible to get a second opinion from an independent professional or another expert in assessing capacity. As per point 4.11, when there has been reason to assess a person's capacity, the assessment should be retained in the appropriate records.

4.108 Chapter 11 has other suggestions for dealing with disagreements. But if a disagreement cannot be resolved, the person who is challenging the assessment may be able to apply to the court. The court can rule on whether a person has capacity to make the decision covered by the assessment.

Retrospective assessments

4.109 In some circumstances there may be doubt about whether a person had capacity to make a decision at a point of time in the past. It may not always be necessary to try and determine whether they had capacity if it is possible to support them to make the decision now.

4.110 In many situations, it is good practice to keep a record of the conclusion of a capacity assessment (see paragraphs 4.102 – 4.104). This means it will be much easier to address any doubt about the person's capacity afterwards.

4.111 However, in some cases it will be necessary to reach a conclusion about whether a person had capacity to make a decision in the past without any record of assessment. These are likely to be situations where a court is involved and are likely to involve questions about whether a particular document should be seen as having legal effect.

4.112 Where a person's capacity to make a decision is assessed retrospectively, a different approach is required from an assessment carried out at the time the decision is made. For example, it is not possible to provide support to enable the person to make the decision. Instead, it will be necessary to gather and consider as much evidence as possible from relevant records and the surrounding circumstances in order to determine whether the person had capacity at the time.

4.113 Importantly, the assumption of capacity operates differently where capacity is being assessed retrospectively. Where there are proper grounds to suggest that the person lacked capacity, anyone asserting that the person did have capacity will need to establish this on the balance of probabilities. Who bears this burden will depend on the particular circumstances.

Chapter 5
Best Interests

Key Points

A decision-maker trying to work out the best interests of a person who lacks capacity to make a particular decision ('lacks capacity') should:

- Identify the available options.
- Consider the factors in the best interests checklist set out in the Act.
- Avoid restricting the person's rights by seeing if there are other options that may be less restrictive of the person's rights and explaining reasoning if the least restrictive option is not pursued.
- Weigh up all of these factors in order to work out what is in the person's best interests.
- Consider whether a record of the decision needs to be made.
- Where ascertainable, wishes and feelings, beliefs and values should be treated as a paramount consideration when determining best interests.

Key Terms

Best interests The legal requirement that any action taken or decision made on behalf of a person who lacks capacity must be in that person's best interests, as set out within section 6 of the Act (Best interests).

Decision-maker The person responsible for making the decision on behalf of someone who lacks capacity.

Least restrictive option The requirement to consider whether the purpose of an act or decision can be achieved in a way that is less restrictive of the person's rights and freedoms.

Relevant circumstances The facts and factors that matter for the specific decision at the time it needs to be made.

Best interests principles

5.1 As explained in Chapter 2 (Statutory Principles), the first of the Act's seven statutory principles, set out in section 3 (The principles), is that a person must be assumed to have capacity to make a decision or act for themselves unless it is established that they lack capacity. Individuals with capacity are entitled to make their own decisions, even where others consider those decisions not to be in their best interests. Such decisions do not, in themselves, indicate a lack of capacity.

5.2 However, there may be grounds for concern where a decision is uncharacteristic or exposes the person to a risk of harm. In such cases, it may be appropriate to assess capacity. A determination of best interests only arises where all practicable steps have been taken, without success, to support the person to make the decision themselves or to give consent to an act.

5.3 The best interests' principles underpin the Act and apply throughout its provisions. They are set out in section 3 (The principles), which provides that any act done, or decision made, on behalf of a person who lacks capacity must be in that person's best interests.

5.4 Section 3(6) and 3(7) of the Act (The principles) confirms that the principle applies to any act done and/or any decision made, on behalf of someone where there is reasonable belief that the person lacks capacity under the Act. This covers informal day-to-day decisions and actions as well as decisions made by the courts.

5.5 These principles cover all aspects of financial, personal welfare and healthcare decision-making and actions, whether the decision is a day-to-day matter, like what to wear, or a significant issue, like whether to provide particular healthcare.

5.6 The best interests' principles apply to anyone making decisions on behalf of a person who lacks capacity or anyone acting under the provisions of the Act, including:

- family carers, other carers and paid care workers
- parents
- healthcare and social care staff
- attorneys appointed under an Enduring Power of Attorney, Receivers and Appointees
- the court.

5.7 As long as these acts or decisions are in the best interests of the person who lacks capacity to make the decision for themselves, or to consent to acts concerned with their care or treatment, then the decision-maker or carer will be protected from liability (see Chapter 6: Protection for people providing care or treatment).

"Best interests" definition

5.8 The term 'best interests' is not defined in the Act, but it can best be thought of representing the decision or action that is right for that particular person as an individual at the time that the decision needs to be made or action taken. It does not necessarily mean doing what the decision-maker would do. 'Best interests' encompasses not just a person's medical interests, but also their social, cultural and psychological interests.

5.9 The Act does not prescribe what is in a person's best interests but sets down a process to follow that requires specific questions to be asked, steps to be followed, and matters to be considered. That process is designed to recognise, in particular, that a conclusion that the person is not able to make their own decision is not an 'off switch' for their rights and freedoms.

5.10 Acting or making a decision in a person's best interests is not the same as identifying the best possible option in theory. If a particular option is not realistically available, it cannot be regarded as being in the person's best interests.

5.11 When determining what is in the best interests of a person who lacks capacity, decision-makers must consider all relevant factors that it would be reasonable to take into account (see best interests checklist at paragraphs 5.24-5.25), not just those they personally regard as important. They must not base their decision on what they would choose for themselves but instead must have regard to the person's own wishes, feelings, beliefs, and values.

5.12 Working out what is in someone else's best interests may be difficult. The Act makes it necessary to follow certain steps for the purposes of determining whether a particular act or decision is in a person's best interests. In some cases, there may be disagreement about what someone's best interests really are. Provided that the person has taken reasonable steps to assess whether the individual has capacity and, where the individual lacks capacity, has made all reasonable efforts to determine what is in their best interests and acted in accordance with section 6 of the Act (Best interests), they will be protected by law.

Scenario

Best Interests

Mr P has a severe learning disability and lives in a care home. He has dental problems which cause him a lot of pain but refuses to open his mouth for his teeth to be cleaned.

The staff suggest that it would be a good idea to give Mr P an occasional general anaesthetic so that a dentist can clean his teeth and fill any cavities. Mr P lacks the capacity to consent to this. His mother is worried about the effects of an anaesthetic, but she hates to see him distressed and suggests instead that he should be given strong painkillers when needed.

While the views of Mr P's mother and carers are important in working out what course of action would be in his best interests, the decision must not be based on what would be less stressful for them. Instead, it must focus on Mr P's best interests. Having talked to others, the dentist involves Mr P in the decision, with the help of his key worker, to find out the cause and location of the problem and to explain to him that they are trying to stop the pain. The dentist ascertains whether any other forms of dental care would be better, such as a mouthwash or dental gum.

The dentist concludes that it would be in Mr P's best interests for:

1. a proper investigation to be carried out under anaesthetic so that immediate treatment can be provided

2. options for his future dental care to be reviewed by the care team, involving Mr P as far as possible.

Decision-makers

5.13 In the Code, and in everyday use, the term "decision-maker" is frequently used. However, in general, it is important to understand that the Act does not identify any formal decision-makers. The exceptions are:

- where the court makes the decision on behalf of the person, or
- independently of the Act, where an Enduring Power of Attorney has been made and registered, or a receiver under the MHA has been appointed under a court order. In those circumstances, the attorney or receiver will be the decision-maker for decisions within the scope of their authority.

5.14 In every other case, the Act does not specify a particular person or type of person as the decision-maker. Wherever appropriate, a decision as to what is in the best interests of a person unable to take the relevant decision should be reached informally and collaboratively between those involved in their care or interested in their welfare, whether paid, professional or unpaid. This means that:

- being a person's next of kin does not give them any legal authority to make decisions on that person's behalf, but also that
- a professional does not have a right to make the decision on behalf of the person simply because they occupy a particular position.

5.15 Anyone who wants out to carry an act in connection with the care or treatment of another will only be protected from criminal and civil liability if they reasonably believe that the person lacks capacity to make the relevant decision and that the action to be taken is in the person's best interests (see Chapter 6: Protection for people providing care or treatment).

5.16 In some cases, the person carrying out the act may also be regarded as the 'decision-maker', as they must determine whether they hold the reasonable belief required to rely on the Act's protection from liability. For instance:

- A GP taking a blood sample from a patient who they reasonably believe to lack capacity to consent would be the decision-maker as to whether taking that blood is in their patient's best interests.
- The paid care worker who has to decide whether to step in to intervene to prevent a person with dementia from injuring themselves will have to decide there and then whether they reasonably believe that the person lacks capacity and that the step is in their best interests. If it amounts to restraint, they must also consider whether the additional conditions discussed in Chapter 6 are met.

5.17 In other cases, the person carrying out the act may be acting on the direction of another, under supervision, or in accordance with a plan produced by someone else. In these situations, that person must still be satisfied that they are acting in the individual's best interests before carrying out the act, although they may rely on the views set out in the plan. In such cases, the person responsible for the plan may be regarded as the "decision-maker." For example, in a hospital setting, the consultant responsible for the patient's clinical care would usually be considered the decision-maker.

5.18 In any such situation, especially if there are different staff involved in the person's care from different organisations, it is important that there is one person who is identified as having the responsibility for the coordination of the process to determine what is in the individual's best interests. This may be the person who can be seen as the "decision-maker" in the way set out above, but in some cases, it could be more appropriate for that person to delegate this task to someone who has the right set of skills to facilitate the process of considering all the matters set out under the Act.

5.19 In all cases involving an organisation, there must ultimately be one person who takes responsibility on behalf of that organisation for the conclusion that the step being taken is in the best interests of the individual concerned. This does not mean that they have the authority to make the decision, but rather that they are accountable for it.

5.20 It is important that everyone involved in the best interests decision-making process knows and agrees who the decision-maker is, and that, no matter who is making the decision, the most important thing is that the decision-maker tries to work out what would be in the best interests of the person who lacks capacity. The decision-maker should try to identify any of their own unconscious biases to ensure these do not influence the best interests decision.

Scenario

Coming to a joint decision

Ms D has severe autism and learning disabilities and receives nutrition through a feeding tube. She has quickly lost weight and needs to undergo investigative medical procedures under anaesthetic. Ms D does not like to be touched and on a previous occasion suffered extreme distress when police officers restrained her for transfer by ambulance in an emergency.

A capacity assessment by her GP confirms that she lacks capacity with respect to medical treatment decisions. The hospital convenes a meeting, attended by members of the medical team including the anaesthetist and hospital safeguarding team, Ms D's father and sister, and her GP. Decisions made in the meeting enable the medical team to create a detailed care and support plan based on Ms D's best interests.

Her family will encourage her to be voluntarily secured on a stretcher for transfer to hospital. The anaesthetist will prescribe a small dose of pre-medication the night before to relieve her anxieties. Her mother will accompany her in the ambulance. Ms D will be first on the hospital morning list as this is less disruptive for her.

On the day of the procedure, Ms D is calm and her family support her to get in the ambulance with a minimum of distress. She goes straight to the CT suite with the anaesthetist, where she is anaesthetised for the scan, with CT and endoscopic procedures conducted consecutively to avoid unnecessary trips to hospital and unnecessary further use of chemical restraint. This positive experience gives Ms D reassurance about future procedures.

Available options

5.21 Most best interests decisions will involve a choice, either between a person doing something and not doing something (for instance carrying out a medical procedure) or making a choice on behalf of the individual between two or more options (for instance where they might live). Where the choice is being made on behalf of the individual, that choice can only be between options which are actually available to them.

5.22 The process of best interests decision-making therefore needs to start with the identification of what options are available. In some cases, this may appear very clear. In other cases, it may be necessary to make this identification on a provisional basis if not all information is yet available. In every case, it may be that a further option becomes clear during the process of considering the person's best interests. For instance, it might become apparent that it is so important to them that they remain at home that they would be prepared to tolerate a higher degree of risk to them than professionals might previously have considered acceptable. If so, the option of them remaining at home might therefore become available in a way that it had not previously done before. It is therefore important to consider the options available throughout the process and revisit them if required.

5.23 When considering the available options, the decision-maker must consider whether the purpose can be as effectively achieved in a way that is less restrictive of the person's rights and freedom (see principle 7).

Working out best interests: The checklist

5.24 Because every case – and every decision – is different, the law can't set out all the factors that will need to be considered in working out someone's best interests.

5.25 Section 6 of the Act (Best interests) sets out some common factors that must always be considered when trying to work out someone's best interests. The factors are summarised in the checklist here:

The Best Interests Checklist

- Working out what is in someone's best interests cannot be based simply on someone's age, appearance, condition (whether temporary or permanent) or behaviour (see paragraphs 5.34-5.36 for full details).
- All relevant circumstances that the decision-maker is aware of should be considered when determining someone's best interests (see paragraphs 5.37-5.39 for full details).
- As far as reasonably practicable, every effort should be made to enable, encourage and/or improve the ability of the person lacking capacity to take part in any act done or any decision made. (see paragraphs 5.40-5.45 for full details)
- If there is a chance that the person will regain the capacity to make a particular decision, then it may be possible to put off the decision until later if it is not urgent (see paragraphs 5.56-5.50 for full details).
- Where practicable and appropriate, consult and take into account the views of:
  anyone named by the person lacking capacity as someone to be consulted, those close to them, individuals involved in their care or treatment, and any person with legal authority to act on behalf of the person —particularly regarding what the person would have wanted. (see paragraphs 5.83-5.94 for further details)
- The person's past and present wishes and feelings, (whether expressed orally, in writing or by behaviour) and beliefs and values (that are likely to influence their decision) should be taken into account. This includes any relevant written statement made when the person had capacity and any other relevant factors, such as cultural. (see paragraphs 5.60-5.66 and 5.71-5.80 for further details).
- Where ascertainable, the person's wishes, feelings, beliefs and values must be a paramount consideration when determining the person's best interest.

- Special considerations apply to decisions about life-sustaining treatment (see paragraphs 5.51-5.59 for further details).

5.26 These duties apply to:

- anyone making decisions under the Act
- anyone acting under a legal authority on behalf of the person that lacks capacity, and
- anyone who reasonably believes a person lacks capacity.

5.27 By following these steps, the requirements will be met as long as it is reasonably believed the decision or action is in the person's best interests.

5.28 It is important not to take shortcuts in working out best interests. An appropriate and objective assessment must be carried out. In urgent situations, there may not be time to examine all possible factors, but the decision must still be made in the best interests of the person who lacks capacity.

5.29 Even though the factors in the best interests checklist must always be considered, not all of them will be relevant to every decision or action. In many cases, additional factors will also need to be considered, although some may ultimately be found not to be relevant. For example, relevant considerations may include promoting independence, preserving dignity or assessing the impact of significant changes in the person's circumstances.

5.30 What is in a person's best interests may well change over time. This means that even where similar actions need to be taken repeatedly in connection with the person's care or treatment, the person's best interests should be regularly reviewed.

5.31 Any staff involved in the care of a person who lacks capacity should make sure a record is kept of the process used to work out the best interests of that person for each relevant decision, setting out:

- how the best interests decision was reached
- what the reasons for reaching the decision were
- who was consulted to help work out best interests, and
- what factors were taken into account.

A record of the above should remain on the person's file.

5.32 Record keeping is critical for anyone caring for a person who lacks capacity.

Best interests: Safeguards and the Act

5.33 Section 3(8) of the Act (The principles) sets out:

> Before the act is done, or the decision is made, regard must be had to whether the purpose for which it is needed can be as effectively achieved in a way that is less restrictive of the person's rights and freedom of action.

5.34 Additionally, section 3(3) of the Act (The principles) says:

> In making the determination the person making the determination must not make it merely on the basis of:
>
> (a) the person's age or appearance, or
>
> (b) a condition of the person (whether permanent or temporary) or an aspect of the person's behaviour.

5.35 The Act states, anyone determining someone's best interests must not make unjustified assumptions about what that person's best interests might be simply on the basis of the person's age, appearance, condition or any aspect of their behaviour. In doing so, the Act ensures that people who lack capacity to make decisions for themselves are not subject to discrimination or treated any less favourably than anyone else.

5.36 'Appearance' is a broad term and refers to all aspects of physical appearance, including skin colour, mode of dress and any visible medical problems, disfiguring scars or other disabilities. A person's 'condition' also covers a range of factors including physical disabilities, learning difficulties or disabilities, age-related illness or temporary conditions (such as drunkenness or unconsciousness). 'Behaviour' refers to behaviour that might seem unusual to others, such as talking too loudly or laughing inappropriately but in itself does not prove a lack of capacity. It may also relate to the person's cultural background.

Relevant circumstances to the individual

5.37 When trying to work out someone's best interests, the decision-maker should try to identify all the issues that would be most relevant to the individual who lacks capacity and to the particular decision, as well as those on the best interest checklist. It is not always possible or practical to investigate in depth every issue which may have some relevance to the person who lacks capacity or the decision in question. Relevant circumstances are defined in section 6(3) of the Act (Best interests) as those:

> a) of which the person making the determination is aware, and
>
> b) which it would be reasonable to regard as relevant.

5.38 The relevant circumstances will vary from case to case. These may include both short-term and long-term implications. For example, when making a decision about major medical treatment, a doctor would need to consider the clinical needs of the patient, the potential benefits and burdens of the treatment on the person's health and life expectancy and any other factors relevant to making a professional judgement. However, it would not be reasonable to consider issues such as life expectancy when working out whether it would be in someone's best interests to be given medication for a minor problem.

5.39 It is good practice that decision-makers should always keep the individual who lacks capacity at the heart of the decision-making process and refer back to the best interests test as it applies to that individual; no single rule can apply in every case.

Working out best interests: Involving the person who lacks capacity

5.40 The decision-maker should make sure that all practicable means are used to enable and encourage the person to understand and participate as fully as possible in the decision-making process and any action taken as a result, or to help the person improve their ability to participate (section 6(4) – Best interests). This may include taking into account any relevant collective decision-making processes in the person's family or wider cultural background.

5.41 Even if the person lacks capacity to make the decision, they may have wishes and feelings on matters affecting the decision, and on what outcome would be preferred. These should be ascertained where possible (see paragraph 5.60). Their involvement can help work out what would be in their best interests. When finding out these views, the decision-maker should also consider the circumstances under which they were expressed to ensure the person's wishes and feelings are not a result of coercion by other people.

5.42 It is the duty of the decision-maker to take all practical measures to enable and encourage the person to participate as fully as possible in the decision-making process and any action taken as a result, or indeed to help the person improve their ability to participate (see Chapter 3: Helping people to make their own decisions).

5.43 Consulting the person who lacks capacity will involve taking time to explain what is happening and why a decision needs to be made. This may mean that other people are required to communicate with the person to establish their views. For example, a trusted relative, independent advocate, friend, or a carer may be able to help the person to express wishes or aspirations or to indicate a preference between different option.

5.44 Taking steps to enable and encourage the person to participate in the decision may lead to a rethinking about whether they lack capacity to make the decision with the support available.

If this is the case, it is important to go back and reassess their capacity to determine whether the person is able to make the decision for themselves.

5.45 The person who lacks capacity should also be informed of the outcome of the decision, unless there is a good reason for them not to be informed. Where it is decided not to inform them, the reason for this should be recorded.

Working out best interests when there is chance of regaining and developing capacity.

5.46 There are some situations where decisions may be deferred, if someone who currently lacks capacity may regain the capacity to make the decision at a later time. Section 6(5) of the Act (Best interests) requires the decision-maker to consider the following:

- is the individual concerned likely to regain the capacity to make that particular decision in the future?
- if so, when is this likely to be?

5.47 Depending on the nature of the decision it may be possible to delay the decision until the person regains capacity enough to make the decision in question.

5.48 In emergency situations – such as when urgent medical treatment is needed – it may not be possible to wait to see if the person may regain capacity so they can decide for themselves whether or not to have the urgent treatment.

5.49 Where a person currently lacks capacity to make a decision relating to their day-to-day care, the person may – over time and with the right support – be able to develop the skills to do so. Though others may need to make the decision on the person's behalf at the moment, all possible support should be given to that person to enable them to develop the skills so that they can make the decision in the future.

5.50 Some factors which may indicate that a person may regain or develop capacity in the future are:

- the cause of the lack of capacity can be treated, either by medication or some other form of treatment or therapy
- the lack of capacity is likely to decrease with time, for example, where it is caused by the effects of medication or alcohol, or following a traumatic event
- a person with learning disabilities may learn new skills or be subject to new experiences which increase their understanding and ability to make certain decisions

- the person may have a condition which causes capacity to come and go at various times, such as some forms of mental illness, or
- a person previously unable to communicate may learn a new form of communication. See Chapter 3: Helping people to make their own decisions.

Best interests relating to life-sustaining treatment

5.51 A special factor in the best interest checklist applies to decisions about 'life-sustaining treatment', this is set out in section 6(11) of the Act (Best interests). The fundamental rule is that anyone who is deciding whether or not life-sustaining treatment is in the best interests of someone who lacks capacity to consent to or refuse such treatment must not be motivated by a desire to bring about the person's death.

5.52 Whether a treatment is 'life-sustaining' depends not only on the type of treatment, but also on the particular circumstances in which it may be provided. For example, in some situations giving antibiotics may be life-sustaining, whereas in other circumstances antibiotics are used to treat a non-life-threatening condition. It is up to the doctor or healthcare professional providing treatment to assess whether the treatment is life-sustaining in each particular situation.

5.53 This should not be interpreted to mean that doctors are under an obligation to provide, or to continue to provide, life-sustaining treatment where that treatment is not in the best interests of the person. Futile treatments are not in a person's best interests. Doctors must apply the best interests principle and use their professional skills to decide whether life-sustaining treatment is in the person's best interests.

5.54 Alongside the guidance in the Code, doctors and other staff should refer to relevant professional guidance for the process of making the decision, including the need (for instance) for a second opinion.

5.55 If a treatment is not clinically appropriate or reasonable to provide, the Act does not require the treating doctor to offer it. The best interests decision-making process does not place a person who lacks capacity in a better position than a person who has capacity. Therefore, where a particular treatment would not be offered to a person with capacity in the same circumstances, there is no obligation to include or offer that treatment as part of the best interests decision.

5.56 In making a best interests decision about giving or continuing life-sustaining treatment, there is a strong presumption that it will be in the patient's best interests to attempt to prolong their life. The decision-maker must not be motivated by a desire to bring about the person's death, whatever the reason, including where that desire arises from a sense of compassion.

5.57 However, the strong presumption in favour of attempting to prolong life can be displaced (not followed) where:

- there is clear evidence that the person would not want the treatment in question in the circumstances
- the treatment itself would be overly burdensome for the patient, in particular, by reference to what is known about whether it is more important to the patient to be kept alive at all costs or to be kept comfortable, or
- there is no prospect that the treatment will restore the patient to a level of quality of life that the patient would consider acceptable. The important viewpoint is that of the patient, not of the doctors or healthcare professionals.

5.58 Where a person has made an advance directive to requests or refuse particular medical treatments or a written statement, such as clinically assisted nutrition and hydration (CANH), these requests should be taken into account by the treating doctor in the same way as requests made by a patient who has the capacity to make such decisions. Like anyone else involved in making this decision, the doctor must weigh advance directives and written statements alongside all other relevant factors to decide whether it is in the best interests of the patient to provide or continue life-sustaining treatment.

5.59 Where there is any doubt about the patient's best interests, an application should be made to the court for a decision as to whether withholding or withdrawing life-sustaining treatment is in the patient's best interests. This is particularly likely to be necessary where:

- the decision as to the person's best interests is finely balanced
- there is a difference of medical opinion; or
- there is a lack of agreement between those involved in the person's care, for example between clinicians and family members.

An application to the court is also likely to be required where there is a potential conflict of interest which cannot be appropriately managed, such that the professionals involved cannot reasonably conclude that they are acting in the person's best interests without the court's determination.

Decisions in relation to life-sustaining treatment should be kept under regular review. The fact that treatment was initiated because it was in the person's best interests does not mean that it will remain so indefinitely. The frequency of review will depend on the individual circumstances of the case.

How do a person's wishes and feelings, beliefs and values affect working out best interests?

5.60 Section 6(9) of the Act (Best interests) requires the decision-maker to consider, as far as they are 'reasonably ascertainable'.

1. the person's past and present wishes and feelings whether expressed orally, in writing or by behaviour
2. any relevant written statement made by the person when the person had capacity
3. the beliefs and values that the person would likely be influenced by if the person had capacity, and
4. the other factors that the person would be likely to consider if the person were able to do so including those which were not present when the person made an expression of their wishes in relation to a particular matter.

5.61 Section 6 of the Act (Best interests) puts the person who lacks capacity at the centre of the decision to be made even if they cannot make the decision. Their wishes, feelings, beliefs and values should be taken fully into account whether expressed in the past or in the moment the decision needs to be made. But their wishes, feelings beliefs and values will not necessarily be the deciding factor in working out their best interests.

5.62 Asking what is in a person's best interests is not the same as asking 'what the person would have done.' The final decision must be based on a reasonable belief of what is in the person's best interests having complied with the requirements of section 6 of the Act (Best interests).

5.63 Section 6(10) of the Act (Best interest) says that if the matters referred to in section 6(9) are ascertainable, they should be the 'paramount consideration', and as such, must be taken into account and can be the deciding factor.

5.64 In every case, the decision-maker must take the steps set out at the best interests checklist earlier in this chapter – i.e. participation of person, consultation, wishes and feelings, especially identification of written statements, thinking about beliefs and values. In many—but not all—cases, following this process will enable the decision-maker to form a clear view of what the person would have decided, had they been able to do so.

5.65 In other cases, taking into account all the relevant circumstances (as required by section 6 of the Act -Best interests) means that a different decision is taken to that which the person would have taken. Examples of where this may be appropriate might include:

- where giving effect to the person's wishes would be to expose the person to a level of risk that the person is unable to take into account for themselves, or

- where the person is unable to understand or weigh up the information relevant to a decision.

5.66 In any case where the decision-maker reaches a conclusion that the decision or action that is in the person's best interests is not that which the person would have taken, the decision-maker should be prepared to justify their decision.

Recording best interests decisions

5.67 Careful and considered record keeping is always advised. Any staff involved in the care of a person who lacks capacity should make sure a record is kept of the process of working out the best interests for each decision.

5.68 The record that is kept of the process of working out the best interests of the person in respect of any decision will depend upon the nature of the decision. Where other people are going to be implementing the decision, it will be important for them to be able to clearly understand why it is thought the act of care or treatment is in the person's best interests. In most cases, this will mean including a record in the person's care and support plan or file of:

- how the decision about the person's best interests was reached
- the views, wishes and feelings of the person, particularly if different from the decision made
- what the reasons for reaching the decision were
- who was consulted to help work out best interests, and
- what particular factors were taken into account, including any relevant cultural factors.

5.69 More serious decisions will require more detailed records. Certain decisions taken by health and social professionals or bodies will represent so serious an interference with the person's rights under the European Convention on Human Rights that a detailed record should be prepared. Preparation of such a record serves three purposes:

1. to ensure that the decision-maker has considered all relevant matters necessary to rely on the defence provided by section 6 of the Act (Best interests)
2. to ensure that, wherever possible, disputes in relation to serious issues are identified at an early stage so that consideration can be given as to how they can be resolved (including by the court) before the action is taken – this is particularly important if the action in question will be irreversible, and
3. to ensure accountability after the event.

5.70 After the decision is made, the decision-maker should ensure that it is documented and communicated to everyone involved and that there is opportunity for all participants to offer feedback or raise objections. This information should remain on the person's record.

'Reasonably ascertainable'

5.71 How much a decision-maker can learn about a person's past and present views will depend on the decision, circumstances and the time available. The decision-maker is under a duty to take all practicable steps to obtain and consider as much relevant information as possible, usually by talking to the person or those who know them, in the time available. What is available in an emergency will be different to what is available in a non-emergency. But even in an emergency, there may still be an opportunity to try to communicate with the person or their friends, family or carers (see Chapter 3: Helping people make their own decisions, for guidance on helping communication).

Past and present wishes and feelings

5.72 The Act requires the decision-maker to consider the person's past and present wishes and feelings. This requires consideration of both the person's current wishes and feelings, as expressed through their words or behaviour, and any wishes and feelings they have expressed in the past. Where current and past wishes appear to be in conflict, the decision-maker must consider that conflict carefully in light of the particular circumstances in order to determine what is in the person's best interests.

5.73 People who cannot express their current wishes and feelings in words may express themselves through their behaviour. Expressions of pleasure or distress and emotional responses will also be relevant in working out what is in their best interests. It is also important to be sure that other people have not influenced a person's views. Finally, just because a person cannot express a clear and consistent wish, it does not mean that they do not have feelings which have to be taken into account.

5.74 The person may have held strong views in the past which could have a bearing on the decision to be made now. All reasonable efforts must be made to find out whether the person has expressed views in the past that should inform the decision to be made. This could have been through oral or written communication, behaviour or habits, or recorded in any other way (for example, videos or voice recordings or posts on social media). When finding out these views, the decision-maker should also consider the circumstances under which they were expressed to ensure the person's wishes and feelings were not influenced by other people's views.

5.75 Section 6(9)(b) of the Act (Best interests) places special emphasis on any relevant written statements the person might have made before losing capacity. These could provide a lot of information about a person's wishes.

5.76 The decision-maker should consider written statements carefully. If their decision does not follow something a person has put in writing, they must record the reasons why. They should be able to justify their reasons if someone challenges their decision.

5.77 A doctor should take written statements made by a person before they lost capacity, requesting specific treatments, with the same seriousness as those made by individuals who currently have capacity to make treatment decisions. However, a doctor is not required to follow such a request if the treatment is clinically unnecessary or inappropriate for the person's condition and therefore not in their best interests. Similarly, if a treatment is not available, it need not be considered as part of the best interests decision-making process.

5.78 In many situations, the healthcare team and the person may have worked together to produce a Future Care and Support Plan to record their treatment and care wishes. The plan will help guide decision-making at a point when the person does not have capacity to make their own decisions. This plan may contain details of any relevant written statements and advance directives. See paragraph 5.58 for more detail.

Scenario

Using a future care and support plan

Ms G has advanced Alzheimer's dementia and lives in a nursing home. In the last 2 months she has been admitted to hospital twice because she became feverish and stopped eating. She was very distressed and agitated in hospital, which her daughters felt was due to the change in her environment.

The GP and nursing home manager meet with one of Ms G's daughters who says that she does not think that her mother should be admitted to hospital if this should happen again. The GP assesses Ms G as lacking capacity to make decisions about her treatment and participate in discussions, with no realistic chance of recovery of capacity.

A formal meeting is held to agree a future care and support plan for Ms G. Careful consideration is given as to who should be consulted. Ms G is a widow with three daughters, one of whom lives a long way away. The home manager speaks with her by telephone. The daughters identify Ms G's long-term close friend as someone who should be consulted.

The nursing home manager, friend and 2 daughters meet. Everyone involved agrees that if Ms G developed another chest infection it would be in her best interests to remain in the nursing home with good symptom control, and not to receive antibiotics to prolong her life.

The nursing home manager confirms the outcome of meeting to the other daughter who agrees with the care and support plan. A future care and support plan document is completed recording these recommendations, confirming how the principles of best interests decision-making have been followed.

One month later, Ms G becomes very unwell. An out of hours GP is called and assessment Ms G as having signs of a chest infection which could be fatal if she is not treated with intravenous antibiotics, and that she may die even with treatment because of her underlying conditions. The agency nurses on duty at the home do not know Ms G well, but show the future care and support plan to the out of hours GP. He unsuccessfully attempts to contact the daughters by phone.

The GP can see from the future care and support plan that a robust process has been followed which follows the principles of the Capacity Act best interests decision-making. Informed largely by the future care and support plan, the GP is able to make a best interests decision to prescribe medicine to keep Ms G comfortable in the nursing home, and she dies the next day.

Beliefs and values

5.79 Everyone's beliefs and values influence the decisions they make. They may become especially important for someone who lacks capacity to make a decision because of a progressive illness such as dementia. Evidence of a person's beliefs and values can be found in things like their:

- cultural background
- religious beliefs
- political convictions, and
- past behaviours or habits.

5.80 Some people set out their beliefs and values in a written statement while they still have capacity. These should be respected and considered in best interests decision-making. Others may never have had capacity to make a decision or the ability to express their wishes and feelings.

Other factors a decision-maker should consider

5.81 Section 6(9)(d) of the Act (Best interests) requires decision-makers to consider any other factors the person who lacks capacity would consider if they were able to do so. This may include factors that were not present when the person previously expressed their wishes about the matter, as well as considerations such as the impact of the decision on others, any obligations to dependants, or the responsibilities of a member of society.

5.82 The Act allows actions that benefit other people, provided those actions are in the best interests of the person who lacks capacity to make the decision. For example, having considered all the circumstances of a particular case, a decision might be made to take a blood sample from a person who lacks capacity to consent in order to investigate a potential genetic link to cancer within the family, where this may benefit other family members. It may

nevertheless still be in the best interests of the person who lacks capacity. The concept of 'best interests' extends beyond the person's immediate interests.

Best interests: Who to consult

5.83 Section 6(7) of the Act (Best interests) places a duty on the decision-maker, where practicable and appropriate, to consult those close to the person who lacks capacity about what would be in the person's best interests. The primary purpose of consultation is to understand what the person's decision would be if they were able to make it.

5.84 This duty applies to those involved in caring for the person and those interested in the person's welfare. For more serious decisions, it may be appropriate to seek views from a wider group of people, while respecting confidentiality.

5.85 Under section 6(7), where practicable and appropriate, the decision-maker must take into account the views of:

- anyone named by the person as someone who should be consulted
- anyone involved in caring for the person or interested in their welfare, including care workers, medical professionals, parents, family carers, other close relatives, or education staff where appropriate, and
- anyone with legal authority to act or make decisions on the person's behalf.

5.86 Any decision-maker must show they have thought carefully about whom to speak to. If it is practicable and appropriate to speak to the above people, they must do so and must take their views into account.

5.87 The decision-maker must be able to give reasons for not consulting a particular person where, viewed objectively, that person appears to be someone who should have been consulted. It is good practice to keep a clear record of those reasons. A failure to consult someone interested in the person's welfare, where it is practicable and appropriate to do so, may mean that the decision-maker cannot rely on the defence in section 8 of the Act (Acts in connection with care or treatment).

5.88 It is also good practice for the decision-maker to record at the end of the process why they think a specific decision is in the person's best interests. This is particularly important if the decision-maker goes against the views of somebody who has been consulted while determining the person's best interests.

5.89 The decision-maker should try to find out:

- what those consulted believe to be in the person's best interests in this matter, and

- if such persons can give information on the individual's wishes and feelings, beliefs and values, for example how the person has lived their life, what has been important to the and what they think the person would say now.

5.90 The views of everyone consulted should be given equal consideration, even where those views differ. They must be considered alongside the wishes and feelings of the person who lacks capacity and all other relevant factors.

5.91 This information may be available from a person whom the individual named, before they lost capacity, as someone they wished to be consulted. People close to the person who lacks capacity, such as close family members, are often likely to know them well. They may also be able to assist with communication or help interpret signs that indicate the person's present wishes and feelings.

5.92 However, being regarded as the person's next of kin does not mean that a person's views should be given greater weight than those of others who can provide relevant information. All views obtained through consultation should be considered carefully, even where they differ. They must be weighed alongside the wishes and feelings of the person who lacks capacity and all other relevant factors.

5.93 When consulting others, the decision-maker should be alert to any potential conflicts of interest, including situations where a person consulted may stand to gain financially from the decision. This does not necessarily mean that the person should be excluded from the decision-making process. However, their views should be considered with appropriate care, and the decision-maker must remain focused on the relevant issues, particularly the wishes, feelings, beliefs, and values of the person who lacks capacity.

5.94 Where an individual has been legally authorised to make decisions on behalf of someone who lacks capacity, such as an enduring power of attorney (property and financial affairs), they must act within the areas they are appointed to manage. They should also be consulted, where practical and appropriate, on other relevant decisions affecting the person.

Scenario

Considering other people's views

Ms L has an acquired brain injury with severe communication difficulties. She is cared for at home by her parents and attends a day centre a couple of days a week.

The day centre staff would like to take some of the service users on a day trip to a farm educational centre. They explain the trip to Ms L using clear language and pictures which show Ms L what she can expect on the trip. Ms L's body language suggests she likes the idea of visiting the farm animals. A capacity assessment is completed, and it is believed that Ms L lacks capacity to make the decision about the trip due to her inability to weigh up the information in order to make a decision. The day

centre staff speak to her parents as part of the process of assessing whether the trip would be in her best interests. Ms L's parents think that the trip would be a good experience for her. However, they are aware that Ms L gets anxious particularly with strangers who don't know how to communicate with her.

The staff and Ms L's parents discuss how to manage this in Ms L's best interests. A risk assessment is completed where it is agreed that a care assistant, to whom Ms L is particularly close, will accompany her throughout her time at the farm centre. The care assistant will use social situation stories throughout the trip to help Ms L's communication and minimise her anxiety.

Decision-makers: Confidentiality

5.95 Decision-makers must balance the duty to consult other people with the right to confidentiality of the person who lacks capacity. If confidential information is to be discussed, the decision-maker should only seek the views of those who it is appropriate to consult, and where their views are relevant to the decision to be made in the particular circumstances.

5.96 There may be occasions where it is in the person's best interests for personal information (e.g. about their medical condition, if the decision concerns the provision of medical treatment) to be revealed to those consulted as part of the process of working out their best interests (further guidance on this is given in Chapter 12) . Healthcare and social care staff who are determining a person's best interests must follow their professional guidance, as well as other relevant guidance, about confidentiality and also act in line with the Applied GDPR legislation.

When do the best interests principles apply?

5.97 Sections 3(6) and (7) of the Act (The principles) prescribe that the best interests principle applies to any act done, or any decision made, on behalf of an individual where there is reasonable belief that the person lacks capacity under the Act. This covers informal day-to-day decisions and actions as well as decisions made by the courts.

Reasonable belief about a person's best interests

5.98 Section 6(13) of the Act (Best interests) provides that if someone acts or makes a decision in the reasonable belief that what they are doing is in the best interests of the person who lacks capacity, provided they have followed the requirements of section 6 of the Act (Best interests), they will have complied with their duty under the Act to act in the best interests of a person who lacks capacity.

5.99 Coming to an incorrect conclusion about someone's capacity or best interests does not necessarily mean that the decision-maker would not be protected from liability. It is necessary to evidence that it was reasonable for them to think that the person lacked capacity and that they were acting in the person's best interests at the time when the

decision was made or the action taken. In doing so, they must also have considered whether the aim of their action or decision could be achieved in a way that is less restrictive of the person's rights and freedom.

5.100 Where a court is required to make a decision, the court is likely to require formal evidence of what might be in the person's best interests. This will include evidence from relevant professionals. However, in most day-to-day situations, generally there is little need for such formality. Moreover, in emergency situations, it may not be practical or possible to gather formal evidence.

5.101 Where the court is not involved, those acting or making decisions on behalf of a person who lacks capacity must still have reasonable grounds for believing that they are acting in that person's best interests. Decision-makers must not simply impose their own views; they must be able to point to objective reasons for their decision. They should be able to demonstrate that they have considered all relevant circumstances and applied each element of the best interests checklist in section 6 of the Act (Best interests).

Scenario

Demonstrating reasonable belief

Ms Z was attacked in the street and was brought to hospital unconscious, with severe injuries, having lost a lot of blood. The medical team decided that an urgent blood transfusion was in her best interests as it was required to save her life, and the transfusion was carried out.

As Ms Z had no form of identification with her an appeal was put out to identify her and her family was later traced. When they were contacted, they advised the hospital that Ms Z's beliefs meant that she would have refused the blood transfusion had she had capacity to make the decision.

As Ms Z arrived at the hospital unconscious and with no identification, the medical team had no information about her beliefs at the time they needed to make the urgent decision about emergency treatment. At the time the doctors made the best interests decision they had reasonable grounds for believing that the decision was in their patient's best interests. Therefore, they were protected from liability.

Once the hospital team was aware of Ms Z's beliefs, they considered them, in consultation with her family, in subsequent best interests decisions about her medical treatment while she lacked capacity to make the decisions for herself.

Best interests decisions: Potential problems

5.102 It is important that the best interests principle and checklist are used flexibly. In some cases, a balance sheet of pros and cons of options may be a useful tool to ensure all factors have been included. However, it should only be used as an aid and not as a substitute for decision-making. The fact that there are many entries in one column does not, in itself, give the answer. There may be only one entry in the second column, but it is of such importance that

it outweighs all of the entries in the first column, sometimes referred to as being a situation where there is a factor of "magnetic importance". In all cases, it is important that proper consideration is given to prioritising all relevant factors, so the outcome is the best possible for the person who lacks capacity to make the particular decision. Some decisions will be straightforward, and others more complex.

Conflicting concerns

5.103 A decision-maker may be faced with people who disagree about a person's best interests. Family members, partners and carers may disagree between themselves. Or they might have different memories about what views the person expressed in the past. Carers and family might disagree with a professional's view about the person's care or treatment needs.

5.104 The decision-maker will need to find a way of balancing these concerns or deciding between them. The first approach should be to review all elements of the best interests checklist with everyone involved. They should include the person who lacks capacity (as much as they are able to take part) and anyone who has been involved in earlier discussions. It may be possible to reach an agreement at a meeting to air everyone's concerns. But an agreement in itself might not be in the person's best interests. Ultimate responsibility for working out best interests lies with the decision-maker. Disagreements are covered in more detail in Chapter 11: Settling disagreements and disputes about issues covered in the Act.

Family, partners and carers who are consulted

5.105 If disagreement continues, the decision-maker will need to weigh up the views of different parties. This will depend entirely upon the circumstances of each case, the people involved and their relationship with the person who lacks capacity. Sometimes the decision-maker will find that carers have an insight into how to interpret a person's wishes and feelings that can help them reach a decision.

5.106 At the same time, paid care workers and voluntary sector support workers may have specialist knowledge about up-to-date care options or treatments. Some may also have known the person for many years.

5.107 People with conflicting interests should be included in the process (e.g. those who stand to inherit from the person's will, may still have a right to be consulted about the person's care or medical treatment). But decision-makers must always ensure that the interests of those consulted do not overly influence the process of working out a person's best interests. In weighing up different contributions, the decision-maker should consider:

- how long an individual has known the person who lacks capacity

- what their relationship is
- the level of contact they have with the person
- whether they have a vested interest in the decision, and/or
- whether their past or current conduct has been detrimental to the person who lacks capacity, and, if so, in what way.

Settling disputes about best interests

5.108 If someone wants to challenge a decision-maker's conclusions, there are several options:

- arranging a meeting for interested parties to discuss matters in detail
- request a second opinion, or
- attempt some form of mediation.

See Chapter 11, for further information about settling disagreements and disputes about issues covered in the Act.

5.109 Ultimately, if all other attempts to resolve the dispute have failed, the court might need to decide what is in the person's best interests.

The court

5.110 The court must ultimately take responsibility for the person who lacks capacity. This is true when:

- the person who lacks capacity has no close family or friends to take an interest in their welfare
- family members disagree about the person's best interests
- family members and professionals disagree about the person's best interests
- there is a conflict of interest for people who have been consulted in the best interests assessment, for example the sale of a family property where the person lives
- the proposed course of action may lead to the use of restraint or other restrictions on the person who lacks capacity, or
- there is a concern about the protection of an adult at risk.

Chapter 6
Protection For People Providing Care Or Treatment

Key Points

- Section 8 of the Act (Acts in connection with care or treatment) provides protection from liability for people who provide care or treatment for someone who lacks capacity, as long as they have acted reasonably and, in the persons best interests under section 6 of the Act (Best interests).
- Before acting or making a decision, reasonable steps must be taken to establish whether the person has capacity to consent to the care or treatment.
- Care and treatment should be the least restrictive option that can safely achieve the purpose.
- If restraint is being considered, it must be necessary to prevent harm to the person who lacks capacity and be proportionate to both the likelihood of the person suffering harm and to the seriousness of that harm.
- Records should be kept of the reasons for actions taken, the steps used to support decision-making, and the basis for any reasonable belief.
- Using a person's money to buy goods or services must only be for what is necessary and in their best interests, and any withdrawal from their accounts or sale of their property for this purpose requires legal authority.
- Protection from liability only applies where the person reasonably believes the individual lacks capacity and that the action or decision is in their best interests.

Key Terms

Consent A person's voluntary and informed agreement to an action or decision.

Harm In accordance with the Act, harm includes physical, psychological, financial or other harm and what constitutes harm will vary depending on the circumstances.

Least restrictive option The requirement to consider whether the purpose of an action or decision can be achieved in a way that is less restrictive of the person's rights and freedoms.

Reasonable belief A belief based on proper steps, as set out in the Act, relevant information and sound reasoning – not guess work or assumptions – that leads the decision-maker to conclude that what they are doing is in the person's best interests.

Restraint Actions that involve using or threatening force or limiting a person's freedom of movement whether or not they are resisting.

Protection from liability Legal protection granted to anyone who has acted or made decisions in line with the Act's principles.

Protection for those caring for those who lack capacity

6.1 Every day, millions of acts are done to and for people who lack capacity either to:

- take decisions about their own care or treatment, or
- consent to someone else caring for them.

6.2 Such actions range from day-to-day tasks of caring (for example, helping someone to wash) to life-changing events (for example, serious medical treatment or arranging for someone to go into a care home).

6.3 In theory, many of these actions could be against the law. Legally, people have the right to a private and family life, home and correspondence, and to stop others from interfering with their body or property unless they give permission. Carers who dress people who cannot dress themselves are potentially interfering with someone without their consent, so could theoretically be prosecuted for assault. A neighbour who enters and cleans the house of a person who lacks capacity could be trespassing on the person's property.

6.4 The Act addresses these concerns and provides a legal basis for protecting people who care for those without capacity.

6.5 This 'protection from liability' for actions in connection with care or treatment is set out at sections 8 (Acts in connection with care or treatment) and section 9 (Section 8: limitations) of the Act. It stops people who carry out these everyday actions from being pursued for acts that could otherwise be classed as civil wrongs or crimes. By protecting family and other carers from liability, the Act allows necessary caring actions or treatment to take place as if a person who lacks capacity to consent had consented to them. People providing care of this sort do not therefore need to get formal authority to act.

6.6 Importantly, section 8 of the Act (Acts in connection with care or treatment) does not give people caring for or treating someone the power to make any other decisions on behalf of those who lack capacity to make their own decisions. It does however offer protection from liability so that they can act in connection with the person's care or treatment.

6.7 Carrying out actions in a way which does not comply with section 8 of the Act (Acts in connection with care or treatment) may leave the person carrying out the action liable for any consequences.

Record keeping and protection from liability

6.8 All staff involved in the care of a person who lacks capacity should make sure a record is kept of the process of working out the best interests of that person for each relevant decision. The sort of record that is kept of the process of working out the person's best interests will depend upon the nature of the decision. Appropriately detailed records should be kept of decisions made. Chapter 5: Best Interests, contains more detail on this.

6.9 For healthcare and treatment decisions, responsibility for deciding and recording what is in a person's best interests lies with the member of healthcare staff responsible for the person's treatment. They should record their decision, how they reached it and the reasons for it in the person's clinical notes. As long as they have recorded objective reasons to show that the decision is in the person's best interests, and the other requirements of section 8 of the Act (Acts in connection with care or treatment) are met, all healthcare staff taking actions in connection with the particular treatment will be protected from liability.

6.10 Where decisions represent a serious interference with the person's rights under the European Convention on Human Rights a detailed record should be made. This is to ensure that the decision-maker has considered all the matters necessary in order to be able to rely upon the defence in section 8 of the Act (Acts in connection with care or treatment). Details of decisions this may cover and of what such a record should include is set out in Chapter 5.

What type of actions might have protection from liability?

6.11 Section 8(1) of the Act (Acts in connection with care or treatment) provides possible protection for actions carried out in connection with care or treatment. The action may be carried out on behalf of a person who is reasonably believed to lack capacity to consent to it, provided that all practicable steps have been taken, without success, to support the person to make the decision and the action is in that person's best interests (see Chapter 5: Best interests). The Act does not define 'care' or 'treatment'. Those terms should be understood as having their everyday meaning. Section 52(1) of the Act (Interpretation), however, makes clear that treatment includes diagnostic or other procedures.

What actions might be covered by section 8 (Acts in connection with care or treatment)?

6.12 Personal care

- supporting with washing, dressing or personal hygiene
- supporting with eating and drinking
- supporting with communication
- supporting with mobility or moving around

- supporting someone take part in education, social or leisure activities
- going into a person's home to drop off shopping or to see if they are alright
- shopping or buying necessary goods with the person's money
- arranging household services, for example arranging repairs or maintenance for gas and electricity supplies
- providing services that help with domestic and household tasks, such as cleaning and laundry
- undertaking actions related to community care services, for example day care, residential accommodation or nursing care, and
- helping someone to move home, including moving property and clearing the former home.

6.13 Healthcare and treatment

- carrying out diagnostic examinations and tests to identify an illness, condition or other problem
- providing professional medical, dental and similar treatment
- giving medication
- taking someone to hospital for assessment or treatment
- providing nursing care, whether in hospital or in the community
- carrying out any other necessary medical procedures, for example taking a blood sample, or therapies, for example physiotherapy or chiropody or
- providing care in an emergency.

6.14 A person is only protected from liability if they:

- have taken reasonable steps to establish whether the individual in question lacks the relevant decision-making capacity
- reasonably believe that the person lacks capacity, or
- believe that the act is in the person's best interests.

6.15 What amounts to reasonable steps will depend on the decision in question. In some cases, the person may need to carry out their own assessment and take steps to support the individual to make the decision. In other cases, it may be appropriate to rely on an assessment carried out by someone else (see paragraph 6.42 onwards). Some acts connected with care or treatment may result in major life changes and have significant consequences for the person concerned. Those requiring particularly careful consideration include:

- a change of residence, perhaps into a care home or nursing home
- restriction of contact with certain people
- major decisions about healthcare and medical treatment
- administration of 'covert' medication or treatment, or
- administration of medication or treatment against a person's known wishes.

6.16 Such decisions are likely to represent a serious interference with the person's rights under the European Convention on Human Rights. A detailed record of the decisions taken should therefore be prepared to ensure that the decision-maker has considered all the matters necessary to be able to rely upon the defence in section 8 of the Act (Acts in connection with care or treatment).

Change of residence

6.17 Sometimes a person cannot get sufficient or appropriate care to safely remain in their own home, and they may have to move – perhaps to live with relatives or to go into a care home or nursing home. In the first instance steps should be taken to support the person to make their own decision if they have capacity to do so.

6.18 If the person lacks capacity to make the decision about a change of residence, the decision-maker must consider whether the move is in the person's best interests by referring to the best interests checklist (in particular the person's past and present wishes and feelings, as well as the views of other relevant people). The decision-maker must also consider whether there is another less restrictive option.

6.19 The decision-maker should wherever practicable speak to:

- anyone currently involved in the person's care
- carers and family members close to the person and interested in their welfare
- others who have an interest in the person's welfare
- anyone the person has previously named as someone to be consulted, and
- an attorney who has been legally appointed to make particular decisions about the funding of care on the person's behalf.

6.20 Sometimes the final outcome may not be what the person who lacks capacity wanted. They may have wished to stay at home but there may be no alternative to moving them. Such a move would normally require the person's formal consent if they had capacity to give or refuse it. In cases where a person lacks capacity to consent, section 8 of the Act (Acts in connection with care or treatment) allows those involved in their care and treatment to carry out actions relating to the move – as long as the Act's principles and the requirements for

working out best interests have been followed. This applies even if the person continues to object to the move.

6.21 If there is a serious disagreement between parties about the need to move the person that cannot be settled in any other way, an application to court should be considered (see Chapter 11: Settling disagreements and disputes about issues covered in the Act).

6.22 Section 8 of the Act (Acts in connection with care or treatment) outlines the types of acts that may be carried out in connection with care or treatment, but it does not grant unrestricted authority to enforce these changes at any cost. Section 9 of the Act (Section 8: limitations) places clear limits on the use of restraint by only permitting restraint to be used (for example, to transport the person to their new home) where this is necessary to protect the person from harm and is a proportionate response to the risk of harm. Any action taken to move the person concerned or their property could incur liability unless protected under section 8 of the Act.

6.23 Section 9(1) of the Act (Section 8: limitations) sets out that harm includes, but is not limited to, physical, physiological, financial or other harm. In accordance with section 9(2) (Section 8: limitations), restraint means the use, or threat of use of force to secure the doing of an act which a person resists, or, restricting a person's liberty of movement whether or not the person resists.

Restriction of contact

6.24 In some circumstances, it may be necessary to restrict or supervise contact between the person and another person or category of people. In some cases, that restriction or supervision may align with the wishes of the person (for instance, they may not wish to see someone who has previously abused them). A record should be kept of why the steps have been taken and how they align with the wishes of the person.

6.25 In other cases, contact may be restricted or supervised even where it is clear that the person wishes to see the other person or people. Such a restriction may interfere with the person's right to respect for private and family life under Article 8 of the European Convention on Human Rights and must therefore be considered with particular care. Any interference must be lawful, necessary and proportionate, and justified by reference to the risks which the person would otherwise be exposed to, or to the rights and freedoms of others. The decision-maker should consider whether the person's interests can be secured by less intrusive measures, such as supported contact, supervised contact, limits on the time, place or manner of contact, or other safeguards. The record of the decision should show the reasons for any restriction, the risks identified, the person's wishes and feelings, the alternatives considered,

and why the restriction imposed is the least intrusive option that will adequately protect the person's interests. See paragraphs 5.67–5.70: Recording best interests decisions.

6.26 Only the court can make a decision on a person's behalf not to see someone, and an application to the court is likely to be necessary in any situation where there is doubt or disagreement about whether the restriction is in the person's best interests.

Healthcare and treatment decisions

6.27 Section 8 of the Act (Acts in connection with care or treatment) also allows actions to be taken to ensure a person who lacks capacity to consent receives necessary medical treatment. This could involve taking the person to hospital for out-patient treatment or arranging for admission to hospital. Even if a person who lacks capacity to consent objects to the proposed treatment or admission to hospital, the action might still be allowed under section 8 of the Act.

6.28 There are limits about whether force or restraint can be used to impose treatment (see paragraph 6.64).

6.29 Major healthcare and treatment decisions will need special consideration. This also includes treatment against a person's known wishes and covert treatment. Healthcare staff must carefully work out what would be in the person's best interests (see the best interests checklist in Chapter 5), including having regard to any applicable advance directive or written statement in regard to requests for or refusals of particular medical treatments in certain circumstances. As part of the process of working this out in line with the best interests checklist, healthcare staff must consider (where practicable and appropriate):

- the past and present wishes and feelings, beliefs and values of the person who lacks capacity to make the treatment decision, including any applicable written statement the person made setting out their wishes when they had capacity
- the views of anyone previously named by the person as someone to be consulted
- the views of anyone engaged in caring for the person, and
- the views of anyone interested in their welfare.

6.30 Healthcare staff must show they have thought carefully about who to speak to. If it is practicable and appropriate to speak to the above people, they must do so and must take their views into account.

6.31 Healthcare staff must be able to explain why they did not speak to a particular person when it would appear objectively that that person should be consulted. It is good practice to have a clear record of the reasons. A failure to consult with someone properly interested in the

person's welfare when it is practicable and appropriate to do so will mean that the decision-maker cannot rely upon the defence in section 8 of the Act (Acts in connection with care or treatment).

6.32 Healthcare staff must also consider whether there are alternative treatment options that might be less intrusive or restrictive. When deciding about the provision or withdrawal of life sustaining treatment, anyone working out what is in the best interests of a person who lacks capacity must not be motivated by a desire to bring about the person's death.

6.33 Multi-disciplinary meetings are often the best way to decide on a person's best interests. They bring together healthcare and social care staff with different skills to discuss the person's options and may involve those who are closest to the person concerned. Final responsibility for deciding what is in a person's best interest lies with the member of healthcare staff responsible for the person's treatment. They should record their decision, how they reached it and the reasons for it in the person's clinical notes. As long as they have properly ascertained that a person lacks capacity, applied the best interests checklist outlined in Chapter 5, recorded objective reasons to show that the decision is in the person's best interests, and that the other requirements of section 8 of the Act (Acts in connection with care or treatment) are met, all healthcare staff taking actions in connection with the particular treatment should be protected from liability.

6.34 Although a decision to put a DNACPR (Do Not Attempt Cardio-Pulmonary Resuscitation) recommendation in the person's records is not strictly a best interests decision, the same principles should apply.

Scenario

A Do Not Attempt Cardio-Pulmonary Resuscitation (DNACPR) recommendation

Ms R had experienced deteriorating health for some time, including chronic lung and kidney problems, and low immunity. When she became very ill with a chest infection her support team called an ambulance.

Ms R was admitted to hospital. Medically she was not responding to treatment and it was clear to her support team that she was becoming unresponsive to the people around her. Blood tests showed her condition was deteriorating.

Ms R's consultant met with the manager of her support team, her social worker and the learning disability nurse to make a decision about her care and treatment. Ms R did not have close family and her niece who was consulted said she did not feel she knew Ms R well enough to be involved.

The consultant was the decision-maker and aware that in order to make this decision, he needed to speak to people who knew Ms R well and who could explain what they thought she would want to happen.

The consultant explained the different outcomes for Ms R, including if she recovered from her chest infection. The doctor's medical opinion was that Ms R was very unlikely to recover and if she did, she would likely need to stay in hospital until the end of her life, most probably in a coma.

The consultant wanted to understand what Ms R's wishes and preferences would be in relation to her care. Her support manager had spoken with the support team about this and everyone agreed that Ms R would not want to stay in hospital. The support manager and social worker also explained how difficult the past few months had been for Ms R as she became more ill.

Following a long discussion to understand more about Ms R and what she would want, the consultant made a decision to put a DNACPR recommendation in place for Ms R.

When should the court be asked to make a healthcare or treatment decision?

6.35 In some cases, the court must or should be asked to make the relevant decision, as without the court's scrutiny it is likely that medical professionals will not be able to say that they have a reasonable belief that they are acting in the person's best interests so as to be protected from liability under section 8 (Acts in connection with care or treatment) (see Chapter 8: The role of the court).

Healthcare and treatment decisions for 16-17 year olds

6.36 Chapter 7 explains that decision-making in relation to 16 and 17 year olds who lack capacity can, in many cases, be undertaken either by reference to the Act or by reference to the Children and Young Persons Act 2001 and the operation of parental responsibility. Professionals can therefore choose which regime to apply but should be clear as to which one they are using. If they are using the Act, they will be able to rely on section 5 providing they correctly follow the principles of the Act.

Who is protected from liability by section 8 of the Act

6.37 Section 8 of the Act (Acts in connection with care or treatment) is most likely to affect:

- family carers and other kinds of carers
- care workers
- healthcare and social care staff
- others who may occasionally be involved in the care or treatment of a person who lacks capacity to consent, for example emergency services, housing workers, police officers and volunteer support workers, and
- staff caring for 16–17-year-olds who lack capacity.

6.38 At any time, it is likely that several people will be carrying out tasks that are covered by section 8 of the Act (Acts in connection with care or treatment). Section 8 does not:

- give one person more rights than another to carry out tasks
- specify who has the authority to act in a specific instance
- allow somebody to make decisions relating to subjects other than the care or treatment of the person who lacks capacity, or
- allow somebody to give consent on behalf of a person who lacks capacity to do so.

6.39 To receive protection from liability under section 8 of the Act (Acts in connection with care or treatment) all actions must be related to the care or treatment of the person who lacks capacity to consent. Before taking action, carers must first reasonably believe that:

- the person lacks the capacity to make that particular decision at the time it needs to be made, where all practicable support to enable them to make the decision has been given without success, and
- the action is in the person's best interests.

6.40 This is explained further in paragraphs 6.42–6.57 below.

Scenario

Protecting multiple carers

Mr R has early-stage dementia, and lives in his own home with the help of several people. Mr R's daughter cooks and brings meals and essential shopping for him. A nurse regularly visits him to change the dressing on a pressure sore, and a close friend takes Mr R for a walk most days, guiding him when they cross the road.

Mr R often has capacity to make decisions about aspects of his care, such as what to have for lunch or where to go for a walk. When he does, those caring for him must act in accordance with his decision.On occasions however, Mr R gets confused. When his carers have taken reasonable steps to check whether Mr R has capacity to make a specific decision, and this leads to the reasonable belief that he lacks capacity to decide, they make that decision in his best interests. If they follow these steps each of them is protected from liability under section 8 of the Act.

6.41 Section 8 of the Act (Acts in connection with care or treatment) may also protect carers who use a person's money to pay for goods or services that the person needs, where the person lacks capacity to make the purchase. However, there are strict controls over who may have access to another person's money. See paragraphs 6.71-6.87 for more information.

6.42 Carers who provide personal care services must not carry out specialist procedures that are normally done by trained healthcare staff. If the action involves medical treatment, the doctor

or another member of healthcare staff with responsibility for the patient will be the decision-maker who has to decide whether the proposed treatment is in the person's best interests. For example, a doctor can delegate responsibility for giving the treatment to other people in the clinical team who have the appropriate skills or expertise. A person who acts outside the scope of their experience or qualifications may not be able to rely on the Act's protection from liability.

Care support or treatment planning

6.43 Decisions about a person's care or treatment are often made by a multi-disciplinary team by drawing up a care plan for the person. The preparation of a care and support or treatment plan should always include an assessment of the person's capacity to consent to the actions covered by the care and support plan; a record of steps taken to support the person to make their own decision; and confirmation that those actions are agreed to be in the person's best interests. Healthcare and social care staff may then be able to assume that any actions they take under the care plan are in the person's best interests and therefore receive protection from liability under section 8 of the Act (Acts in connection with care or treatment). However, a person's capacity and best interests must still be reviewed regularly.

What steps should people take to be protected from liability?

6.44 As well as taking the following steps, somebody who wants to be protected from liability should bear in mind the Statutory Principles set out in section 3 of the Act (The principles) (see Chapter 2: Statutory Principles).

6.45 First, reasonable steps must be taken to find out whether a person has the capacity to make a decision about the proposed action (section 8(1)(a) of the Act-Acts in connection with care or treatment). If the person has capacity, they must consent before anyone can take action on their behalf. The person taking the action will only be protected from liability if that consent has been obtained. For more detailed guidance on what is classed as 'reasonable', see paragraphs 6.49-6.57.

6.46 Reasonable steps must always include:

- taking all practicable and appropriate steps to help people to make a decision about an action themselves, and
- applying the test of capacity. See Chapter 4: What capacity means and how to assess it.

6.47 The person who is going to take the action must have a 'reasonable belief' that the individual lacks capacity to give consent for the action at the time it needs to be taken.

6.48 The person proposing to take action must have reasonable grounds for believing that the action is in the best interests of the person who lacks capacity. They should apply all elements of the best interests checklist (see Chapter 5: Best interests), and in particular:

- consider whether the person is likely to regain capacity to make this decision in the future
- consider whether a less restrictive option is available. See Chapter 2, principle 7, and
- have objective reasons for thinking an action is in the best interests of the person who lacks capacity to consent to it.

Define *'reasonable'*

6.49 Carers do not have to be experts in assessing capacity. However, they must be able to evidence that they have taken reasonable steps to establish, on the balance of probabilities, that the person has capacity to make the specific decision, in accordance with section 4(3) of the Act (Lack of capacity). Only then will they have reasonable grounds for believing the person lacks capacity in relation to that particular matter.

6.50 As outlined in Chapter 4, anyone assessing a person's capacity to make decisions for themselves or give consent must focus wholly on whether the person has capacity to make a specific decision at the time it needs to be made and not the person's capacity to make decisions generally.

Reasonable grounds

6.51 Most of the time, formal assessment processes are unlikely to be required. In some circumstances, formal processes should be carried out (e.g. where consent to medical treatment is required, the doctor will need to assess and record the person's capacity to consent). Under section 8 of the Act (Acts in connection with care or treatment), carers and professionals will be protected from liability as long as they are able to provide objective reasons that explain why they believe that the person lacks capacity to consent to the action. If somebody challenges their belief, both carers and professionals should be protected from liability as long as they can show that they took reasonable steps to find out whether the person has capacity and that they have a reasonable belief that the person lacks capacity.

6.52 It is important to note that section 9 (section 8: limitations) acts as a safeguard to prevent misuse of section 8 (Acts in connection with care or treatment). Section 8 (Acts in connection with care or treatment) only protects lawful actions relating to care or treatment. It is not a shortcut or workaround for decisions that fall outside the Act or require higher authority.

6.53 Similarly, to avoid liability, carers, relatives, and others involved in caring for a person who lacks capacity must have reasonable grounds for believing that their action is in that person's best interests. They must not simply impose their own views, instead they must be able to demonstrate that they have considered all relevant circumstances and applied the best interests checklist. This includes showing that they have sought to involve the person who lacks capacity and to ascertain their wishes, feelings, beliefs, and values. They must also consult others where practicable and appropriate. The level of formality required should be proportionate to the seriousness of the decision.

6.54 If health and social care staff are involved, their skills, knowledge and professional role will affect what is considered "reasonable". For example, a doctor assessing capacity to consent to treatment will be expected to exercise the level of skill and judgement appropriate to a medically qualified professional. They should record the steps taken and the reasons for their finding in the person's healthcare record. If somebody challenges their decision, they will be protected from liability if they can show that it was reasonable for them to believe that their action was in the person's best interests – in all the circumstances of that particular case. See paragraph 6.8 – 6.10 and Chapter 5 for guidance on recording these decisions.

6.55 Healthcare and social care staff should apply normal clinical and professional standards when deciding what treatments to offer. They must then decide whether the proposed treatment is in the best interests of the person who lacks capacity to consent. This includes considering all relevant circumstances and applying the best interests checklist.

6.56 Healthcare and social care staff can be said to have 'reasonable grounds for believing' that a person lacks capacity if:

- they are working to a person's care, support or treatment plan, and
- the care planning process involved an assessment of the person's capacity to make a decision about actions in the care plan.

6.57 It may be reasonable for them to rely on the care planning process as having considered the person's best interests. However, they should still make reasonable efforts to communicate with the person, to confirm whether they continue to lack capacity and whether the proposed action remains in their best interests.

Scenario

Working with a care and support plan

Ms M has physical disabilities and complex mental health needs. She lives in a nursing home and the multi-disciplinary team has prepared a care and support plan for her, in consultation with her relatives. The care and support plan covers the medication Ms M has been prescribed, the

physiotherapy she needs, help with her personal care and recommended therapeutic activities such as art therapy.

Although attempts were made to involve Ms M in the care planning process, the doctor responsible for her care assessed her as lacking capacity to consent to most aspects of her care and support plan. The care and support plan is therefore relied on by the nurse or care assistant who administers the medication, by the physiotherapist and art therapist, and also by the care assistant who helps with Ms M's personal care. It provides them with reasonable grounds for believing that they are acting in her best interests.

However, as each act is performed, these professionals each take reasonable steps to communicate with Ms M to explain what they are doing and to ascertain whether she has the capacity to consent to the act in question at that time. If they believe that she does, they must obtain Ms M's consent for the care or treatment before proceeding.

Emergency situations

6.58 Sometimes people who lack capacity to consent will require emergency medical treatment to save their life or prevent them from serious harm. In these situations, what is considered 'reasonable' steps will likely differ to those in non-urgent cases. In emergencies, it will almost always be in the person's best interests to give urgent treatment without delay.

Negligence

6.59 Section 8 of the Act (Acts in connection with care or treatment) does not provide a defence in cases of negligence – either in carrying out a particular act or by failing to act where necessary. For example, a doctor may be protected against a claim of battery for carrying out an operation that is in a person's best interests. However, if that doctor performs the operation negligently, they are not protected from a charge of negligence. So, the person who lacks capacity has the same rights in cases of negligence as someone who has consented to the operation.

Limits on protection from liability

6.60 Section 9 of the Act (Section 8: limitations) imposes some important limitations on acts which can be carried out with protection from liability under section 8 of the Act (Acts in connection with care or treatment) (as described in the first part of this chapter). The key areas where acts might not be protected from liability are where there is inappropriate use of restraint.

Using restraint

6.61 Section 9(2) of the Act (Section 8: limitations) states that someone is using restraint if they:

- uses, or threaten to use, force to secure the doing of an act which a person resists, or
- restricts a person's liberty of movement, whether or not the person resists

6.62 Any action intended to restrain a person who lacks capacity will not attract protection from liability unless the following two conditions are met:

- the person taking action must reasonably believe that restraint is necessary to prevent harm to the person who lacks capacity, and
- the amount or type of restraint used and the amount of time it lasts must be a proportionate response to the likelihood of the person suffering harm and seriousness of that harm.

6.63 Any use of restraint must be lawful, necessary to prevent harm, and proportionate to the likelihood and seriousness of that harm (see paragraphs 6.66-6.70 for more explanation of the terms necessary, harm and a proportionate response).

6.64 In addition to the Act, the common law allows necessary and proportionate steps to be taken to prevent the immediate risk of serious harm to another person. Restraint for these purposes should always be used for the shortest period possible to enable the de-escalation of the situation. Consideration should be given to what legal frameworks are available to address the position (e.g. assessment for admission under the Mental Health Act 1998).

6.65 In addition to the Code, further detailed guidance on the use of restraint or physical intervention should be accessible through individual organisations policies, professional frameworks, regulatory standards and training programmes so that individuals understand when restraint may be appropriate and how to use it safely and lawfully. Clear requirements for accurate and timely record keeping should also be in place, so that any use of restraint is properly documented, reviewed, and subject to oversight.

Necessary restraint

6.66 Anybody considering using restraint must have objective reasons to justify that restraint is necessary. They must be able to show that the person being cared for is likely to suffer harm unless proportionate restraint is used. A carer or professional must not use restraint just so that they can do something more easily. If restraint is necessary to prevent harm to the person who lacks capacity, it must be the minimum amount of force for the shortest time possible. There is less likelihood of restraint being necessary when the principles of the Act are followed and there is a real understanding of the person's wishes, feelings, beliefs and values.

6.67 There will be circumstances in which staff must intervene to stop a person from causing harm to others. Nothing in the Act prevents necessary action being taken to protect others where there is a risk of harm. Any wider legal or operational requirements continue to apply, and

actions should always safeguard the wellbeing and safety of those who may be affected. This extends to situations where staff may need to restrain or remove a person to protect against harm to themselves or to others.

Scenario

Appropriate use of restraint

Mr D has learning disabilities and has started behaving in a challenging way. Staff at his care home think he might have a medical condition that is causing him distress. They take him to the doctor, who examines Mr D and thinks that he might have a hormone imbalance. The doctor needs to take a blood test to confirm this.

Mr D is comfortable with being in the doctor's consulting room and talking with him and his carer. The doctor and Mr D's carers explain to Mr D in clear language why the doctor needs to take the blood sample, and what will happen. This is in order to take all reasonable steps to support Mr D to make the decision to have the test. However, the doctor concludes from Mr D's behaviour that he does not have capacity to understand why the test is needed or make the decision. The doctor decides that having the test is in Mr D's best interests, because (although the result might be negative) failing to treat a problem like a hormone imbalance might make it worse.

When the doctor tries to take the blood sample Mr D becomes frightened and attempts to fight him off. The doctor decides that it is in Mr D's best interests to be restrained momentarily in order to have the blood sample taken. He therefore calls for the support of two colleagues who are trained in holding a patient effectively for a blood test in a way that causes as little distress as possible. In this way, and along with Mr D's carers talking to him to reassure him as much as possible throughout the procedure, Mr D is restrained safely for the minimum time needed to take the blood sample.

The temporary restraint is in proportion to the likely harm caused by failing to treat the possible medical condition.

Harm

6.68 The Act does not define 'harm', because harm will vary depending on the situation. Section 9(1)(b) of the Act (Section 8: limitations) does, however, outline that harm includes physical, psychological, financial or other harm. Simple measures can often be put in place to reduce the risk of harm (e.g. by locking away poisonous chemicals or removing obstacles). Care planning should include risk assessments and set out appropriate actions to try to minimise possible risks. It is impossible to remove all risk, and a proportionate response is needed when the risk of harm does arise.

Proportionate response

6.69 A 'proportionate response' means using the least intrusive type and minimum amount of restraint necessary to achieve an outcome in the best interests of the person who lacks capacity. Where force is necessary, carers, health and social care staff should use the

minimum amount of force for the shortest possible time. For example, a carer may need to hold a person's arm while crossing the road if the person does not understand the dangers of traffic. However, it would not be proportionate to prevent the person from going outdoors altogether. Similarly, while a secure lock on a door facing a busy road may be appropriate, locking a person in their bedroom at all times to prevent them from attempting to cross the road would not be proportionate.

6.70 Staff must consider less restrictive options before using restraint. It may also be appropriate to seek input from a relevant professional. This could include a behaviour specialist, someone within the organisation responsible for oversight of restrictive practices. They can work with the person to explore whether restraint can be avoided or reduced.

Scenario

Avoiding restraint

Mr U has a learning disability and attends college. He says he enjoys his time at college and he is learning new skills. However, on occasion he behaves aggressively towards others and himself, sometimes hitting a wall and hurting himself.

Mr U's support worker stays with him at college, to support him. This includes when Mr U's behaviour is causing concern. The support worker is trained to use de-escalation techniques, and in some events to restrain Mr U physically, if he is at risk of harming himself, others or significant risk to the environment.

In order to manage these risks and reduce the need for restraint, the support worker and community team work with Mr U on a positive behaviour plan to identify and understand the triggers leading to his stress and subsequent aggressive behaviour. This also involves encouraging Mr U to develop self-management strategies.

Through ongoing work with Mr U, it is believed that his behaviours of concern (sometimes referred to as challenging behaviours) are linked to anxiety and frustration. His support worker works with the college to put in place strategies to minimise the noisy and unpredictable environments which cause him stress. Mr U and his support worker work together to increase his awareness of his anxiety and practise using sign language or visual aids so when he does recognise himself feeling anxious, he can take time out. The plan is written down so that all members of the college team can support Mr U by recognising his tools to manage his anxiety. In this way Mr U's positive behaviour plan reduces the likelihood of challenging behaviour and the need for restraint.

Who can pay for goods or services?

6.71 Under the Act, a person lacking capacity is allowed and can be supported to manage small, everyday spending independently, if they have capacity for those decisions.

A person providing care or treatment, for example a paid care worker, a carer or a family member, may also have to spend money on behalf of someone who lacks capacity to purchase necessary goods or services. This may be for something simple such as a milk

delivery, buying clothes in a shop or a takeaway food order. A person providing care or treatment is likely to be protected from liability if their actions are properly taken under section 8 of the Act (Acts in connection with care or treatment) and are in the best interests of the person who lacks capacity.

6.72 In general, a contract entered into by a person who lacks capacity to make the contract cannot be enforced if the other person knows, or must be taken to have known, of the lack of capacity. Section 11 of the Act (Payment for necessary goods and services) modifies this rule and states that where the contract is for 'necessary' goods or services for a person who lacks capacity to make the arrangements for themselves, that person must pay a reasonable price for them.

6.73 Anyone spending money on behalf of someone who lacks capacity may also need formal legal authority (such as via a legal advocate or court process) to manage complex financial matters.

6.74 For example, if the person cannot sign contracts, arrangements to make the necessary agreements must be made on their behalf, through either:

- an Enduring Power of Attorney (an "EPA") as defined by the Power of Attorneys Act 1987, or
- a court Appointed Mental Health Receiver (a "receiver") as set out in the Mental Health Act 1998, section 103.

6.75 These legal safeguards ensure the person is protected from signing something they don't understand, while still being free to spend money day to day.

6.76 Capacity can change, so relevant parties must regularly check whether:

- the person can understand more complex money tasks, and
- the person can manage daily spending safely.

Necessary goods and services

6.77 Necessary means something that is suitable to the person's condition in life (their place in society, rather than any mental or physical condition) and their actual requirements when the goods or services are provided (section 11(2)- Payment for necessary goods and services).

6.78 What is "necessary" will depend on the person's circumstances. For a person who has never had capacity, necessary goods and services are those required to maintain a reasonable quality of life. For a person who previously had capacity, what is necessary should be understood by reference to what is needed to support them to live at a standard broadly consistent with the life they led before losing capacity.

For example, if a person who now lacks capacity previously chose to buy expensive designer clothes, those items may still be regarded as necessary, provided they remain affordable. However, the same would not necessarily apply to a person who had always chosen to wear budget clothing, regardless of their wealth.

6.79 Goods are not necessary if the person already has a sufficient supply of them. For example, buying one or two new pairs of shoes for a person who lacks capacity could be necessary. But a dozen pairs would probably not be necessary.

6.80 Section 11(3) of the Act (Payment for necessary goods and services) also sets out that services can include the provision of accommodation.

Arranging payments for necessary goods and services

6.81 If a person lacks capacity to arrange payment for necessary goods and services, sections 8 (Acts in connection with care or treatment) and 10 (Expenditure) of the Act may permit a person acting in connection with the individuals care or treatment (e.g. a paid care worker, a carer or family member), to arrange payment on their behalf, provided the conditions in those sections are met.

6.82 The person who is arranging payment must first take reasonable steps to check whether a person can arrange for payment themselves or has the capacity to consent to the person who is doing it for them. If the person lacks the capacity to consent or pay themselves, the person arranging payment must decide what goods or services would be necessary for the person and what is in their best interests. The person arranging payment can then lawfully deal with payment for those goods and services in one of three ways:

- If neither the person arranging payment nor the person who lacks capacity can produce the necessary funds, the person arranging payment may promise that the person who lacks capacity will pay.
- If the person who lacks capacity has cash, the person arranging payment may use that money to pay for goods or services, for example to pay for a milk delivery or for a haircut.
- The person arranging payment may choose to pay for the goods or services with their own money. The person who lacks capacity must pay them back. This may involve using cash in the person's possession or running up an IOU. This is not appropriate for paid care workers, whose organisational policy might stop them handling their clients' money.

6.83 The person who is arranging payment should keep bills, receipts and other proof of payment when paying for goods and services. They will need these documents when asking to get

money back. Keeping appropriate financial records and documentation is a requirement for regulated providers and paid carers.

Access to a person's assets

6.84 The Act does not give a person providing care or treatment access to a person's income or assets, nor does it allow them to sell the person's property.

6.85 Anyone wanting access to money in a person's bank or building society will need formal legal authority. They will also need legal authority to sell a person's property.

6.86 Sometimes another person will already have legal control of the finances and property of a person who lacks capacity to manage their own affairs. This authority may arise in several ways, including:

- Enduring Power of Attorney: An Enduring Power of Attorney ("EPA"), as defined by the Power of Attorneys Act 1987, is created before a person loses mental capacity. The EPA can only be registered once a medical practitioner formally confirms that the person has lost the capacity to manage their own property and financial affairs. Once registered, the Enduring Power of Attorney is legally authorised to access the person's bank accounts, pay bills, manage benefits, sign contracts and oversee savings, pensions and property.
- Mental Health Receiver: The court may appoint a Mental Health Receiver (a "Receiver") as set out in the Mental Health Act 1998, section 103. Before doing so, the person must be certified by a medical practitioner as mentally incapable of managing their property and affairs. The court must also be satisfied that the proposed Receiver is suitable. A court-appointed Receiver has legal authority to deal with banking, bills, contracts, benefits, savings, pensions and property.
- Appointee for Social Security Benefits: An individual may be appointed under Social Security Regulations to act as an "Appointee", enabling them to claim and manage state benefits on behalf of a person who lacks capacity to manage their own claim. However, an Appointee's authority is strictly limited to benefit-related income and does not extend to other assets, savings or property.

6.87 Section 9(3) of the Act (Section 8: limitations) makes clear that a family carer or other carer cannot make arrangements for goods or services to be supplied to a person who lacks capacity if this conflicts with a decision made by someone who has formal powers over the person's money and property, such as an enduring power of attorney acting within the scope of their authority. Where there is no conflict and the person providing care or treatment has

paid for necessary goods and services, the person providing care or treatment may ask for money back from the person with formal powers over the person's money.

Chapter 7
The Act & Children And Young People

Key Points

- The Act does not generally apply to children under 16, except for limited provisions including that the court may make decisions about the property and financial affairs of a child under the age of 16 where the child is likely to still lack capacity at 18.
- Most of the Act applies to young people aged 16–17 years, who may lack the relevant capacity to make a particular decision.
- The same principles and approach that apply to adults also apply to determine the best interests regarding care or treatment of a young person who lacks capacity to make a decision. This means considering the factors set out in the best interests checklist (see Chapter 5, Best Interests) to ascertain what is right for the young person when the decision needs to be made.
- Depending on the situation, either the Capacity Act or the Children and Young Persons Acts may apply. The Capacity Act only applies if the young person lacks capacity to make the decision. If neither law is suitable, other options (such as the Mental Health Act or the High Court's powers) may need to be used.
- Professionals may consider it more appropriate, due to the circumstances of the case, to rely upon the consent of a person with parental responsibility regarding the young person's care and treatment.

Key Terms

Best interests The legal requirement that any action taken or decision made on behalf of a person who lacks capacity must be in that person's best interests, as set out within section 6 of the Act (Best interests).

Child For the purpose of the Code, a person under 16.

Gillick competence The common law test of whether a child under 16 has sufficient maturity, intelligence and understanding to make a particular decision for themselves, especially about medical treatment or care, without parental consent.

Parental responsibility The authority/responsibility parents (or others) may have to make decisions for a child or young person in certain circumstances, acting in the child or young person's best interests.

Young person For the purpose of the Code, a person aged 16 or 17.

7.1 Within the Code, 'child' refers to those aged below 16. 'Young people' refers to those aged 16 and 17. This differs from the Children and Young Person Act 2001, where the term 'child' is used to refer to those aged under 18.

The Act and under 16-year-olds

7.2 The Act does not generally apply to people under the age of 16. There are two exceptions:

- where the court can make a decision for matters relating to a child's property or finances if the child lacks capacity where it is likely that they will continue to lack capacity to manage those affairs when they reach 18, and
- where the offence of ill-treatment or deliberate neglect under section 42 of the Act (Ill-treatment or neglect) applies to individuals of any age, including children under 16 who lack capacity. Paragraph 7.25 has more details on offences.

The Act and 16- and 17-year-olds

7.3 The Act applies to 16- and 17-year-olds in relation to decisions they lack capacity to make, applying the definition of lack of capacity in section 4 of the Act (Lack of capacity), as explained in Chapter 4 of the Code.

7.4 Decision-making in relation to 16- and 17-year-olds who lack the relevant capacity can in many cases be undertaken either by reference to the Act or by reference to the Children and Young Persons Acts 1966 and 2001 and the operation of parental responsibility. Professionals can therefore choose which regime to apply but should be clear as to which one they are using.

7.5 However, there may also be situations where neither of these Acts provides an appropriate solution. In such cases, it may be necessary to look to the powers available under the Mental Health Act 1998 or the High Court's inherent powers to deal with cases involving young people.

7.6 Possible examples where the Capacity Act may be the most appropriate option:

- It may be appropriate for the court to make a welfare decision concerning a young person who lacks capacity to decide for themselves, for example regarding where the young person should live if the court determines that the parents are not acting in the young person's best interests.

- It might be appropriate to refer a case to the court where there is disagreement between a person interested in the care and welfare of a young person and the young person's medical team about the young person's best interests or capacity.

The Act and care or treatment of young people aged 16 to 17

Background information: Competent young people

7.7 Section 8 of the Family Law Reform (Isle of Man) Act 1971 applies to consent for medical, surgical or dental treatment, including diagnosis, by young people aged 16–17, and gives their consent the same legal effect as that of an adult. However, it does not extend to procedures that are not for the young person's therapeutic benefit, such as living organ donation or non-therapeutic research, which are governed by separate legal frameworks and may require additional safeguards, including court involvement.

7.8 For those under 16, decision-making is generally guided by Gillick competence and parental responsibility. Unlike adults and 16–17 year olds, younger children are not presumed to have legal capacity to consent, but nor are they automatically presumed to lack it.

7.9 Gillick competency refers to the principle that a child may make their own decisions about matters such as medical treatment if they are sufficiently mature to grasp what the decision entails. The concept originates from a 1980s court ruling which established that the key consideration is not age, but whether the young person can understand the information provided, consider the pros and cons, and recognise the likely consequences of their choice. Where this level of understanding is present, professionals may accept the young person's choice without requiring parental consent.

7.10 If a young person has capacity to agree to treatment, their decision to consent must be respected. Difficult issues can arise if a young person has legal and mental capacity and refuses to consent – especially if a person with parental responsibility wishes to give consent on the young person's behalf. The court can hear cases where disagreement cannot be resolved otherwise.

7.11 It may be unclear whether a young person lacks capacity for the purposes of section 4(1) of the Act (Lack of capacity). In those circumstances, it would be prudent for the person providing care or treatment for the young person to seek a declaration from the court.

The common law: Young people outside of the scope of the Act

7.12 Even where a young person is presumed to have legal capacity to consent to treatment, they may appear to be unable to make the relevant decision. It may not be clear if this is due to an impairment or disturbance in the functioning of their mind or brain. For example, they

may appear to be overwhelmed by the implications of the decision, having never had to make such a decision previously. In such a situation, the apparent or initial inability to make a decision may be resolved where the young person is supported with as much time and explanation as practicable to enable them to make the decision. If appropriate, expert assistance should be sought to identify whether or not the young person's inability to make the decision stems from an identifiable impairment or disturbance in the functioning of the mind or brain.

7.13 If a young person aged 16 or 17 lacks capacity to consent in line with section 4(1) of the Act (Lack of capacity) because of an impairment of, or a disturbance in the functioning of, the mind or brain then the Act will apply in the same way as it does to those who are 18 and over.

7.14 If the young person remains unable to make the decision even with support, and those involved do not reasonably consider that the young person lacks capacity within the meaning of section 4(1) of the Act (Lack of capacity), consent could be obtained from a person with parental responsibility, or, alternatively and exceptionally, the doctrine of necessity may apply. This would provide a defence for any action immediately required to secure the young person's interests. If the decision relates to an ongoing situation (for example admission to and remaining in hospital), the young person should continue to be given support, and their decision-making ability be kept under review.

The common law: Parental responsibility

7.15 Where a young person lacks the relevant capacity under section 4(1) of the Act (Lack of capacity), professionals may, where circumstances indicate that it is appropriate to do so, choose to seek consent from those with parental responsibility rather than relying on the best interest provisions within the Act (set out in Chapter 5: Best Interests). Where a person with parental responsibility gives or refuses consent they must make a decision based upon what is in the young person's best interests.

7.16 If professionals consider that the person with parental responsibility is not acting in the young person's best interests, and if they cannot reach agreement with this person as to what should be done, then they will need to make an application to court. This will be particularly important if the professionals consider that the person with parental responsibility is refusing to give consent to a particular treatment on behalf of the young person and that such a decision is not in the best interests of the young person.

7.17 Where nobody has been identified as having parental responsibility for a young person who lacks capacity, the Act's framework must be applied to make decisions.

Applying the Act and care and treatment decisions

7.18 The principles and approach that apply to adults may be used when considering the decision-making capacity of a young person. A professional can generally act upon the consent of a young person to any surgical, medical or dental treatment if they reasonably believe that the young person has the capacity to give that consent. (See 7.10 – 7.11 for further information).

7.19 However if a young person lacks the capacity to make a specific care or treatment decision within section 4(1) of the Act (Lack of capacity), healthcare staff providing treatment, or a person providing care to the young person, can carry out treatment or care with protection from liability (section 8 of the Act – Acts in connection with care or treatment) whether or not a person with parental responsibility consents. They must follow the Act's principles and make sure that the actions they carry out are in the young person's best interests. They must make every effort to work out and consider the young person's wishes, feelings, beliefs and values – both past and present – and consider all other factors in the best interests checklist (see Chapter 5: Best interests).

7.20 When assessing a young person's best interests, professionals must take into account the wishes, feelings, beliefs and values of anyone involved in caring for the young person and anyone interested in their welfare, where it is practicable and appropriate to do so. This may include the young person's parents and others with parental responsibility for the young person. Care should be taken not to unlawfully breach the young person's right to confidentiality.

7.21 If a young person has said they do not want their parents to be consulted, it may not be appropriate to involve them (for example, where there have been allegations of abuse).

7.22 If there is a disagreement about whether the proposed care or treatment is in the best interests of a young person, or there is disagreement about whether the young person lacks capacity and there is no other way of resolving the matter, it would be prudent for those in disagreement to seek a declaration or other order from the court.

Scenario

Working out a young person's best interests

Ms M is 16 and has Down's syndrome. Her mother accompanies her to a dental check-up and tells the dentist that she thinks Ms M should have a dental treatment which is not medically necessary but will improve the appearance of Ms M's teeth.

The dentist must decide whether to go ahead with the cosmetic treatment. To be protected under section 8 of the Act (Acts in connection with care or treatment), she must consider whether Ms M has capacity to agree to the treatment and, if not, what would be in her best interests. The dentist talks with Ms M and assesses her as lacking the capacity to understand what is involved in the treatment or the possible consequences, and therefore lacking capacity to make the decision.

However, observing and talking to Ms M shows that she is very self-conscious about her teeth and has been upset by comments people have made about them. She says she wants her teeth to look better.

The dentist takes Ms M's wishes into account when deciding whether the treatment is in Ms M's best interests. She also consults both of Ms M's parents as well as her teacher and GP to see if there are other relevant factors to take into account. The teacher confirms Ms M's self-consciousness about her appearance, and the GP advises there would be no medical issues arising from the treatment.

The dentist decides that the treatment is likely to improve Ms M's confidence and self-esteem and is in her best interests.

7.23 There may be particular difficulties where young people with mental health problems require in-patient psychiatric treatment and are treated informally rather than detained under the Mental Health Act 1998.

7.24 The Act and its principles apply to decisions related to the care and treatment of young people who lack capacity to consent, including treatment for mental disorder. As with any other form of treatment, somebody assessing a young person's best interests should consult anyone involved in caring for the young person or anyone interested in their welfare, as far as is practicable and appropriate. This may include the young person's parents or those with parental responsibility for the young person. In certain cases, Mental Health Act 1998 and the safeguards provided under that Act might be appropriate. Chapter 9 provides more detail regarding the Act and the Mental Health Act 1998.

What if somebody mistreats or neglects a child or young person who lacks capacity?

7.25 Section 42 (Ill-treatment or neglect) covers the offences of ill-treatment or deliberate neglect of a person who lacks capacity. This section also applies to children under 16 and young people aged 16 or 17. However, it only applies if the child's lack of capacity to make a decision for themselves is caused by an impairment or disturbance that affects how their mind or brain works (see Chapter 4: What capacity means and how to asses it). If the lack of capacity is solely the result of the child's youth or immaturity, then the ill-treatment or deliberate neglect would be dealt with under the separate offences of child cruelty or neglect under the Children and Young Persons Act 1966.

Powers of the court and young people

7.26 A case involving a young person who lacks capacity to make a specific decision could be heard in the Family Business division of the High Court or in the Civil division of the High Court.

7.27 If a case might require an ongoing order (because the young person is likely to still lack capacity when they are 18), it may be more appropriate for the court to hear the case. For one-off cases not involving property or finances, the Family Business division may be more appropriate.

Chapter 8
The Role Of The Court

Key Points

- The court has powers to decide whether a person has capacity to make decisions for themselves.
- The court can make declarations, decisions or orders on health or welfare matters affecting people who lack capacity to make such decisions, which are legally binding and must be followed unless changed or discharged by the court.
- If the court refuses medical treatment on behalf of a person, then it will not be lawful to give it.
- When reaching any decision, the court must apply all the statutory principles set out in section 3 of the Act (The principles).

Key Terms

Court
Here refers to the Isle of Man Courts of Justice.

Declaration
A formal statement or ruling by the court about the legal position.

Decision
A determination made by the court that resolves an issue or question before it.

Order
A binding direction made by the court requiring a person or organisation to do, or not do, something.

Suitable Person
The Act sets out this is someone, appointed by the court, to act in the name of, or on behalf of, or to represent the person to whom the court proceedings relate.

Overview: Powers of the court

8.1 The court can make decisions about capacity and best interests. This may include making decisions for and on behalf of adults (and children and young people in a few cases) where there is reason to believe that they lack capacity to make specific decisions for themselves.

8.2 When reaching any decision, the court must apply all the statutory principles set out in section 3 of the Act (The principles). In particular the court must be satisfied that all practicable steps have been taken to help the person make the decision without success before finding that the person lacks capacity to make the decision in question. If they do lack that capacity, the court must make a decision in the best interests of the person.

What declarations can the court make?

8.3 Section 22 of the Act (Powers of the court to make declarations) provides the court with powers to make a declaration (a ruling) on specific issues. For example, it can make a declaration as to whether a person has capacity to make a particular decision or give consent to a particular action.

8.4 The court will require evidence of any assessment of the person's capacity. It is also likely to require relevant written evidence (for example, a diary, letters or other papers), and may wish to hear evidence from professionals, family members and friends.

If the court decides the person has capacity to make that decision, the court will not take the case further. The person can then make the decision for themselves.

8.5 In some cases, the only declaration that the court may be asked to make is whether a person has capacity to make a particular decision. This could be where:

- professionals disagree about a person's capacity to make a specific, usually serious, decision
- there is a dispute over whether the person has capacity, for example between family members, or
- a person wants to challenge an assessment by a professional that they lack capacity.

8.6 Under section 46 of the Act (Interim orders and directions), the court can make an interim declaration that it has reason to believe that the person lacks capacity to make the decision in question whilst the relevant evidence is gathered.

8.7 In most cases, where the court makes a final declaration, based on all the evidence, that a person lacks capacity to make a particular decision or decisions, it will then consider how the decision should be made.

8.8 Under section 22 (1) (b) (Powers of the court to make declarations) the court can also make a declaration as to whether a specific act relating to a person's care or treatment is lawful (either where somebody has carried out the action or is proposing to). Caselaw decisions have made clear that this is a power that should only rarely be used. It may, however, be relevant in a situation where a person has fluctuating capacity to make a decision, because the court has the power to make a declaration as to what can and cannot be done in relation to the person at the point when they lack capacity.

8.9 Under Section 22(2) of the Act (Powers of the court to make declarations), an act for these purposes can include an omission or a course of conduct.

What decisions can the court make?

8.10 Under section 23 (1) (a) of the Act (Powers to make decisions and appoint delegates: general), if the court has declared that a person lacks capacity to make a specific decision or decisions, it can make the decision on behalf of the person that lacks capacity in relation to the matter or matters.

8.11 When the court is making the decision itself, it is choosing between the options which are available to the person at the time and are in their best interests.

8.12 If the decision is in relation to medical treatment, the court is consenting or refusing on behalf of the person. If the court refuses medical treatment on behalf of a person, then it will not be lawful to give it. Providing that they act reasonably and without negligence, the person's clinical team will therefore not be in breach of any duty to their patient if they withhold or withdraw the treatment.

Declarations and decisions the court cannot make

8.13 The court cannot make any decisions on behalf of a person who has the capacity to make that decision. It can, though, declare that the person has that capacity, which can be important if there is a dispute.

8.14 If there is concern about the welfare or interests of a person who has capacity to make the relevant decisions, but reasonably appears to be vulnerable, then an application will need to be made to the court. A judge of the court can issue orders that are necessary and proportionate to secure the interests of the person concerned.

8.15 The court can only grant declarations that fall within the scope of section 22 of the Act (Powers of the court to make declarations). There are some declarations that do not fall within its scope. If such a declaration is needed to secure the person's interests, then this will have to be granted by the court in the exercise of its inherent jurisdiction.

8.16 The court cannot decide on behalf of a person to accept or refuse medical treatment for mental disorder where that person is detained under the Mental Health Act 1998 and is subject to the compulsory treatment regime under that Act.

8.17 The court may ultimately only consider the actual options available to a person when deciding on behalf of them, the court cannot create options that are not available.

8.18 For example, where the Department has applied statutory eligibility criteria and decided that a person is not eligible for a particular social care service, the court may examine the reasons for that decision. However, it cannot require the Department to provide a service that is not available under the relevant statutory scheme. In most cases, any challenge to that decision must be brought by way of judicial review.

The same applies where clinicians decide that a particular treatment is not being offered, whether because it is not clinically appropriate or for another reason. The court may examine the reasons for that decision, but it cannot require clinicians to provide treatment that is not available. In most cases, any challenge to such a decision must be brought by way of judicial review.

Applications to the court

8.19 In most cases concerning personal welfare matters, the core principles of the Act and the processes set out in Chapters 5 and 6 will be sufficient to help people take action or make decisions in the best interest of someone who lacks capacity or even to settle disagreements about their own care or treatment. However, sometimes an application to the court is necessary.

8.20 An application may be necessary for:

- particularly difficult decisions
- disagreements that cannot be resolved in any other way, or
- situations where ongoing decisions may need to be made about the personal welfare of a person who lacks capacity to make decisions for themselves.

Property and affairs

8.21 The following provisions are independent of the Act and fall under the Mental Health Act 1998 or the Power of Attorney Act 1987; these consist of Receivership and Enduring Powers of Attorney.

8.22 If no Enduring Power of Attorney (EPA) is in place and a person becomes mentally incapable of managing their financial and property affairs, an application can be made to the court to appoint a Receiver to manage their property and finances.

8.23 An EPA is a legal document made while a person has capacity to appoint someone to act on their behalf if they lose capacity. Unlike an ordinary power of attorney, an EPA remains valid after capacity is lost, but it must be registered with the Isle of Man Courts to take effect.

8.24 An order of the court will usually be necessary for matters relating to the property and affairs of people who lack capacity to make specific financial decisions for themselves, unless legal authority to act in regard to the persons property and affairs already exist.

Medical treatment

8.25 In some cases, the court must be asked to make the relevant decision in order to secure the person's rights under the European Convention on Human Rights. In particular, the court must be asked to make the decision on behalf of the person as to whether or not to consent to life-sustaining medical treatment where, at the end of the decision-making process described in Chapter 5:

- the decision is finely balanced
- there is a difference of medical opinion, or
- there is a lack of agreement as to the proposed course of action from those with an interest in the person's welfare.

8.26 Where the treatment is to be carried out against the patient's known wishes, feelings, beliefs or values, medical professionals should consider and document:

- on what basis they can properly say that they reasonably believe the treatment is in the person's best interests
- whether they have considered all other options which are less restrictive, and
- whether delivery of the treatment will require the use of physical force, and if so, whether this will require the authority of the court.

8.27 In any case involving medical treatment, even if not life-sustaining, the presence of any of the factors set out at paragraph 8.25 (fine balance, disagreement or doubt) will mean it is unlikely that the medical professionals can properly say that they reasonably believe they are acting in the best interests of the person, so as to be protected from liability under section 8 of the Act (Acts in connection with care or treatment). If they cannot resolve the issue, the court should be asked to decide what is in the best interests of the person.

8.28 There may also be situations in which those involved in the decision-making process have a potential conflict of interest. Given that best interests decision-making needs to involve consultation with all those close to the person, as well as those who are involved with their care, it would be rare to find a case in which one or more of those involved could not be said to have a potential conflict of interest of one kind or another. For instance:

- A decision to continue life-sustaining treatment can mean that a care home continues to receive income, that the family is spared from experiencing the final loss of their loved one or that the clinical team does not have to face managing treatment withdrawal and end-of-life care.
- Conversely, a decision to withdraw treatment can mean that the commissioner of a service or a service provider would no longer have to fund or provide ongoing care or that a family member would be relieved of caring duties or responsibilities or may benefit sooner from a patient's will.
- Either way, different individuals, both professionals and family members, may have their own strongly held views.

8.29 These types of potential conflicts are part of everyday life and do not necessarily mean that people are unable to participate in decision-making, so long as they are able to maintain focus on what the relevant issues, in particular, what the person would have wanted. Clinical bodies are used to dealing with potential conflicts of interest, including by ensuring that there is transparency as to potential conflicts. If a potential conflict of interest cannot be appropriately managed, then an application to the court is likely to be required so that the medical professionals involved can properly say that they reasonably believe they are acting in the best interests of the person.

8.30 Medical professionals should also consider asking the court to decide on the person's behalf in relation to medical treatment which will involve a serious interference with their right to private life (including their right to autonomy) protected by Article 8 of the European Convention on Human Rights. This is the case even if everyone concerned with the person's welfare is in agreement as to the person's capacity and best interests. Examples of such cases include:

- where a medical procedure or treatment is for the primary purpose of sterilisation
- where the procedure is for the purpose of a donation of an organ, bone marrow, stem cells, tissue or bodily fluid to another person
- where a procedure for the covert insertion of a contraceptive device or other means of contraception
- where the use of deception to deliver medical treatment to the person

- where it is proposed that an experimental or innovative treatment is to be carried out, or
- where a case involving a significant ethical question in an untested or controversial area of medicine.

8.31 Without the scrutiny of the court in such a case, it is likely that medical professionals will not be able to say that they have a reasonable belief they are acting in the person's best interests so as to be protected from liability under section 8 of the Act (Acts in connection with care or treatment).

Other cases

8.32 In any other case where there is doubt or disagreement between those interested in the person's welfare which cannot be resolved, the court should be asked to make the decision on their behalf if it is believed that they do not have capacity to make the decision.

8.33 Examples of other types of cases where a court decision might be appropriate include where:

- there is a major disagreement regarding a serious decision, for example about where a person who lacks capacity to decide for themselves should live
- a family carer asks for personal information about someone who lacks capacity to consent to that information being revealed, for example where there have been allegations of abuse of a person living in a care home, or
- someone suspects that a person who lacks capacity to make decisions to protect themselves is at risk of harm or abuse from a named individual. The court may issue an order prohibiting that individual from contacting the person who lacks capacity.

Delay

8.34 The Act imposes an obligation to take all practicable steps to enable the individual to gain or regain a level of capacity to make the decision required. Agreement should also be sought, if possible, between those involved in the decision-making process. However, taking such steps must not come at the cost of the person's welfare, especially if the delay would have a bearing on potential treatment outcomes (for instance the chances of surviving a particular form of cancer). Early consideration must always be given as to how long it is reasonable to spend seeking to support the person or reaching agreement before making an application to the court.

Implementing a declaration or decision of the court

8.35 Anyone implementing a declaration or decision of the court must still also follow the Act's principles. They are bound by the court's declaration regarding capacity and any decision

made in the person's best interests. There may be a need to go back to court if the person's capacity has changed or the decision is no longer in their best interests.

Cases involving young people aged 16 or 17

8.36 Either a court dealing with family proceedings or the court can hear cases involving people aged 16 or 17 who lack capacity. In some cases, the court can hear cases involving people younger than 16 (for example, when somebody needs to be appointed to make longer-term decisions about their financial affairs). The court can transfer cases concerning children to a court that has powers under the Children and Young Persons Act 1966 and 2001. Likewise, those courts may transfer cases to the court where appropriate.

Bringing an application to the court?

8.37 The person making an application to the court will depend on the nature of the issue, but persons would need to bear in mind the need, in most cases, to get permission beforehand. Such would include:

- If social care staff are concerned about a decision that affects the welfare of a person who lacks capacity, the Department should make the application.
- In cases involving issues as to medical treatment, the organisation which is, or will be, responsible for commissioning or providing clinical or caring services to the person should normally be the applicant.
- Where there is a disagreement among family members, a family member may wish to apply to the court to settle the disagreement – bearing in mind the need, in most cases, to get permission beforehand.
- A person wishing to challenge a determination that they lack capacity may apply to the court, supported by others where necessary.
- Any person who is otherwise interested in the person's welfare can make an application to court, but in most cases, they are likely to require permission.

8.38 When deciding whether to give permission for an application, the court must consider:

- the applicant's connection to the person the application is about the reasons for the application
- whether a proposed order or direction of the court will benefit the person the application is about, and
- whether it is possible to get that benefit another way.

8.39 There will usually be a fee for applications to the court. The court usually sits in public, with reporting restrictions to protect the identity of the person involved. The court is able to make orders or declarations at any time of the day or night if necessary.

8.40 Persons who the Act say do not need permission include:

- a person who lacks or is alleged to lack capacity in relation to a specific decision or action, or anyone with parental responsibility if the person is under 18 years
- the Department
- an attorney of the Enduring Powers of Attorney an application relates to, and
- the Attorney General.

Suitable person

8.41 Section 49(2)(e) of the Act (High Court Rules) gives the court the power to make provision for the process of finding and appointing a "suitable person" to act in the name of, or on behalf of the person to whom the proceedings relate.

Right of appeal

8.42 Section 50 of the Act (Rights of appeal) describes the rights of appeal against any decision taken by the court. It may be advisable for anyone who wishes to appeal a decision made by the court to seek legal advice.

Chapter 9
The Act & The Mental Health Act 1998

For the purposes of this chapter, Mental Health Act 1998 will be referred to as MHA and the Capacity Act 2023/the Act will be referred to as the Act.

Key Points

- The Act and the MHA work alongside each other.
- The MHA provides the legal framework for assessment, detention and treatment of people where they have a serious mental disorder and there are risks.
- The Act can apply to people with mental disorder who lack capacity, but there are situations where the MHA should be used instead.
- Part 4 of the MHA sets out when treatment for mental disorder can be given to detained patients without consent. Where it applies, it authorises treatment for mental disorder and the Act cannot be used to give that treatment.
- The Act continues to apply to physical healthcare and to treatment for mental disorder where Part 4 does not apply.
- If a person is subject to guardianship under the MHA, the guardian has the exclusive right to take certain decisions, including where the person is to live. Therefore, nobody else can use the Act to arrange for the person to live elsewhere.
- Under the Act, treatment can usually be given in best interests if capacity is lacking, whereas under the MHA, some treatments require the patient's own informed consent and cannot proceed without it.

Key Terms

Compulsory treatment Treatment for mental disorder that may be given under the MHA without the patient's consent where permitted and required safeguards are met.

Guardianship Arrangements made under the MHA. The appointment of a guardian is designed to ensure that the person gets the care they need in the community.

Medical treatment MHA defines medical treatment as including "nursing, and also includes care, habilitation and rehabilitation under medical supervision"

Mental disorder Under the MHA, mental disorder means "mental illness, arrested or incomplete development of mind, psychopathic disorder and any other disorder or disability of mind".

Patient For the purpose of this chapter, patient is as described under the MHA; a person who is suffering from (or believed to be suffering from) a mental disorder and who is admitted, detained, treated, assessed, or placed under guardianship.

MHA overview

9.1 This chapter explains the relationship between the Act and the MHA. It describes how the Act may apply to people lacking the relevant capacity who are also subject to the MHA; it explains when doctors cannot give certain treatments to someone who lacks capacity to consent to them; and sets out the position in relation to the MHA. This chapter does not provide a full description of the MHA. The MHA has its own Code of Practice, to guide people about how to use it.

9.2 The MHA provides the legal framework for the assessment, detention and treatment of people when they have a serious mental disorder that puts them or other people at risk. Part 3 of the MHA includes provisions for civil patients and those who go to hospital through decisions made in the criminal justice system.

9.3 Generally, the MHA does not distinguish between people who have the capacity to make decisions and those who do not. Many people subject to the MHA have the capacity to make decisions for themselves. Most people who lack capacity to make decisions about their treatment will never be affected by the MHA, even if they need treatment for a mental disorder.

9.4 There are cases where decision-makers must decide whether to use the Act or MHA, or both, to meet the needs of people with mental health disorders who lack capacity to make decisions about their own treatment.

The Act: Limitations

9.5 Section 8 of the Act (Acts in connection with care or treatment) provides legal protection for people who care for or treat someone who lacks capacity (see Chapter 6: Protection for people providing care or treatment). To rely on this protection, they must follow the Acts statutory principles and may only take action that is in a person's best interests. This applies to care or treatment for physical and mental health conditions. As such, it can apply to treatment for people with mental disorders, however serious those disorders are.

9.6 Section 8 of the Act (Acts in connection with care or treatment) has limits. For example, somebody using restraint only has protection if the restraint is:

- necessary to protect the person who lacks capacity from harm, and
- in proportion to the likelihood and seriousness of that harm.

9.7 There is no protection under section 8 of the Act (Acts in connection with care or treatment) for actions intended to restrain a person lacking capacity (unless the relevant exceptions

apply (see section 9(1) of the Act (Section 8: limitations) and Chapter 6, Protection for people providing care or treatment, for guidance).

9.8 None of these restrictions apply to treatment for mental disorder given under the MHA – but other restrictions do.

Detention under the MHA

9.9 A person may be taken into hospital and detained for assessment under section 2 of the MHA for up to 28 days if:

- they have a mental disorder that is serious enough for them to be detained in a hospital for assessment (or for assessment followed by treatment) for at least a limited period, and
- they need to be detained to protect their health or safety, or to protect others.

9.10 A person may be admitted to hospital and detained for treatment under section 3 of the MHA if:

- they have a mental illness, severe mental impairment, psychopathic disorder or mental impairment (the MHA sets out definitions for these last three terms)
- their mental disorder is serious enough to need treatment in hospital
- treatment is needed for the person's health or safety, or for the protection of other people – and it cannot be provided without detention under this section, and
- if the person has a mental impairment or psychopathic disorder treatment is likely to improve their condition or stop it getting worse.

9.11 Decision-makers should consider using the MHA if, in their professional judgment, they are not sure it will be possible, or sufficient, to rely on the Act. They do not have to apply to the court to rule that the Act does not apply before using the MHA.

9.12 If a clinician believes that they can safely assess or treat a person under the Act, they do not need to consider using the MHA. In this situation, it would be difficult to meet the requirements of the MHA.

9.13 Occasions when it might be necessary to consider the MHA rather than the Act include when:

- it is not possible to give the person the care or treatment they need without carrying out an action that might deprive them of their liberty
- the person needs treatment for their mental health condition that cannot be given under the Act

- it is not possible to assess or treat the person safely or effectively without treatment being compulsory, for example because the person is expected to regain capacity to consent, but might then refuse to give consent
- the person lacks capacity to decide on some elements of the treatment but has capacity to refuse a vital part of it – and they have done so, or
- there is some other reason why the person might not get the treatment they need, and they or somebody else might suffer harm as a result.

9.14 It is important to remember that a person cannot be treated under the MHA unless they meet the relevant criteria for being detained. Unless they are sent to hospital under part 3 of the MHA in connection with a criminal offence, people can only be detained where:

- the conditions summarised in paragraphs 9.9 or 9.10 are met
- the relevant people agree that an application is necessary, normally two doctors and an approved social worker, and
- in the case of section 3, the patient's nearest relative has not objected to the application.

9.15 'Nearest relative' is defined in section 37 of the MHA; it is usually, but not always, a family member.

Scenario

Using the MHA

Mr O has a learning disability and lives in supported living accommodation. For the last four years, he has had depression from time to time and has twice had treatment for it at a psychiatric hospital. He now has severe depression and his care workers are worried about the deterioration in his condition.

On assessing Mr O's condition, the consultant would like to increase his medication, however, Mr O lacks the capacity to consent to medical treatment. The consultant is concerned about the previous treatment Mr O has received. The consultant shares his concerns with an approved social worker and advises that the increase in the medication would be in Mr O's best interests and that a care and support plan should also be drawn up, to include Mr O being detained in hospital.

This will allow close observation and is necessary for Mr O's own health and safety. The consultant thinks an application should be made under section 2 of the MHA. In the first instance and can be reviewed before the end of 28 days to see if Mr O would need to be sectioned under section 3 of the MHA.

The approved social worker explains the consultant's concerns and his observations to Mr O's nearest relative, his mother, as is ascertained under the MHA. She raises concerns regarding the treatment, and the need for Mr O to be detained, when he has not needed this in the past. But after she raises her concerns with the consultant, and listens to his answers, she does not object to the application.

As Mr O lacks capacity to consent to treatment, the consultant is able to provide it without consent if he follows the MHA's principles. However, the consultant recommends that it would be appropriate to record Mr O's capacity to consent to the decision on his care, on the care and support plan.

Mr O's mother, with the consultant and approved social worker, sit with Mr O and provide him with the relevant information about the decision to be made and explain what will happen and why. Mr O appears to listen but shows no visible response to what is being communicated to him and they also attempt to explain by using an 'easy read' leaflet.

The approved social worker makes the application, on the basis of two medical recommendations. Mr O is then detained in the hospital so that his new treatment for depression can begin.

9.16 Compulsory treatment under the MHA is not an option if:

- the patient's mental disorder does not justify detention in hospital, or
- the patient needs treatment only for a physical illness or disability.

9.17 There will be some cases where a person who lacks capacity cannot be treated either under the MHA or the Act – even if the treatment is for mental disorder.

Scenario

Deciding whether to use the MHA or the Act

Ms C is in her 80s and has dementia. Somebody finds her wandering in the street, confused and angry. A neighbour takes Ms C home and calls her doctor. At home, it looks like she has been deliberately smashing things. There are cuts on her hands and arms, but she won't let the doctor touch them, and she hasn't been taking her medication.

Ms C's doctor wants to admit her to hospital for assessment, as he is concerned about her welfare. Ms C gets angry and says that they'll never keep her in hospital. The doctor thinks that it might be necessary to use the MHA. He arranges for an approved social worker to visit, who discovers that Ms C was expecting her son this morning, but he has not turned up.

They find out that he has been delayed but could not call because Ms C's telephone has become unplugged.

When she is told that her son is on his way, Ms C brightens up. She lets the doctor treat her cuts – which the doctor thinks is in her best interests to do as soon as possible. When Ms C's son arrives, the approved social worker explains the doctor is very worried, especially that Ms C is not taking her medication. The son explains that he will help his mother take it in future. It is agreed that the Act will allow him to do that.

The approved social worker sits with Ms C and provides her with the relevant information about the decision to be made and whether she understands the reason for the medication, the risks of not taking the medication and that her son will ensure she takes her medication daily. Ms C is able to understand, retain and use the relevant information being explained to her and is able to communicate her decision and agrees to listen her son and take her medication.

The approved social worker arranges to return a week later to review Ms C's capacity and calls the doctor to say that she thinks Ms C can get the care she needs without being detained under the MHA. The doctor agrees.

The Act and Guardianship under the MHA

9.18 Section 7(5) of the MHA sets out who can be a guardian. Guardianship gives a named individual or the Department the exclusive right to decide where a person should live, but in doing this they cannot deprive the person of their liberty.

9.19 The guardian can also require the person to:

- attend, at specified places and times, for treatment, work, training or education at specific times and places, and
- allow a registered medical practitioner, approved social worker or other relevant person to have access to the person wherever they live.

9.20 Guardianship can apply whether or not the person has the capacity to make decisions about care and treatment. It does not give anyone the right to treat the person without their permission or to consent to treatment on their behalf.

9.21 An application can be made for a person who has a mental disorder to be received into guardianship under section 7 of the MHA when:

- the situation meets the conditions summarised in paragraph 9.22
- the relevant people agree an application for guardianship should be made, normally two registered medical practitioners and an approved social worker, and
- the person's nearest relative does not object. This is required by Section 11(4) of the MHA.

9.22 An application can be made for a person who has a mental disorder and is 16 years or over to be received into guardianship under section 7 of the MHA when:

- they have a mental disorder, severe mental impairment, psychopathic disorder or mental impairment that is serious enough to justify guardianship. See paragraph 9.24 below, and
- it is necessary in the interests of the welfare of the patient or to protect other people.

9.23 Applicants (usually approved social workers) and registered medical practitioners supporting the application will need to determine whether they could achieve their aims without

guardianship. For people who lack capacity, the obvious alternative will be action under the Act.

9.24 The fact that the person lacks capacity to make a relevant decision is not the only factor that applicants need to consider. They need to consider all the circumstances of the case. They may conclude that guardianship is the best option for a person with a mental disorder who lacks capacity to make those decisions if, for example:

- they think it is important that one person or authority should be in charge of making decisions about where the person should live, for example, where there have been long-running or difficult disagreements about where the person should live
- they think the person will probably respond well to the authority and attention of a guardian, and so be more prepared to accept treatment for the mental disorder, whether they are able to consent to it or it is being provided for them under the Act, or
- they need legal authority to return the person to where they are to live, for example, a care home if they go absent.

9.25 Decision-makers must never consider Guardianship as a way to avoid applying the Act.

9.26 A guardian has the exclusive right to decide where a person lives, so nobody else can use the Act to arrange for the person to live elsewhere. Somebody who knowingly helps a person leave the place a guardian requires them to stay may be committing a criminal offence under the MHA.

9.27 A guardian also has the exclusive power to require the person to attend set times and places for treatment, occupation, education or training. However, this does not stop other people using the Act to make similar arrangements or to treat the person in their best interests. People cannot use the Act in any way that conflicts with decisions which a guardian has a legal right to make under the MHA. See paragraph 9.19 above for general information about a guardian's powers.

Application of the Act to a patient subject to after-care under supervision under the MHA, section 28

9.28 When people subject to section 3 of the MHA are discharged from detention for medical treatment, their responsible medical officer may seek to place them on after-care under supervision. The responsible medical officer is usually the person's consultant psychiatrist. Another registered medical professional and an approved social worker must support their application.

9.29 After-care under supervision means:

- the person can be required to live at a specified place, where they can be taken to and returned, if necessary
- the person can be required to attend for treatment, occupation, education or training at a specific time and place, where they can be taken, if necessary, and
- their supervisor, any doctor or approved social worker, or any other relevant person approved by the supervisor must be given access to the patient wherever they live.

9.30 Responsible medical officers can apply for after-care under supervision under section 28 of the MHA if:

- the person is 16 or older and is liable to be detained in hospital for treatment under section 3, and certain other sections, of the MHA. 'Liable to be detained' means that a hospital is allowed to detain them. Patients who are liable to be detained are not always actually in hospital, because they may have been given permission to leave hospital for a time
- the person has a mental illness, severe mental impairment, psychopathic disorder or mental impairment
- without after-care under supervision, the person's health or safety would be at risk of serious harm or they would be at risk of serious exploitation, or other people's safety would be at risk of serious harm, and
- after-care under supervision is likely to help make sure the person gets the after-care services they need.

9.31 After-care under supervision can be used whether or not the person lacks capacity to make relevant decisions. If a person lacks capacity, decision-makers will need to decide whether action under the Act could achieve their aims before making an application. The kinds of cases in which after-care under supervision might be considered for patients who lack capacity to take decisions about their own care and treatment are similar to those for guardianship.

How does the Act effect people covered by the MHA?

9.32 There is no reason to assume a person lacks capacity to make their own decisions just because they are subject (under the MHA) to detention, guardianship, or after-care under supervision.

9.33 People who lack capacity to make specific decisions are still protected by the Act even if they are subject to the MHA (this includes people who are subject to the MHA as a result of court proceedings). However, there are three important exceptions:

1. If someone is liable to be detained under the MHA, decision-makers cannot normally rely on the Act to give mental health treatment or make decisions about that treatment on someone's behalf.
2. If somebody can be given mental health treatment without their consent because they are liable to be detained under the MHA, they can also be given mental health treatment that goes against an advance directive or written statement to refuse treatment excluding electroconvulsive therapy unless an emergency.
3. If a person is subject to guardianship, the guardian has the exclusive right to take certain decisions, including where the person is to live.

Implications for people who need treatment for a mental disorder

9.34 Subject to certain conditions, Part 4 of the MHA allows doctors to give patients who are liable to be detained treatment for mental disorders without their consent – whether or not they have the capacity to give that consent. Paragraph 9.37 below lists a few important exceptions.

9.35 Where Part 4 of the MHA applies, the Act cannot be used to give medical treatment for a mental disorder to patients who lack capacity to consent. This is because Part 4 of the MHA already allows clinicians, if they comply with the relevant rules, to give patients medical treatment for mental disorder even though they lack the capacity to consent. In this context, medical treatment includes nursing and care, habilitation and rehabilitation under medical supervision.

9.36 Clinicians treating people for mental disorder under the MHA cannot simply ignore a person's capacity to consent to treatment. As a matter of good practice (and in some cases in order to comply with the MHA) they will always need to assess and record:

- whether patients have capacity to consent to treatment, and
- if so, whether they have consented to or refused that treatment.

For more information, see Chapter 15 of the MHA Code of Practice, Medical treatment.

9.37 Part 4 of the MHA does not apply to patients:

- admitted in an emergency under section 4(4)(a) of the MHA, following a single medical recommendation and awaiting a second recommendation
- temporarily detained, held in hospital, under section 5 of the MHA while awaiting an application for detention under section 2 or section 3

- remanded by a court to hospital for a report on their medical condition under section 54A of the Criminal Jurisdiction Act 1993 or section 27A of the Summary Jurisdiction Act 1989
- detained under section 131 or 132 of the MHA in a place of safety, or
- this includes patients who are conditionally discharged by the Mental Health Review Tribunal and not recalled to hospital.

9.38 Since the MHA does not allow treatment without consent for the types of patients in the above list the Act therefore applies even if the treatment is for mental disorder. Even when the MHA allows patients to be treated for mental disorders, the Act still applies for the treatment of physical disorders.

9.39 However, sometimes healthcare staff may decide to focus first on treating a detained patient's mental disorder in the hope that they will regain capacity to make a decision about treatment for their physical disorder.

9.40 Where a person is subject to guardianship or after-care under supervision under the MHA, the Act applies in the usual way to decisions about treatment. Guardianship and after-care under supervision do not, in themselves, authorise treatment without the person's consent.

Scenario

Using the Act to treat a patient who is detained under the MHA

Mr P is detained in hospital under section 3 of the MHA and is receiving treatment under Part 4 of the MHA. Mr P has paranoid schizophrenia, delusions, hallucinations and thought disorder. He refuses all medical treatment. Mr P has recently developed blood in his urine and staff persuaded him to have an ultrasound scan. The scan revealed suspected renal carcinoma.

His consultant believes that he needs a CT scan and treatment for the carcinoma. But Mr P refuses a general anaesthetic and other medical procedures. The consultant assesses Mr P as lacking capacity to consent to treatment under the Acts test of capacity. The MHA is not relevant here, because the CT scan is not part of Mr P's treatment for mental disorder.

Under section 8 of the Act, doctors can provide treatment without consent. But they must follow the principles of the Act and believe that treatment is in Mr P's best interests.

9.41 The MHA also gives various rights to a patient's nearest relative (defined at section 37 of the MHA). These include the right to:

- insist that the Department instructs an approved social worker to consider whether the patient should be made subject to the MHA
- apply for the patient to be admitted to hospital or guardianship
- object to an application for admission for treatment

- order the patient's discharge from hospital, subject to conditions in section 27 of the MHA, and
- order the patient's discharge from guardianship.

Section 65 & the Act

9.42 Section 65 of the MHA states that any surgical operation for destroying brain tissue or for destroying the functioning of brain tissue requires:

- the consent of the patient
- the written certification of an independent doctor and two other people, not being registered medical practitioners, that the patient can give informed consent to the surgery, and
- certification, in writing, from the independent doctor that, having regard to the treatment alleviating or preventing a deterioration of the patient's condition, the treatment should be given.

9.43 The same rules apply to other treatments specified in regulations under section 65 of the MHA.

9.44 The combined effect of section 65 of the MHA and section 39 of the Act (Mental Health Matters) is that a person who lacks the capacity to consent to one of these treatments for mental disorder may never be given it.

9.45 Healthcare staff cannot use the Act as an alternative way of giving these kinds of treatment.

Chapter 10
Protection For People Who Lack Capacity

Key Points

- Abuse covers a wide range of behaviours or omissions that result in harm, distress or breach of a person's rights.
- Everyone has a role to play in safeguarding people who lack capacity and those working with people who lack capacity should be familiar with safeguarding procedures.
- Suspicions of abuse or neglect of a person who lacks capacity should always be reported to the relevant agency.
- The Act helps to support the safeguarding framework designed to protect people who may lack capacity, reducing their vulnerability to abuse, neglect, coercion, or exploitation.
- Under the Act, a person who has responsibility for the care, support, or representation of an individual lacking capacity commits a criminal offence if they:
  - Ill-treat by acting deliberately or recklessly in a way that mistreats, or
  - Deliberately neglects by knowingly failing to carry out duties or care they are responsible for providing.

Key Terms

Self-neglect A situation where a person neglects their own health, care, hygiene or living environment, including extreme hoarding. There may be no third-party abuser, but serious harm risks remain.

Vulnerable adult / Adult at Risk
A person aged 18 or over who:

- Has care and support needs
- Is experiencing or at risk of abuse or neglect
- Is unable to protect themselves because of those needs.

What is Abuse?

10.1 The term "abuse" covers a wide range of actions and behaviours. In some cases, abuse is deliberate and intentionally harmful. In others, it may arise because a person does not know how to act appropriately, or has not received the necessary help, training, or support.

10.2 Abuse should be prevented wherever possible. Where there are concerns that a person has been abused or neglected, enquiries should be made to establish what action is needed to safeguard that person and, where relevant, others who may also be at risk.

10.3 Abuse can be:

- a single act
- a series of repeated acts
- a failure to provide necessary care, or failure to take appropriate action.

10.4 Abuse can take place anywhere for example, in a person's own home, a care home, a hospital, or another setting.

10.5 Types of abuse can include**:**

This is not an exhaustive list. The information set out in this table arises from safeguarding guidance and applies independently of, and alongside, the Act.

Type of abuse	Examples
Financial/Material	• Fraud • Theft • Taking property without permission • Assuming ownership of money or items • Scamming (which can be in person, by letter, phone and internet) • Coercion in relation to financial affairs or arrangements, including wills, property, inheritance or financial transactions • Misuse or misappropriation of property, possessions or benefits *Financial abuse can involve small and large amounts of money or value of property. Financial abuse can be a criminal act. Financial abuse can be insidious and be perpetrated by people well known to the adult at risk.
Physical	• Assault • Hitting • Slapping • Pinching • Pushing • Misuse of medication • Inappropriate holding or restraint. • Inappropriate sanctions or punishment and rough handling

Domestic Violence	Can be any of these types of abuse: • Psychological • Physical • Sexual • Financial • Emotional • So called 'honour' based violence • Forced marriage • Female genital mutilation
Sexual	• Rape or attempted rape • Sexual assault • Indecent exposure • Sexual harassment • Inappropriate looking or touching • Sexual teasing or innuendo • Sexual photography • Subjection to pornography or witnessing sexual acts • Sexual acts or indecent exposure to that which the adult has not consented or was pressured into, including revenge porn and sexting.
Emotional/Psychological	• Emotional abuse • Grooming • Threats of harm, or abandonment • Deprivation of contact • Humiliation and ridicule • Blaming • Controlling • Intimidation • Coercion • Harassment • Isolation • Cyber bullying • Shouting and swearing, verbal abuse • Unreasonable and unjustified withdrawal of services or supportive networks • Denial of cultural or religious needs • Denial of access to the development of social skills • Extortion (black mail) • Threats to restrict someone's liberty
Discriminatory Abuse	Discriminatory abuse is often on the grounds of: • Age • Race • Sex and gender reassignment • Culture • Marriage and civil partnership • Religion or belief • Sexual orientation • Disability • Pregnancy and maternity

Self-neglect	• Self-neglect covers a wide range of behaviour including neglect to care for one's personal hygiene, health, medical needs or surroundings and can include hoarding when it becomes extreme (including animal hoarding). In these circumstances there is no third-party abuser.
Neglect (and acts of omission)	• Ignoring medical, emotional or physical needs • Failure to provide access to appropriate health, care and support or educational services. • Withholding the necessities of life including medication, adequate nutrition and heating.
Organisational/Institutional Abuse	• Neglect and poor care practice within an institution or care setting such as a hospital or care home, for example, or in relation to care provided in one's own home. • Neglect or poor professional practice as a result of the structure, policies, processes and practices within an organisation. • One-off incidents or ongoing ill-treatment.
Modern Slavery	Modern slavery refers to the offences of: • Human trafficking • Slavery • Servitude, including domestic • Forced or compulsory labour Victims of modern slavery are exploited in a range of ways. Both adults and children can be trafficked for the purposes of exploitation, with sexual exploitation, labour exploitation or criminal exploitation being the most common types reported in the UK. Other types also exist. Traffickers and slave masters use whatever means they have at their disposal to coerce, deceive and force individuals into a life of abuse, servitude and inhumane treatment.
Female Genital Mutilation (FGM)	• Female Genital Mutilation (FGM) is recognised internationally as a violation of the human rights of girls and women. • The World Health Organisation (WHO) defines FGM as 'all procedures that involve partial or total removal of the external female genitalia or other injury to the female genital organs for non-medical reasons.
Hate Crime	• Hate crime involves acts of violence or hostility directed at people because of who they are, or who someone thinks they are. Hate crimes happens because of prejudice or hostility based on a person's disability, race, religion, sexual orientation or gender identity.
Mate Crime	• Mate crime is a form of crime in which a perpetrator befriends a vulnerable person with the intention of exploiting them.

Self-neglect

10.6 Due to the risks associated with self-neglect, refusal of services should not simply be taken at face value.

10.7 Practitioners have a duty of care to consider whether the adult has the mental capacity to understand the risks arising from the decisions they make; and the impact these have upon their own safety and wellbeing, or the safety and wellbeing of others. The adult must also have the ability to carry out their decisions (executive functioning).

10.8 Applying the Act is fundamental to working with self-neglect.

What if someone thinks a person who lacks capacity may be at risk of abuse or neglect?

10.9 Those working with people who lack capacity should be familiar with safeguarding procedures.

10.10 Raising a safeguarding concern enables appropriate enquiry, advice and support to be considered and where necessary, coordinated action to be taken to protect the person.

Adults

10.11 The Isle of Man Safeguarding Board multi-agency adult safeguarding procedures define a vulnerable adult (adult at risk) as any person aged 18 or over who:

- has care and support needs (irrespective of whether such needs are being formally met)
- is experiencing or is at risk of abuse or neglect, and
- is unable to protect themselves because of their care and support needs.

10.12 Anyone who has a concern that an adult may be experiencing abuse or neglect should share that concern or seek advice and guidance through the appropriate safeguarding routes. Further information and advice is available from Isle of Man Safeguarding Board 'Reporting a Concern' procedures.

Children and young people

10.13 The Act and its core principles apply to young people aged 16 and 17 in relation to capacity assessments, acts and decisions made for them where they may lack capacity.

10.14 The Act does not displace Children and Young Person Act 2001 responsibilities, safeguarding duties, common law or child protection intervention.

10.15 Anyone who has a concern that a child or young person may be experiencing abuse or neglect should share that concern or seek advice and guidance through the appropriate safeguarding routes. Further information and advice is available from Isle of Man Safeguarding Board 'Reporting a Concern' procedures.

Other protections

10.16 Some abuse will be a criminal offence, such as physical assault, sexual assault, rape, theft, fraud and some forms of financial exploitation. In these instances, the person who suspects abuse should contact the police immediately.

10.17 A criminal investigation may take priority over all other forms of enquiry, particularly where there is risk of harm or loss of evidence. Agencies must work together to ensure the alleged abuse is investigated effectively while continuing to take any necessary safeguarding action to protect the individual.

10.18 The Fraud Act 2017 sets out the offence of 'fraud by abuse of position'. This offence may apply to a range of people, including, but not limited to:

- attorneys acting under an Enduring Power of Attorney
- Mental Health Receivers, and
- Appointees managing Social Security benefits on behalf of another person.

10.19 People who suspect fraud should report the case to the relevant agency and/or the Police.

10.20 If someone is concerned about the health or social care provided to a person who lacks capacity, there are formal and informal ways of complaining about the care or treatment (see Chapter 11: Settling disagreements and disputes about issues covered in the Act for further information on this).

10.21 If there are concerns about the standards of care by a provider registered under the Regulation of Care Act 2013, the Isle of Man Registration and Inspection Team may be contacted for further advice and guidance.

Who should check that staff are safe to work with the people they are caring for?

10.22 Employers are responsible for checking whether staff are safe to work with people they are caring for. This includes requesting a check via the Disclosure and Barring Service (DBS) and following safer recruitment processes. Employers can request a more enhanced check for certain roles, for example some roles in healthcare or social care for children or adults, or both.

How the Act protects people from abuse

10.23 The Act helps to support the safeguarding framework designed to protect people who may lack capacity, reducing their vulnerability to abuse, neglect, coercion, or exploitation.

10.24 The Act explicitly requires that any decision or action taken on behalf of a person who lacks capacity must be in their best interests.

10.25 Principles of the Act ensure that decision-makers cannot act in ways that exploit, harm or disadvantage the individual and emphasises empowerment over substitution meaning people should be supported to make decisions wherever possible.

10.26 The Act creates criminal offences for ill-treatment or deliberate neglect of a person who lacks capacity.

Criminal offences of ill-treatment and deliberate neglect

10.27 The Act introduces two new criminal offences: ill-treatment and deliberate neglect of a person who lacks capacity to make relevant decisions (section 42 of the Act). The offences may apply to anyone caring for a person who lacks capacity. This includes family carers, health and social care staff providing care in hospitals, care homes and those providing care in a person's home.

10.28 These people may be guilty of an offence if they ill-treat or deliberately neglect the person they care for or represent if that person lacks capacity at the time. Penalties range from a fine to a sentence of imprisonment of up to five years, or both.

10.29 Ill-treatment and deliberate neglect are separate offences. For a person to be found guilty of ill-treatment, they must either:

- have deliberately ill-treated the person, or
- be reckless in the way they were ill-treating the person or not.

10.30 It does not matter whether the behaviour was likely to cause, or actually caused, harm or damage to the victim's health.

10.31 A single act is sufficient to show ill-treatment.

10.32 The meaning of 'deliberately neglects' varies depending on the circumstances. It usually means that a person has deliberately failed to carry out an act they knew they had a duty to do. This applies even if the person failed to act because they panicked. Genuine errors or accidents are not within the scope of this offence.

Chapter 11
Settling Disagreements And Disputes About Issues Covered In The Act

Key Points

- When disagreements occur about issues that are covered in the Act, it is usually best to try and settle them before they become serious.
- Disagreements are informal differences of view, whereas disputes are sustained/formal conflict requiring escalation.
- Organisations should have processes for dealing with disagreements and disputes.
- Where there is a concern about healthcare or social care provided to a person who lacks capacity, there are formal and informal ways of complaining.
- Guidance does not address disputes relating to financial and property decisions, enduring powers of attorney, or other matters which fall outside of the scope of the Act.
- Court determination is sometimes necessary.
- Safeguarding is separate and takes priority over dispute processes.
- Urgent/emergency action may proceed to prevent serious harm.

Key Terms

Court determination A decision made by the Court where a dispute cannot be resolved by other means, providing an authoritative ruling on matters.

Disagreement A difference of view about a person's capacity, best interests, care or treatment, which may be resolvable through discussion, clarification or review without formal escalation.

Dispute A sustained or formal disagreement where early or informal resolution has not been possible and escalation is required (e.g. organisational escalation, second opinion/review, mediation, legal advice and/or court determination).

Escalation A step up to a more senior/independent level of review or decision making when an issue cannot be resolved at the current level (e.g. managerial review, second opinion, legal advice or court).

11.1 Sometimes people will disagree about a person's capacity to make a decision, what is in a person's best interests or a decision or action someone is taking on behalf of a person who lacks capacity.

11.2 A disagreement refers to an early or informal difference of view that may often be resolved through discussion or clarification. A dispute refers to a more sustained or formal disagreement where resolution has not been possible, and further steps may need to be considered.

11.3 This chapter provides guidance on addressing disagreements and dispute resolution in relation to decisions or actions made under the Act. It does not address disputes relating to financial and property decisions, enduring powers of attorney, or other matters outside the scope of the Act.

11.4 Wherever possible, disagreements on matters in relation to the Act should be resolved locally, promptly, and at the lowest appropriate level before they become serious. Escalation, including referral to the court, may be necessary where local resolution cannot be achieved.

11.5 All disputes and disagreements arising should be clearly recorded. Clear and proportionate records assist in addressing concerns, promotes transparency and may help any subsequent review or court determination.

11.6 Some decisions required on behalf of those who lack capacity, are so serious that the court should always make them. For example, where there is a difference of medical opinion on life-sustaining treatment.

Addressing disagreements

11.7 Disagreements may arise between a range of people, including:

- the person who carried out the capacity assessment
- the person who has been assessed as lacking capacity to make a decision. See Chapter 4: What capacity means and how to assess it, for guidance on challenging a capacity assessment
- family members or others concerned with the person's care and welfare, and
- health or social care professionals who may hold differing views about what would be in the person's best interests.

11.8 A decision may be finely balanced with differing, but legitimate views. Such decisions are difficult to agree rather than a 'dispute'.

11.9 It is usually best to try and settle disagreements before they escalate. Often the issues can be settled by communicating effectively, taking the time to listen and to address worries. Where disagreement is strong or persistent, mediation may assist in exploring concerns.

11.10 Mediators are independent and do not make decisions or impose outcomes. Instead, they support individuals to reach a mutually acceptable agreement, helping to resolve issues at an early stage. Mediation can offer a wider range of solutions than court proceedings and is often less stressful, more cost-effective, and quicker for all involved. A fee may be charged for the mediator's services.

11.11 Where there is a disagreement, steps to consider include:

- listening to, acknowledging and addressing worries
- setting out the different options in a way that is easy to understand
- using an independent advocate to support and represent the person who lacks capacity
- arranging a meeting for interested parties to discuss matters in detail
- where the situation is not urgent, allowing everybody time to think it over, and
- inviting a colleague to talk to the family and offer a second opinion.

11.12 Where issues remain unresolved escalation procedures should be followed such as involving senior management, offering to get independent expert advice or progressing through formal dispute resolution channels.

11.13 Organisations should have arrangements in place to support clear communication and the early resolution of disagreements and, where necessary defined processes for escalation.

Addressing disputes regarding a capacity assessment

11.14 There are likely to be occasions when someone may wish to challenge the results of an assessment of capacity. If someone doesn't agree with the result of a capacity assessment, they should raise it with whoever made the assessment in order to seek clarification or a review. If the challenge comes from the individual who is said to lack capacity, they might need support in doing so (see Chapter 4: What capacity means and how to assess it, for more information).

11.15 The assessor should be able to explain how the statutory test was applied and how the principles of the Act were taken into account. Where differences persist, it may be helpful for an explanation of the assessment to be provided, including how the person's ability to understand, retain, use or weigh, and communicate information was considered and the timing of the assessment.

11.16 In some cases, review or explanation by another suitably qualified professional may assist in resolving disagreement.

11.17 When differences cannot be resolved and continuing with the decision depends on confirming that the person lacks capacity under the Act, it may be appropriate to seek legal advice and to consider whether an application to the court is necessary.

11.18 Responsibility for making any court application will depend on the circumstances of the case.

Addressing disputes regarding best interests

11.19 Where a dispute arises about a best interest decision, the first step should be to identify who the decision-maker is under the Act.

11.20 Discussion, or a best interest meeting, may assist in resolving concerns by clarifying roles, available options, whether less restrictive options were explored and how the best interest principles apply. Where practicable, such meetings should be arranged to enable relevant parties to attend. It may be helpful for the decision-maker not to lead the meeting.

11.21 If differences remain, it is good practice to identify and record agreed next steps.

11.22 Disputes should be managed proportionately, with the aim of resolving matters efficiently while keeping the rights, wishes, feelings and welfare of the person concerned central to considerations (see Chapter 5: Best interests, for further information).

11.23 Where a lack of consensus continues following discussion or a best interest meeting, the decision-maker retains responsibility for making the decision in accordance with the Act, subject to any determination by the court.

11.24 Mediation may, where appropriate and practicable, assist in exploring whether agreement can be reached, but does not remove or limit the authority of the decision-maker.

11.25 Where a dispute raises concerns about the lawfulness of the decision-making process, including whether the principles of the Act were correctly applied or whether the lack of capacity was properly evidenced, it may be appropriate to seek determination by the court.

11.26 Nothing in this guidance limits the authority of the decision-maker or the right of any person interested in the welfare of the person who lacks capacity to seek a court determination where they consider this necessary.

Urgent or emergency decisions

11.27 Urgent or emergency action should not be delayed because of a disagreement or dispute.

11.28 Any outstanding disagreement, dispute or assessment should be addressed as soon as practicable once the immediate risk has passed.

Court determination

11.29 Some disputes cannot be resolved through local or informal processes and may require determination by the court. Court involvement is a legitimate and sometimes necessary part of the framework under the Act.

11.30 Dispute resolution processes do not change who is legally responsible for making a decision under the Act, nor do they remove the right of any person to seek a court determination where they consider this necessary.

Complaints about health and social care

11.31 As set out earlier in this chapter, raising concerns or making a complaint about healthcare or social care provided to a person who lacks capacity is separate to a disagreement or dispute relating to matters under the Act. As such, a complaints process is not the appropriate route to overturn a capacity assessment or reassessment, or a best interests decision.

11.32 Where there is a concern about the healthcare or social care provided to a person who lacks capacity, there are informal and formal ways of complaining about the care or treatment.

11.33 Each organisation should have its own complaints procedure, which should set out how to raise a concern, how to make an informal or formal complaint and how to escalate a complaint that cannot be settled locally, for example, referral to the Health and Social Care Ombudsman Body (HSCOB).

11.34 The HSCOB is a statutory body set up to review unresolved complaints made about health and social care services provided by or funded by the Isle of Man Government.

11.35 Where a complaint relates to an aspect of a dispute, the complaint should be managed separately and should not delay the resolution of the dispute or any best interests decision. This is particularly important where the outcome impacts ongoing care, treatment, or the person's rights.

Safeguarding

11.36 Dispute resolution and safeguarding are distinct processes. Some situations giving rise to disagreement or dispute may also involve safeguarding concerns, such as abuse, neglect, coercion, undue influence, or risk of harm (see Chapter 10: Protecting people who lack capacity).

11.37 Safeguarding concerns must be addressed without delay through established safeguarding procedures and should not be delayed or obstructed by dispute or complaint processes.

11.38 Safeguarding procedures do not remove or limit the right of any person or organisation to seek a court determination where this is necessary.

Chapter 12
Access To Information About A Person Who Lacks Capacity

Key Points

- The Capacity Act 2023 does not create a general right of access to a person's information and does not override data protection legislation.
- Guidance explains how information relating to a person who lacks capacity should be accessed, used, and shared lawfully and proportionately.
- Access to information must always be decision specific, time specific, and limited to what is necessary for the purpose of the act or decision.
- Those accessing or sharing information must consider:
  - whether the person has capacity to control access to their information;
  - whether access is required to support capacity assessments, best interests- decision making, or the provision of care or treatment; and
  - the person's rights to privacy, confidentiality, and respect for their private and family life.
- Those working in health and social care may disclose information about somebody who lacks capacity only when it is in the best interests of the person concerned, or when there is some other, lawful reason for them to do so. Access to information is the viewing, obtaining, use, or disclosure of personal data or confidential information relating to an individual, whether held in health, social care, or other records.

Key Terms

The Applied GDPR The General Data Protection Regulation (EU) 2016/679 as applied in the Isle of Man by the Data Protection (Application of GDPR) Order 2018, together with the Data Protection Act 2018.

Confidential information Information obtained in circumstances giving rise to a duty of confidence, including health, care, or personal information disclosed in professional or caring relationships.

Lawful basis A valid ground under the Applied GDPR that permits personal data to be processed or disclosed.

Privacy and family life The rights protected under Article 8 of the European Convention on Human Rights as applied by the Human Rights Act 2001 (Isle of Man).

Laws and regulations affecting access to information

12.1 People involved in the care or support of someone who lacks capacity may need access to information to:

- assess the person's capacity to make a specific decision
- determine the person's best interests, and
- make appropriate decisions on the person's behalf.

12.2 Much of the information needed to make decisions under the Act is sensitive or confidential. It is regulated by:

- the Data Protection (application of GDPR) Order 2018 ('the Applied GDPR')
- the Island's application of UK common law duty of confidentiality
- professional codes of conduct on confidentiality, and
- Human Rights Act 2001 and European Convention on Human Rights, in particular Article 8 (the right to respect for private and family life).

12.3 The combined effect of these legal duties mean that it is only lawful to reveal someone's personal information if:

- there is a legitimate aim in doing so
- it is necessary in a democratic society, and
- the kind and amount of information disclosed is proportionate in relation to the need.

12.4 Organisations and public bodies should have their own professional codes, procedures and guidance on applying the Data Protection Order 2018 and the disclosure of information.

12.5 Health and social care professionals should also follow the 'Caldicott Principles', which ensure information that can identify a person is protected and only used when appropriate to do so. The key principles underlying use of an individual's identifiable information are summarised by the eight Caldicott principles, namely:

- Principle 1: justify the purpose(s) of using confidential information.
- Principle 2: only use when absolutely necessary.
- Principle 3: use the minimum that is required.
- Principle 4: access should be on a strict 'need to know' basis.
- Principle 5: everyone must understand their responsibilities.
- Principle 6: understand and comply with the law.
- Principle 7: the duty to share information can be as important as the duty to protect patient confidentiality.
- Principle 8: inform people about how their information is used.

Restrictions in accessing a person's information

12.6 Access must be purpose limited. This means people should only access information because they need it to:

- carry out a specific task, or
- make a specific decision.

12.7 Access must be data-minimised. This means even where access is lawful, people should only see:

- the relevant capacity judgement, or
- the specific medical, or other, information needed - not the person's entire record.

12.8 Access is time-specific. This means access is justified at the point in time the task or decision is being made. It does not create:

- ongoing access,
- blanket access, or
- access for future, undefined purposes.

What information do people generally have a right to see?

12.9 Under Article 15 (1) of the Applied GDPR, any data subject (individual) has the right to request access to their personal data that an organisation holds about them. Generally referred to as a Subject Access Request (SAR). They may also authorise someone else to access their information on their behalf. Under Article 15(3) of the Applied GDPR, the entity holding the information has a legal duty to release it.

12.10 Where possible, consent should be obtained from the person before requesting access to their information. Providing this consent to the organisation holding the information should enable the information to be accessed or shared in accordance with the person's wishes.

12.11 A person may have the capacity to agree to someone seeing their personal information, even if they do not have the capacity to make other decisions. In some situations, a person may have previously given consent (while they still had capacity) for someone to see their personal information in the future.

12.12 A request under Article 15 (subject access) should not be confused with disclosure of information to third parties. Different legal tests apply. Paragraphs 12.22-12.30 provides further details on disclosure of information.

12.13 Without consent Doctors and legal advocates cannot ordinarily share information about the individuals they are supporting or representing, or information the individual has shared with them. Sometimes it is fair to assume that a doctor or legal advocate already has someone's consent. For example, patients do not usually expect healthcare staff to get consent every time they share information with a colleague, but staff may choose to get the individual's consent in writing when they begin working with that person. In other circumstances, doctors and legal advocates must get specific consent to 'disclose' information (share it with someone else).

12.14 If someone's capacity changes from time to time, the person needing the information may want to wait until that person can give their consent, or they may decide that it is not necessary to get access to information at all if the person will be able to make a decision on their own in the future.

12.15 If someone lacks the capacity to give consent, disclosure may be permissible in limited circumstances. This will depend on:

- whether the person requesting the information is acting as an agent, a representative recognised by the law, for the person who lacks capacity
- whether disclosure is in the best interests of the person who lacks capacity, and
- what type of information has been requested.

12.16 Where the person has no legal authority to request the information, whether they can access or share it will depend on the situation. In some cases, they may not be able to access the person's information. However, if the person requesting information has a valid reason for needing to, such as representing the person in a complaint about care, they may be able to. If the person requesting information needs to, they can share information with organisations even when they cannot access the person's information.

When can those with legal authority ask to see personal information?

12.17 Those with legal authority (currently limited to Enduring Power of Attorney or Receivership under the Mental Health Act in matters connected to property and finance) can ask to see information concerning the person they are representing. They should only ask for information that helps them to make the decisions they have the legal authority to make. When asking to see personal information, the person with legal authority should bear in mind that their decision must always be in the best interests of the person who lacks capacity to make that decision.

12.18 The person with legal authority may not be aware of all the personal information held by different organisations or individuals about the person they represent. As a result, it may be difficult for them to make a specific request for information. In some cases, they may need to

see a broader range of information in order to determine what is relevant. In doing so, the best interests principle continues to apply.

12.19 The person releasing information must be satisfied that the individual making the request has the necessary legal authority to receive it and may ask for evidence of identity and appointment. Verification of that authority does not automatically require disclosure. Before releasing information, the person holding it should consider whether disclosure is lawful, necessary and proportionate, whether the requester's authority extends to the information sought, and whether any other legal or professional obligations - including duties of confidentiality, safeguarding considerations, legal privilege, data protection requirements or other relevant restrictions - affect what information may be shared.

12.20 The person with legal authority must treat the information confidentially and should be extremely careful to protect it. If they fail to do so, the court might take action for example, cancel the Enduring Power of Attorney.

12.21 The person with legal authority may find that some information is held back (for example, when this contains references to people other than the person who lacks capacity). This might be to protect another person's privacy, if that person is mentioned in the records. It is unlikely that information relating to another individual would help the person with legal authority make a decision on behalf of the person who lacks capacity. The information holder might also be obliged to keep information about the other person confidential. There might be another reason why the person does not want information about them to be released. Under these circumstances, the person with legal authority does not have the right to see that information.

Disclosing health or social care information of a person who lacks capacity

12.22 Those working in health and social care may disclose information about somebody who lacks capacity. Disclosure may occur where it is in the person's best interests or where another lawful basis or legal obligation applies. Paragraph 12.24 provides further details on the lawful basis for disclosing information.

Situations where disclosure is lawful, despite not being directly for the person's best interests include; safeguarding investigations, serious crime investigations, court orders, statutory reporting duties, coroner processes and regulatory investigations.

12.23 The Act's requirement to consult relevant people when working out the best interests of a person who lacks capacity will encourage people to share the information that makes a consultation meaningful. People who release information should be sure that they are acting lawfully and that they can justify releasing the information. They need to balance the

person's right to privacy with what is in their best interests or the wider public interest. (See paragraph 12.28-12.29 for more information regarding public interest).

12.24 A best interests decision may justify disclosure under the common law duty of confidentiality, but it does not remove the need to comply with data protection law. Where personal data is disclosed, the organisation must identify an appropriate lawful basis for processing under the Applied GDPR. Where special category data is involved, such as health or social care information, an additional condition for processing must also be met.

Depending on the circumstances, the relevant lawful basis may include Article 6(1)(e), where processing is necessary for the performance of a task carried out in the public interest or in the exercise of official authority, or Article 6(1)(c), where processing is necessary to comply with a legal obligation. Where special category data is disclosed, the relevant condition may include Article 9(2)(h), for health or social care purposes, Article 9(2)(g), where processing is necessary for reasons of substantial public interest, or, in rare cases, Article 9(2)(c), where processing is necessary to protect vital interests.

Where there is any doubt about whether information should be disclosed, or about the appropriate lawful basis or special category condition, advice should be sought from the organisation's data protection lead.

12.25 Sometimes it will be obvious that staff should disclose information. For example, a doctor would need to tell a new care worker about what drugs a person need or what allergies the person has. This is clearly in the person's best interests.

12.26 Other information may need to be disclosed as part of the process of working out someone's best interests. A social worker might decide to reveal information about someone's past when discussing their best interests with a close family member. Staff should always bear in mind that the Act requires them to consider the wishes and feelings of the person who lacks capacity.

12.27 In both of the above cases, staff should only disclose as much information as is relevant to the decision to be made.

12.28 Disclosure in the public interest includes situations where disclosing information could prevent, or aid investigation of, serious crimes, or prevent serious harm, such as the spread of an infectious disease. It is then necessary to judge whether the public good that would be achieved by the disclosure outweighs both the obligation of confidentiality to the individual concerned and the broader public interest in the provision of a confidential service.

12.29 For disclosure to be in the public interest, it must be proportionate and limited to the relevant details. Those working in health or social care faced with this decision should seek advice from their legal advisers. It is not just things for 'the public's benefit' that are in the public

interest. Disclosure for the benefit of the person who lacks capacity can also be in the public interest (for example, to stop a person who lacks capacity, or someone else, suffering physical or mental harm).

12.30 An information holder should not release information if doing so would cause serious physical or mental harm to anyone, including the person the information is about. This applies to information on health, social care and education records.

Record keeping

12.31 Organisations should keep an appropriate record of any disclosure of information. This should include why the information was accessed, what was disclosed, who received it, the lawful basis and any special category condition relied upon, and why the disclosure was necessary and proportionate.

Where disclosure is justified by reference to a public task, official authority, legal obligation or substantial public interest purpose, the record should also document the legitimate aim pursued, the alternatives considered, and why disclosure was considered to outweigh the person's right to confidentiality.

Complaints and disagreements about disclosures of information

12.32 Disclosure of information can be a sensitive area and disputes often arise. Health and social care staff have a difficult judgement to make. They might feel strongly that disclosing the information would not be in the best interests of the person who lacks capacity and would amount to an invasion of their privacy. This may be upsetting for the people involved in the care and support of someone who lacks capacity, who will probably have good motives for wanting the information.

12.33 In all cases, an assessment of the best interests and needs of the person who lacks capacity should determine whether information should be disclosed.

12.34 If a discussion fails to settle the matter the individual requesting the disclosure may need to use the appropriate complaints procedure or apply to the court for the right to access the specific information. The court would then need to decide if this was in the best interests of the person who lacks capacity to consent. In urgent cases, it might be necessary for person requesting information to apply directly to the court without going through the earlier stages.

12.35 Complaints about a failure to comply with the data protection legislation should be directed to the Information Commissioner's Office.

12.36 The Information Commissioner's Office can give further details on:

- how to request personal information

- restrictions on accessing information, and
- how to appeal against a decision.

Confidentiality after information is shared

12.37 A person involved with the care and support of someone who lacks capacity should treat information received in confidence, and they should not share it with anyone else unless there is a lawful basis for doing so (paragraph 24 provides further information on lawful basis). In some circumstances, the information holder might ask the person who received the information to give a formal confirmation that they will keep information confidential.

12.38 Where the information is in written form, the person receiving the information should store it carefully and not keep it for longer than necessary. In many cases, the need to keep the information will be temporary. The person receiving information should be able to reassure the information holder that they will not keep a permanent record of the information.