

Department for Constitutional Affairs

## **Mental Capacity Act 2005**

# **Code of Practice**

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# Foreword by Lord Falconer

Foreword by Lord Falconer, Secretary of State for Constitutional Affairs and Lord Chancellor

The Mental Capacity Act 2005 is a vitally important piece of legislation, and one that will make a real difference to the lives of people who may lack mental capacity. It will empower people to make decisions for themselves wherever possible, and protect people who lack capacity by providing a flexible framework that places individuals at the very heart of the decision-making process. It will ensure that they participate as much as possible in any decisions made on their behalf, and that these are made in their best interests. It also allows people to plan ahead for a time in the future when they might lack the capacity, for any number of reasons, to make decisions for themselves.

The Act covers a wide range of decisions and circumstances, but legislation alone is not the whole story. We have always recognised that the Act needs to be supported by practical guidance, and the Code of Practice is a key part of this. It explains how the Act will operate on a day-to-day basis and offers examples of best practice to carers and practitioners.

Many individuals and organisations have read and commented upon earlier drafts of the Code of Practice and I am very grateful to all those who contributed to this process. This Code of Practice is a better document as a result of this input.

A number of people will be under a formal duty to have regard to the Code: professionals and paid carers for example, or people acting as attorneys or as deputies appointed by the Court of Protection. But for many people, the most important relationships will be with the wide range of less formal carers, the close family and friends who know the person best, some of whom will have been caring for them for many years. The Code is also here to provide help and guidance for them. It will be crucial to the Code's success that all those relying upon it have a document that is clear and that they can understand. I have been particularly keen that we do all we can to achieve this.

The Code of Practice will be important in shaping the way the Mental Capacity Act 2005 is put into practice and I strongly encourage you to take the time to read and digest it.

Lord Falconer of Thoroton

# Introduction

The Mental Capacity Act 2005, covering England and Wales, provides a statutory framework for people who lack capacity to make decisions for themselves, or who have capacity and want to make preparations for a time when they may lack capacity in the future. It sets out who can take decisions, in which situations, and how they should go about this. The Act received Royal Assent on 7 April 2005 and will come into force during 2007.

The legal framework provided by the Mental Capacity Act 2005 is supported by this Code of Practice (the Code), which provides guidance and information about how the Act works in practice. Section 42 of the Act requires the Lord Chancellor to produce a Code of Practice for the guidance of a range of people with different duties and functions under the Act. Before the Code is prepared, section 43 requires that the Lord Chancellor must have consulted the National Assembly for Wales and such other persons as he considers appropriate. The Code is also subject to the approval of Parliament and must have been placed before both Houses of Parliament for a 40-day period without either House voting against it. This Code of Practice has been produced in accordance with these requirements.

The Code has statutory force, which means that certain categories of people have a legal duty to have regard to it when working with or caring for adults who may lack capacity to make decisions for themselves. These categories of people are listed below.

## How should the Code of Practice be used?

The Code of Practice provides guidance to anyone who is working with and/or caring for adults who may lack capacity to make particular decisions. It describes their responsibilities when acting or making decisions on behalf of individuals who lack the capacity to act or make these decisions for themselves. In particular, the Code of Practice focuses on those who have a duty of care to someone who lacks the capacity to agree to the care that is being provided.

## Who is the Code of Practice for?

The Act does not impose a legal duty on anyone to 'comply' with the Code – it should be viewed as guidance rather than instruction. But if they have not followed relevant guidance contained in the Code then they will be expected to give good reasons why they have departed from it.

Certain categories of people are legally required to 'have regard to' relevant guidance in the Code of Practice. That means they must be aware of the Code of Practice when acting or making decisions on behalf of someone who lacks capacity to make a decision for themselves, and they should be able to explain how they have had regard to the Code when acting or making decisions.

The categories of people that are required to have regard to the Code of Practice include anyone who is:

- an attorney under a Lasting Power of Attorney (LPA) (see chapter 7)
- a deputy appointed by the new Court of Protection (see chapter 8)

- acting as an Independent Mental Capacity Advocate (see chapter 10)
- carrying out research approved in accordance with the Act (see chapter 11)
- acting in a professional capacity for, or in relation to, a person who lacks capacity working
- being paid for acts for or in relation to a person who lacks capacity.

The last two categories cover a wide range of people. People acting in a professional capacity may include:

- a variety of healthcare staff (doctors, dentists, nurses, therapists, radiologists, paramedics etc)
- social care staff (social workers, care managers, etc)
- others who may occasionally be involved in the care of people who lack capacity to make the decision in question, such as ambulance crew, housing workers, or police officers.

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

- care assistants in a care home
- care workers providing domiciliary care services, and
- others who have been contracted to provide a service to people who lack capacity to consent to that service.

However, the Act applies more generally to *everyone* who looks after, or cares for, someone who lacks capacity to make particular decisions for themselves. This includes family carers or other carers. Although these carers are not legally required to have regard to the Code of Practice, the guidance given in the Code will help them to understand the Act and apply it. They should follow the guidance in the Code as far as they are aware of it.

## What does 'lacks capacity' mean?

One of the most important terms in the Code is '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 particular decision or take a particular action for themselves at the time the decision or action 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 everyday 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 a certain time may be able to make that decision at a later date. This may be because they 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 capacity and make decisions for themselves.

Chapter 4 provides a full definition of what is meant by 'lacks capacity'.

## **What does the Code of Practice actually cover?**

The Code explains the Act and its key provisions.

- **Chapter 1** introduces the Mental Capacity Act 2005.
- **Chapter 2** sets out the five 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 given the right help and support to make their own decisions.
- **Chapter 4** explains how the Act defines 'a person who lacks capacity to make a decision' and sets out a single clear test for assessing whether a person lacks capacity to make a particular decision at a particular time.
- **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 providing care or treatment for someone who lacks the capacity to consent to the action being taken.
- **Chapter 7** shows how people who wish to plan ahead for the possibility that they might lack the capacity to make particular decisions for themselves in the future are able to grant Lasting Powers of Attorney (LPAs) to named individuals to make certain decisions on their behalf, and how attorneys appointed under an LPA should act.
- **Chapter 8** describes the role of the new Court of Protection, established under the Act, to make a decision or to appoint a decision-maker on someone's behalf 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 the procedures that must be followed if someone wishes to make an advance decision to refuse medical treatment to come into effect when they lack capacity to refuse the specified treatment.
- **Chapter 10** describes the role of Independent Mental Capacity Advocates appointed under the Act to help and represent particularly vulnerable people who lack capacity to make certain significant decisions. It also sets out when they should be instructed.
- **Chapter 11** provides guidance on how the Act sets out specific safeguards and controls for research involving, or in relation to, people lacking capacity to consent to their participation.
- **Chapter 12** explains those parts of the Act which can apply to children and young people and how these relate to other laws affecting them.
- **Chapter 13** explains how the Act relates to the Mental Health Act 1983.
- **Chapter 14** sets out the role of the Public Guardian, a new public office established by the Act to oversee attorneys and deputies and to act as a single

point of contact for referring allegations of abuse in relation to attorneys and deputies to other relevant agencies.

- **Chapter 15** examines the various ways that disputes over decisions made under the Act or otherwise affecting people lacking capacity to make relevant decisions can be resolved.
- **Chapter 16** summarises how the laws about data protection and freedom of information relate to the provisions of the Act.

## **What is the legal status of the Code?**

### **Where does it apply?**

The Act and therefore this Code applies to everyone it concerns who is habitually resident or present in England and Wales. However, it will also be possible for the Court of Protection to consider cases which involve persons who have assets or property outside this jurisdiction, or who live abroad but have assets or property in England or Wales.

### **What happens if people don't comply with it?**

There are no specific sanctions for failure to comply with the Code. But a failure to comply with the Code can be used in evidence before a court or tribunal in any civil or criminal proceedings, if the court or tribunal considers it to be relevant to those proceedings. For example, if a court or tribunal believes that anyone making decisions for someone who lacks capacity has not acted in the best interests of the person they care for, the court can use the person's failure to comply with the Code as evidence. That's why it's important that anyone working with or caring for a person who lacks capacity to make specific decisions should become familiar with the Code.

### **Where can I find out more?**

The Code of Practice is not an exhaustive guide or complete statement of the law. Other materials have been produced by the Department for Constitutional Affairs, the Department of Health and the Office of the Public Guardian to help explain aspects of the Act from different perspectives and for people in different situations. These include guides for family carers and other carers and basic information of interest to the general public. Professional organisations may also produce specialist information and guidance for their members.

The Code also provides information on where to get more detailed guidance from other sources. A list of contact details is provided in Annex A and further information appears in the footnotes to each chapter. References made and any links provided to material or organisations do not form part of the Code and do not attract the same legal status. Signposts to further information are provided for assistance only and references made should not suggest that the Department for Constitutional Affairs endorses such material.

## **Using the code**

### **References in the Code of Practice**

Throughout the Code of Practice, the Mental Capacity Act 2005 is referred to as 'the Act' and any sections quoted refer to this Act unless otherwise stated. References are shown as follows: section 4(1). This refers to the section of the Act. The subsection number is in brackets.

Where reference is made to provisions from other legislation, the full title of the relevant Act will be set out, for example 'the Mental Health Act 1983', unless otherwise stated. (For example, in chapter 13, the Mental Health Act 1983 is referred to as MHA and the Mental Capacity Act as MCA.) The Code of Practice is sometimes referred to as the Code.

### **Scenarios used in the Code of Practice**

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

### **Alternative formats and further information**

The Code is also available in Welsh and can be made available in other formats on request.



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# 1. What is the Mental Capacity Act 2005?

- 1.1 The Mental Capacity Act 2005 (the Act) provides the legal framework for acting and making decisions on behalf of individuals who lack the mental capacity to make particular decisions for themselves. Everyone working with and/or caring for an adult who may lack capacity to make specific decisions must comply with this Act when making decisions or acting for that person, when the person lacks the capacity to make a particular decision for themselves. The same rules apply whether the decisions are life-changing events or everyday matters.
- 1.2 The Act's starting point is to confirm in legislation that it should be assumed that an adult (aged 16 or over) has full legal capacity to make decisions for themselves (the right to autonomy) unless it can be shown that they lack capacity to make a decision for themselves at the time the decision needs to be made. This is known as the presumption of capacity. The Act also states that people must be given all appropriate 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 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 protected from harm if they lack capacity to make decisions to protect themselves.
- 1.5 The Act sets out a legal framework of how to act and make decisions on behalf of people who lack capacity to make specific decisions for themselves. It sets out some core principles and methods for making decisions and carrying out actions in relation to personal welfare, healthcare and financial matters affecting people who may lack capacity to make specific decisions about these issues for themselves.
- 1.6 Many of the provisions in the Act are based upon 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 which is based on the principles.
- 1.7 The Act introduces several new roles, bodies and powers, all of which will support the Act's provisions. These include:
  - Attorneys appointed under Lasting Powers of Attorney (see chapter 7)
  - The new Court of Protection, and court-appointed deputies (see chapter 8)
  - Independent Mental Capacity Advocates (see chapter 10).



The roles, bodies and powers are all explained in more depth in the specific chapters of the Code highlighted above.

## **What decisions are covered by the Act, and what decisions are excluded?**

- 1.8 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 matters – like what to wear, or what to buy when doing the weekly shopping – or decisions about major life-changing events, such as whether the person should move into a care home or undergo a major surgical operation.
- 1.9 There are certain decisions which can never be made on behalf of a person who lacks capacity to make those specific decisions. This is because they are either so personal to the individual concerned, or governed by other legislation.
- 1.10 Sections 27–29 and 62 of the Act set out the specific decisions which can never be made or actions which can never be carried out under the Act, whether by family members, carers, professionals, attorneys or the Court of Protection. These are summarised below.

### **Decisions concerning family relationships (section 27)**

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
- consenting to have sexual relations
- consenting to a decree of divorce on the basis of two years' separation
- consenting to the dissolution of a civil partnership
- consenting to a child being placed for adoption or the making of an adoption order
- discharging parental responsibility for a child in matters not relating to the child's property, or
- giving consent under the Human Fertilisation and Embryology Act 1990.

### **Mental Health Act matters (section 28)**

Where a person who lacks capacity to consent is currently detained and being treated under Part 4 of the Mental Health Act 1983, nothing in the Act authorises anyone to:

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

Further guidance is given in chapter 13 of the Code.

### **Voting rights (section 29)**

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.

### **Unlawful killing or assisting suicide (section 62)**

For the avoidance of doubt, nothing in the Act is to be taken to affect the law relating to murder, manslaughter or assisting suicide.

- 1.11 Although the Act does not allow anyone to make a decision about these matters on behalf of someone who lacks capacity to make such a decision for themselves (for example, consenting to have sexual relations), this does not prevent action being taken to protect a vulnerable person from abuse or exploitation.

### **How does the Act relate to other legislation?**

- 1.12 The Mental Capacity Act 2005 will apply in conjunction with other legislation affecting people who may lack capacity in relation to specific matters. This means that healthcare and social care staff acting under the Act should also be aware of their obligations under other legislation, including (but not limited to) the:

- Care Standards Act 2000
- Data Protection Act 1998
- Disability Discrimination Act 1995
- Human Rights Act 1998
- Mental Health Act 1983
- National Health Service and Community Care Act 1990
- Human Tissue Act 2004.

### **What does the Act say about the Code of Practice?**

- 1.13 Section 42 of the Act sets out the purpose of the Code of Practice, which is to provide guidance for specific people in specific circumstances. Section 43 explains the procedures that had to be followed in preparing the Code and consulting on its contents, and for its consideration by Parliament.

Section 42, subsections (4) and (5), set 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. More details can be found in the Introduction, which explains the legal status of the Code.

## 2. What are the statutory principles and how should they be applied?

Section 1 of the Act sets out the five 'statutory principles' – the values that underpin the legal requirements in the Act. The Act is intended to be enabling and supportive of people who lack capacity, not restricting or controlling of their lives. It aims to protect people who lack capacity to make particular decisions, but also to maximise their ability to make decisions, or to participate in decision-making, as far as they are able to do so.

The five statutory principles are:

1. A person must be assumed to have capacity unless it is established that they lack capacity.
2. A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.
3. A person is not to be treated as unable to make a decision merely because he makes an unwise decision.
4. An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.
5. 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.

This chapter provides guidance on how people should interpret and apply the statutory principles when using the Act. Following the principles and applying them to the Act's framework for decision-making will help to ensure not only that appropriate action is taken in individual cases, but also to point the way to solutions in difficult or uncertain situations.

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.

### Quick summary

- Every adult has the right to make their own decisions if they have the capacity to do so. Family carers and healthcare or social care staff must assume that a person has the capacity to make decisions, unless it can be established that the person does not have capacity.
- People should receive support to help them make their own decisions. Before concluding that individuals lack capacity to make a particular decision, it is important to take all possible steps to try to help them reach a decision themselves.

- People have the right to make decisions that others might think are unwise. A person who makes a decision that others think is unwise should not automatically be labelled as lacking the capacity to make a decision.
- Any act done for, or any decision made on behalf of, someone who lacks capacity must be in their best interests.
- Any act done for, or any decision made on behalf of, someone who lacks capacity should be an option that is less restrictive of their basic rights and freedoms – as long as it is still in their best interests.

## What is the role of the statutory principles?

2.1 The statutory principles aim to:

- protect people who lack capacity and
- help them take part, as much as possible, in decisions that affect them.

They aim to assist and support people who may lack capacity to make particular decisions, not to restrict or control their lives.

2.2 The statutory principles apply to any act done or decision made under the Act. When followed and applied to the Act's decision-making framework, they will help people take appropriate action in individual cases. They will also help people find solutions in difficult or uncertain situations.

## How should the statutory principles be applied?

**Principle 1:** *'A person must be assumed to have capacity unless it is established that he lacks capacity.'* (section 1(2))

2.3 This principle states that every adult has the right to make their own decisions – unless there is proof that they lack the capacity to make a particular decision when it needs to be made. This has been a fundamental principle of the common law for many years and it is now set out in the Act.

2.4 It is important to balance people's right to make a decision with their right to safety and protection when they can't make decisions to protect themselves. But the starting assumption must always be that an individual has the capacity, until there is proof that they do not. Chapter 4 explains the Act's definition of 'lack of capacity' and the processes involved in assessing capacity.

### Scenario: Assessing a person's capacity to make decisions

When planning for her retirement, Mrs Arnold made and registered a Lasting Power of Attorney (LPA) – a legal process that would allow her son to manage her property and financial affairs if she ever lacked capacity to manage them herself. She has now been diagnosed with dementia, and her son is worried that she is becoming confused about money.

Her son must assume that his mother has capacity to manage her affairs. Then he must consider each of Mrs Arnold's financial decisions as she makes them, giving her any help and support she needs to make these decisions herself.

Mrs Arnold's son goes shopping with her, and he sees she is quite capable of finding goods and making sure she gets the correct change. But when she needs to make decisions about her investments, Mrs Arnold gets confused – even though she has made such decisions in the past. She still doesn't understand after her son explains the different options.

Her son concludes that she has capacity to deal with everyday financial matters but not more difficult affairs at this time. Therefore, he is able to use the LPA for the difficult financial decisions his mother can't make. But Mrs Arnold can continue to deal with her other affairs for as long as she has capacity to do so.

- 2.5 Some people may need help to be able to make a decision or to communicate their decision. However, this does not necessarily mean that they cannot make that decision – unless there is proof that they do lack capacity to do so. Anyone who believes that a person lacks capacity should be able to prove their case. Chapter 4 explains the standard of proof required.

**Principle 2:** *'A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.'* (section 1(3))

- 2.6 It is important to do everything practical (the Act uses the term 'practicable') to help a person make a decision for themselves before concluding that they lack capacity to do so. People with an illness or disability affecting their ability to make a decision should receive support to help them make as many decisions as they can. This principle aims to stop people being automatically labelled as lacking capacity to make particular decisions. Because it encourages individuals to play as big a role as possible in decision-making, it also helps prevent unnecessary interventions in their lives.

- 2.7 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 tapes)
- treating a medical condition which may be affecting the person's capacity or
- having a structured programme to improve a person's capacity to make particular decisions (for example, helping a person with learning disabilities to learn new skills).

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

### **Scenario: Taking steps to help people make decisions for themselves**

Mr Jackson is brought into hospital following a traffic accident. He is conscious but in shock. He cannot speak and is clearly in distress, making noises and gestures.

From his behaviour, hospital staff conclude that Mr Jackson currently lacks the capacity to make decisions about treatment for his injuries, and they give him urgent treatment. They hope that after he has recovered from the shock they can use an advocate to help explain things to him.

However, one of the nurses thinks she recognises some of his gestures as sign language, and tries signing to him. Mr Jackson immediately becomes calmer, and the doctors realise that he can communicate in sign language. He can also answer some written questions about his injuries.

The hospital brings in a qualified sign-language interpreter and concludes that Mr Jackson has the capacity to make decisions about any further treatment.

- 2.8 Anyone supporting a person who may lack capacity should not use excessive persuasion or 'undue pressure'.<sup>1</sup> 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. However, it is important to provide appropriate advice and information.

### **Scenario: Giving appropriate advice and support**

Sara, a young woman with severe depression, is getting treatment from mental health services. Her psychiatrist determines that she has capacity to make decisions about treatment, if she gets advice and support.

Her mother is trying to persuade Sara to agree to electro-convulsive therapy (ECT), which helped her mother when she had clinical depression in the past. However, a friend has told Sara that ECT is 'barbaric'.

The psychiatrist provides factual information about the different types of treatment available and explains their advantages and disadvantages. She also describes how different people experience different reactions or side effects. Sara is then able to consider what treatment is right for her, based on factual information rather than the personal opinions of her mother and friend.

- 2.9 In some situations treatment cannot be delayed while a person gets support to make a decision. This can happen in emergency situations or when an urgent decision is required (for example, immediate medical treatment). In these situations, the only practical and appropriate steps might be to keep a person informed of what is happening and why.

**Principle 3:** *'A person is not to be treated as unable to make a decision merely because he makes an unwise decision.'* (section 1(4))

- 2.10 Everybody has their own values, beliefs, preferences and attitudes. A person should not be assumed to lack the capacity to make a decision just because other people think their decision is unwise. This applies even if family

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<sup>1</sup> Undue influence in relation to consent to medical treatment was considered in *Re T (Adult: Refusal of Treatment)* [1992] 4 All E R 649, 662 and in financial matters in *Royal Bank of Scotland v Etridge* [2001] UKHL 44.

members, friends or healthcare or social care staff are unhappy with a decision.

### **Scenario: Allowing people to make decisions that others think are unwise**

Mr Garvey is a 40-year-old man with a history of mental health problems. He sees a Community Psychiatric Nurse (CPN) regularly.

Mr Garvey decides to spend £2,000 of his savings on a camper van to travel around Scotland for six months. His CPN is concerned that it will be difficult to give Mr Garvey continuous support and treatment while travelling, and that his mental health might deteriorate as a result.

However, having talked it through with his CPN, it is clear that Mr Garvey is fully aware of these concerns and has the capacity to make this particular decision. He has decided he would like to have a break and thinks this will be good for him.

Just because, in the CPN's opinion, continuity of care might be a wiser option, it should not be assumed that Mr Garvey lacks the capacity to make this decision for himself.

2.11 There may be cause for concern if somebody:

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

These things do not necessarily mean that somebody lacks capacity. But there might be need for further investigation, taking into account the person's past decisions and choices. For example, have they developed a medical condition or disorder that is affecting their capacity to make particular decisions? Are they easily influenced by undue pressure? Or do they need more information to help them understand the consequences of the decision they are making?

### **Scenario: Decisions that cause concern**

Cyril, an elderly man with early signs of dementia, spends nearly £300 on fresh fish from a door-to-door salesman. He has always been fond of fish and has previously bought small amounts in this way. Before his dementia, Cyril was always very careful with his money and would never have spent so much on fish in one go.

This decision alone may not automatically mean Cyril now lacks capacity to manage all aspects of his property and affairs. But his daughter makes further enquiries and discovers Cyril has overpaid his cleaner on several occasions – something he has never done in the past. He has also made payments from his savings that he cannot account for.

His daughter decides it is time to use the registered Lasting Power of Attorney her father made in the past. This gives her the authority to manage Cyril's property and affairs whenever he lacks the capacity to manage them himself.

She takes control of Cyril's chequebook to protect him from possible exploitation, but she can still ensure he has enough money to spend on his everyday needs.

**Principle 4:** *'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.'* (section 1(5))

2.12 The principle of acting or making a decision *in the best interests* of a person who lacks capacity to make the decision in question is a well-established principle in the common law.<sup>2</sup> This principle is now set out in the Act, so that a person's best interests must be the basis for all decisions made and actions carried out on their behalf in situations where they lack capacity to make those particular decisions for themselves. The only exceptions to this are around research (see chapter 11) and advance decisions to refuse treatment (see chapter 9) where other safeguards apply.

2.13 It is impossible to give a single description of what 'best interests' are, because they depend on individual circumstances. However, section 4 of the Act sets out a checklist of steps to follow in order to determine what is in the best interests of a person who lacks capacity to make the decision in question each time someone acts or makes a decision on that person's behalf. See chapter 5 for detailed guidance and examples.

**Principle 5:** *'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.'* (section 1(6))

2.14 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. This is called finding the 'less restrictive alternative'. It includes considering whether there is a need to act or make a decision at all.

2.15 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.

2.16 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. But both principles must be applied each time a decision or action may be taken on behalf of a person who lacks capacity to make the relevant decision.

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<sup>2</sup> See for example *Re MB (Medical Treatment)* [1997] 2 FLR 426, CA; *Re A (Male Sterilisation)* [2000] 1 FLR 549; *Re S (Sterilisation: Patient's Best Interests)* [2000] 2 FLR 389; *Re F (Adult Patient: Sterilisation)* [2001] Fam 15



## **Scenario: Finding a less restrictive option**

Sunil, a young man with severe learning disabilities, also has a very severe and unpredictable form of epilepsy that is associated with drop attacks. These can result in serious injury. A neurologist has advised that, to limit the harm that might come from these attacks, Sunil should either be under constant close observation, or wear a protective helmet.

After assessment, it is decided that Sunil lacks capacity to decide on the most appropriate course of action for himself. But through his actions and behaviour, Sunil makes it clear he doesn't like to be too closely observed – even though he likes having company.

The staff of the home where he lives consider various options, such as providing a special room for him with soft furnishings, finding ways to keep him under close observation or getting him to wear a helmet. In discussion with Sunil's parents, they agree that the option that is in his best interests, and is less restrictive, will be the helmet – as it will enable him to go out, and prevent further harm.

### **3 How should people be helped to make their own decisions?**

Before deciding that someone lacks capacity to make a particular decision, it is important to take all practical and appropriate steps to enable them to make that decision themselves (statutory principle 2, see chapter 2). In addition, as section 3(2) of the Act 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 play as big a role as possible in decision-making.

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.

#### **Quick summary**

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

##### *Providing relevant information*

- Does the person have all the relevant information they need to make a particular decision?
- If they have a choice, have they been given information on all the alternatives?

##### *Communicating in an appropriate way*

- Could information be explained or presented in a way that is easier for the person to understand (for example, by using simple language or visual aids)?
- Have different methods of communication been explored if required, including non-verbal communication?
- Could anyone else help with communication (for example, a family member, support worker, interpreter, speech and language therapist or advocate)?

##### *Making the person feel at ease*

- Are there particular times of day when the person's understanding is better?
- Are there particular locations where they may feel more at ease?
- Could the decision be put off to see whether the person can make the decision at a later time when circumstances are right for them?

##### *Supporting the person*

- Can anyone else help or support the person to make choices or express a view?

#### **How can someone be helped to make a decision?**

- 3.1 There are several ways in which people 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 The Act applies to a wide range of people with different conditions that may affect their capacity to make particular decisions. So, the appropriate steps to take will depend on:
- a person's individual circumstances (for example, somebody with learning difficulties may need a different approach to somebody with dementia)
  - the decision the person has to make and
  - the length of time they have to make it.
- 3.3 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.
- 3.4 In most cases, only some of the steps described in this chapter will be relevant or appropriate, and the list included here is not exhaustive. It is up to the people (whether family carers, paid carers, healthcare staff or anyone else) caring for or supporting an individual to consider what is possible and appropriate in individual cases. In all cases it is extremely important to find the most effective way of communicating with the person concerned. Good communication is essential for explaining relevant information in an appropriate way and for ensuring that the steps being taken meet an individual's needs.
- 3.5 Providing appropriate help with decision-making should form part of care planning processes for people receiving health or social care services. Examples include:
- Person Centred Planning for people with learning disabilities
  - the Care Programme Approach for people with mental disorders
  - the Single Assessment Process for older people in England, and
  - the Unified Assessment Process in Wales.

### **What happens in emergency situations?**

- 3.6 Clearly, in emergency medical situations (for example, where a person collapses with a heart attack or for some unknown reason 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 practical or appropriate to delay the treatment while trying to help the person make their own decisions, or to consult with any known attorneys or deputies. However, even in emergency situations, healthcare staff should try to communicate with the person and keep them informed of what is happening.

### **What information should be provided to people and how should it be provided?**

- 3.7 Providing relevant information is essential in all decision-making. For example, to make a choice about what they want for breakfast, people need to know what food is available. 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.

- 3.8 All practical and appropriate steps must be taken to help people to make a decision for themselves. Information must be tailored to an individual's needs and abilities. It must also be in the easiest and most appropriate form of communication for the person concerned.

### **What information is relevant?**

- 3.9 The Act cannot state exactly what information will be relevant in each case. Anyone helping someone to make a decision for themselves should therefore follow these steps.

- 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.
- Try not to give more detail than the person needs – this might confuse them. In some cases, a simple, broad explanation will be enough. But it must not miss out important information.
- What are the risks and benefits? Describe any foreseeable consequences of making the decision, and of not making any decision at all.
- Explain the effects the decision might have on the person and those close to them – including the people involved in their care.
- If they have a choice, give them the same information in a balanced way for all the options.
- 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.

### **Communication – general guidance**

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

- Ask people who know the person well about the best form of communication (try speaking to family members, carers, day centre staff or 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 simple language. Where appropriate, use 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 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.
- Is help available from people the person trusts (relatives, friends, GP, social worker, religious or community leaders)? If so, make sure the person's right to confidentiality is respected.
- Be aware of cultural, ethnic or religious factors that shape a person's way of thinking, behaviour or communication. For example, in some cultures it is important to involve the community in decision-making. Some religious beliefs (for example, those of Jehovah's Witnesses or Christian Scientists) may influence the person's approach to medical treatment and information about treatment decisions.
- If necessary, consider using a professional language interpreter. Even if a person communicated in English or Welsh in the past, they may have lost some verbal skills (for example, because of dementia). They may now prefer to communicate in their first language. It is often more appropriate to use a professional interpreter rather than to use family members.
- If using pictures to help communication, make sure they are relevant and the person can understand them easily. For example, a red bus may represent a form of transport to one person but a day trip to another.
- Would an advocate (someone who can support and represent the person) improve communication in the current situation? (See chapters 10 and 15 for more information about advocates.)

### **Scenario: Providing relevant information**

Mrs Thomas has Alzheimer's disease and lives in a care home. She enjoys taking part in the activities provided at the home. Today there is a choice between going to a flower show, attending her usual pottery class or watching a DVD. Although she has the capacity to choose, having to decide is making her anxious.

The care assistant carefully explains the different options. She tells Mrs Thomas about the DVD she could watch, but Mrs Thomas doesn't like the sound of it. The care assistant shows her a leaflet about the flower show. She explains the plans for the day, where the show is being held and how long it will take to get there in the mini-van. She has to repeat this information several times, as Mrs Thomas keeps asking whether they will be back in time for supper. She also tells Mrs Thomas that one of her friends is going on the trip.

At first, Mrs Thomas is reluctant to disturb her usual routine. But the care assistant reassures her she will not lose her place at pottery if she misses a class. With this information, Mrs Thomas can therefore choose whether or not to go on the day trip.

### **Helping people with specific communication or cognitive problems**

3.11 Where people have specific communication or cognitive problems, the following steps can help:

- Find out how the person is used to communicating. Do they use picture boards or Makaton (signs and symbols for people with communication or

learning difficulties)? Or do they have a way of communicating that is only known to those close to them?

- If the person has hearing difficulties, use their preferred method of communication (for example, visual aids, written messages or sign language). Where possible, use a qualified interpreter.
- Are mechanical devices such as voice synthesisers, keyboards or other computer equipment available to help?
- If the person does not use verbal communication skills, allow more time to learn how to communicate effectively.
- For people who use non-verbal methods of communication, their behaviour (in particular, changes in behaviour) can provide indications of their feelings.
- Some people may prefer to use non-verbal means of communication and can communicate most effectively in written form using computers or other communication technologies. This is particularly true for those with autistic spectrum disorders.
- For people with specific communication difficulties, consider other types of professional help (for example, a speech and language therapist or an expert in clinical neuropsychology).

### **Scenario: Helping people with specific communication difficulties**

David is a deafblind man with learning disabilities who has no formal communication. He lives in a specialist home. He begins to bang his head against the wall and repeats this behaviour throughout the day. He has not done this before.

The staff in the home are worried and discuss ways to reduce the risk of injury. They come up with a range of possible interventions, aimed at engaging him with activities and keeping him away from objects that could injure him. They assess these as less restrictive ways to ensure he is safe. But David lacks the capacity to make a decision about which would be the best option.

The staff call in a specialist in challenging behaviour, who says that David's behaviour is communicative. After investigating this further, staff discover he is in pain because of tooth decay. They consult a dentist about how to resolve this, and the dentist decides it is in David's best interests to get treatment for the tooth decay. After treatment, David's head-banging stops.

### **What steps should be taken to put a person at ease?**

- 3.12 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**

- 3.13 In terms of location, 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 can't 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.

## Timing

3.14 In terms of timing, consider the following:

- Try to choose the time of day when the person is most alert – some people are better in the mornings, others are more lively in the afternoon or early evening. It may be necessary to try 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 practical and appropriate. For example, this might be the case after treatment for depression or a psychotic episode. Obviously, this may not be practical and appropriate if the decision is urgent.
- Some medication could 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.
- 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: Getting the location and timing right**

Luke, a young man, was seriously injured in a road traffic accident and suffered permanent brain damage. He has been in hospital several months, and has made good progress, but he gets very frustrated at his inability to concentrate or do things for himself.

Luke now needs surgical treatment on his leg. During the early morning ward round, the surgeon tries to explain what is involved in the operation. She asks Luke to sign a consent form, but he gets angry and says he doesn't want to talk about it.

His key nurse knows that Luke becomes more alert and capable later in the day. After lunch, she asks him if he would like to discuss the operation again. She also knows that he responds better one-to-one than in a group. So she takes Luke into a private room and repeats the information that the surgeon gave him earlier. He understands why the treatment is needed, what is involved and the likely consequences. Therefore, Luke has the capacity to make a decision about the operation.

### **Support from other people**

3.15 In some circumstances, individuals will be more comfortable making decisions when someone else is there to support them.

- Might the person benefit from having another person present? Sometimes having a relative or friend nearby can provide helpful support and reduce anxiety. However, some people might find this intrusive, and it could increase their anxiety or affect their ability to make a free choice. Find ways of getting the person's views on this, for example, by watching their behaviour towards other people.
- Always respect a person's right to confidentiality.

### **Scenario: Getting help from other people**

Jane has a learning disability. She expresses herself using some words, facial expressions and body language. She has lived in her current community home all her life, but now needs to move to a new group home. She finds it difficult to discuss abstract ideas or things she hasn't experienced. Staff conclude that she lacks the capacity to decide for herself which new group home she should move to.

The staff involve an advocate to help Jane express her views. Jane's advocate spends time with her in different environments. The advocate uses pictures, symbols and Makaton to find out the things that are important to Jane, and speaks to people who know Jane to find out what they think she likes. She then supports Jane to show their work to her care manager, and checks that the new homes suggested for her are able to meet Jane's needs and preferences.

When the care manager has found some suitable places, Jane's advocate visits the homes with Jane. They take photos of the houses to help her distinguish between them. The advocate then uses the photos to help Jane work out which home she prefers. Jane's own feelings can now play an important part in deciding what is in her best interests – and so in the final decision about where she will live.

### **What other ways are there to enable decision-making?**

3.16 There are other ways 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 difficulties may benefit from the help of a designated support worker or being part of a support network.



- If someone is very distressed (for example, following a death of someone close) or where there are long-standing problems that affect someone's ability to understand an issue, it may be possible to delay a decision so that the person can have psychological therapy, if needed.
- Some organisations have produced 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 profound learning disability.
- It may be important to provide access to technology. For example, some people who appear not to communicate well verbally can do so very well using computers.

### **Scenario: Making the most of technology**

Ms Patel has an autistic spectrum disorder. Her family and care staff find it difficult to communicate with her. She refuses to make eye contact, and gets very upset and angry when her carers try to encourage her to speak.

One member of staff notices that Ms Patel is interested in the computer equipment. He shows her how to use the keyboard, and they are able to have a conversation using the computer. An IT specialist works with her to make sure she can make the most of her computing skills to communicate her feelings and decisions.

## 4 How does the Act define a person's capacity to make a decision and how should capacity be assessed?

This chapter explains what the Act means by 'capacity' and 'lack of capacity'. It provides guidance on how to assess whether someone has the capacity to make a decision, and suggests when professionals should be involved in the assessment.

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.

### Quick summary

This checklist is a summary of points to consider when assessing a person's capacity to make a specific decision. Readers should also refer to the more detailed guidance in this chapter and chapters 2 and 3.

#### *Presuming someone has capacity*

- The starting assumption must always be that a person has the capacity to make a decision, unless it can be established that they lack capacity.

#### *Understanding what is meant by capacity and lack of capacity*

- 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.

#### *Treating everyone equally*

- A person's capacity must not be judged simply on the basis of their age, appearance, condition or an aspect of their behaviour.

#### *Supporting the person to make the decision for themselves*

- It is important to take all possible steps to try to help people make a decision for themselves (see chapter 2, principle 2, and chapter 3).

#### *Assessing capacity*

Anyone assessing someone's capacity to make a decision for themselves should use the two-stage test of capacity.

- Does the person have an impairment of the mind or brain, or is there some sort of disturbance affecting the way their mind or brain works? (It doesn't matter whether the impairment or disturbance is temporary or permanent.)
- If so, does that impairment or disturbance mean that the person is unable to make the decision in question at the time it needs to be made?

#### *Assessing ability to make a decision*

- Does the person have a general understanding of what decision they need to make and why they need to make it?

- Does the person have a general understanding of the likely consequences of making, or not making, this decision?
- Is the person able to understand, retain, use and weigh up the information relevant to this decision?
- Can the person communicate their decision (by talking, using sign language or any other means)? Would the services of a professional (such as a speech and language therapist) be helpful?

*Assessing capacity to make more complex or serious decisions*

- Is there a need for a more thorough assessment (perhaps by involving a doctor or other professional expert)?

## **What is mental capacity?**

4.1 Mental capacity is the ability to make a decision.

- This includes the ability to make a decision that affects daily life – such as when to get up, what to wear or whether to go to the doctor when feeling ill – as well as more serious or significant decisions.
- It also refers to a person’s ability to make a decision that may have legal consequences – for them or others. Examples include agreeing to have medical treatment, buying goods or making a will.

4.2 The starting point must always be to assume that a person has the capacity to make a specific decision (see chapter 2, principle 1). Some people may need help to be able to make or communicate a decision (see chapter 3). But 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 – and not the outcome.

## **What does the Act mean by ‘lack of capacity’?**

4.3 Section 2(1) of the Act states:

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

This means that a person lacks capacity if:

- they have an impairment or disturbance (for example, a disability, condition or trauma) that affects the way their mind or brain works, and
- the impairment or disturbance means that they are unable to make a specific decision at the time it needs to be made.

4.4 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, and not their ability to make decisions in general. Section 3 of the Act defines what it means to be unable to make a decision (this is explained in paragraph 4.14 below).

4.5 Section 2(2) states that the impairment or disturbance 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 partial
- the loss of capacity is temporary
- their capacity changes over time.

A person may also lack capacity to make a decision about one issue but not about others.

4.6 The Act generally applies to people who are aged 16 or older. Chapter 12 explains how the Act affects children and young people – in particular those aged 16 and 17 years.

### **What safeguards does the Act provide around assessing someone's capacity?**

4.7 An assessment that a person lacks capacity to make a decision must never be based simply on:

- their age
- their appearance
- assumptions about their condition, or
- any aspect of their behaviour. (section 2(3))

4.8 The Act deliberately uses the word 'appearance', because it covers all aspects of the way people look. So for example, it includes the physical characteristics of certain conditions (for example, scars, features linked to Down's syndrome or muscle spasms caused by cerebral palsy) as well as aspects of appearance like skin colour, tattoos and body piercings, or the way people dress (including religious dress).

4.9 The word 'condition' is also wide-ranging. It includes physical disabilities, learning difficulties and disabilities, illness related to age, and temporary conditions (for example, drunkenness or unconsciousness). Aspects of behaviour might include extrovert (for example, shouting or gesticulating) and withdrawn behaviour (for example, talking to yourself or avoiding eye contact).

#### **Scenario: Treating everybody equally**

Tom, a man with cerebral palsy, has slurred speech. Sometimes he also falls over for no obvious reason.

One day Tom falls in the supermarket. Staff call an ambulance, even though he says he is fine. They think he may need treatment after his fall.

When the ambulance comes, the ambulance crew know they must not make assumptions about Tom's capacity to decide about treatment, based simply on his condition and the effects of his disability. They talk to him and find that he is capable of making healthcare decisions for himself.

## What proof of lack of capacity does the Act require?

- 4.10 Anybody who claims that an individual lacks capacity should be able to provide proof. They need to be able to show, *on the balance of probabilities*, that the individual lacks capacity to make a particular decision, at the time it needs to be made (section 2(4)). This means being able to show that it is more likely than not that the person lacks capacity to make the decision in question.

## What is the test of capacity?

To help determine if a person lacks capacity to make particular decisions, the Act sets out a two-stage test of capacity.

### Stage 1: Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain?

- 4.11 Stage 1 requires proof that the person has an impairment of the mind or brain, or some sort of or disturbance that affects the way their mind or brain works. If a person does not have such an impairment or disturbance of the mind or brain, they will not lack capacity under the Act.
- 4.12 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 brain damage
  - 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.

### Scenario: Assessing whether an impairment or disturbance is affecting someone's ability to make a decision

Mrs Collins is 82 and 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 Collins 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. But he says that although Mrs Collins is anxious about the physical effects the stroke has had on her body, it has not caused any mental impairment or affected her brain, so she still has capacity to make her own decision about selling her house.

## **Stage 2: Does the impairment or disturbance mean that the person is unable to make a specific decision when they need to?**

4.13 For a person to lack capacity to make a decision, the Act says their impairment or disturbance must affect their ability to make the specific decision when they need to. But first people must be given all practical and appropriate support to help them make the decision for themselves (see chapter 2, principle 2). Stage 2 can only apply if all practical and appropriate support to help the person make the decision has failed. See chapter 3 for guidance on ways of helping people to make their own decisions.

## **What does the Act mean by ‘inability to make a decision’?**

4.14 A person is unable to make a decision if they cannot:

1. understand information about the decision to be made (the Act calls this ‘relevant information’)
2. retain that information in their mind
3. use or weigh that information as part of the decision-making process, or
4. communicate their decision (by talking, using sign language or any other means). See section 3(1).

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

## **Understanding information about the decision to be made**

4.16 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 inadequate explanations are not acceptable unless the situation is urgent (see chapter 3 for some practical steps). 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.

4.17 Section 3(2) 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 simple language, sign language, visual representations, computer support or any other means).

4.18 For example:

- a person with a learning disability may need somebody to read information to them. They might also need illustrations to help them to understand what is happening. Or they might stop the reader to ask what things mean. It might also be helpful for them to discuss information with an advocate.
- 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, and ask for help if necessary.
- someone who has a 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 information in a different way (for example, different forms of words, pictures or diagrams). Written information, audiotapes, videos and posters can help people remember important facts.

4.19 Relevant information 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 3(4)). In some cases, it may be enough to give a broad explanation using simple language. But a person might need more detailed information or access to advice, depending on the decision that needs to be made. If a decision could have serious or grave consequences, it is even more important that a person understands the information relevant to that decision.

### **Scenario: Providing relevant information in an appropriate format**

Mr Leslie 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:

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

The leaflet uses simple language and photographs to explain these things. Mr Leslie's carer helps him read the leaflet over the next few days, and checks that he understands it.

Mr Leslie 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. So the doctor concludes that Mr Leslie can understand, retain and use the relevant information and therefore has the capacity to make the decision to have the test.

### **Retaining information**

4.20 The person must be able to hold the information in their mind long enough to use it to make an effective decision. But section 3(3) states that 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. Items such as notebooks, photographs, posters, videos and voice recorders can help people record and retain information.

### **Scenario: Assessing a person's ability to retain information**

Walter, an elderly man, is diagnosed with dementia and has problems remembering things in the short term. He can't always remember his great-grandchildren's names, but he recognises them when they come to visit. He can also pick them out on photographs.

Walter would like to buy premium bonds (a type of financial investment) for each of his great-grandchildren. He asks his solicitor to make the arrangements. After assessing his capacity to make financial decisions, the solicitor is satisfied that Walter has capacity to make this decision, despite his short-term memory problems.

### **Using or weighing information as part of the decision-making process**

- 4.21 For someone to have capacity, they must have the ability to weigh up information and use it to arrive at a decision. Sometimes people can understand information but an impairment or disturbance stops them using it. In other cases, the impairment or disturbance leads to a person making a specific decision without understanding or using the information they have been given.<sup>3</sup>
- 4.22 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. Some people who have serious brain damage might make impulsive decisions regardless of information they have been given or their understanding of it.

### **Inability to communicate a decision in any way**

- 4.23 Sometimes there is no way for a person to communicate. This will apply to very few people, but it does include:

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

If a person cannot communicate their decision in any way at all, the Act says they should be treated as if they are unable to make that decision.

- 4.24 Before deciding that someone falls into this category, it is important to make all practical and appropriate efforts to help them communicate. This might call for the involvement of speech and language therapists, specialists in non-verbal communication or other professionals. Chapter 3 gives advice for communicating with people who have specific disabilities or cognitive problems.

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<sup>3</sup> This issue has been considered in a number of court cases, including *Re MB* [1997] 2 FLR 426; *R v Collins and Ashworth Hospital Authority ex parte Brady* [2001] 58 BMLR 173



- 4.25 Communication by simple muscle movements can show that somebody can communicate and may have capacity to make a decision.<sup>4</sup> 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 4.14, which are explained in more depth in paragraphs 4.16–4.22.

## **What other issues might affect capacity?**

### **People with fluctuating or temporary capacity**

- 4.26 Some people have fluctuating capacity – they have a problem or condition that gets worse occasionally and affects their ability to make decisions. For example, someone who has manic depression may have a temporary manic phase which causes them to lack capacity to make financial decisions, leading them to get into debt even though at other times they are perfectly able to manage their money. A person with a psychotic illness may have delusions that affect their capacity to make decisions at certain times but disappear at others. Temporary factors may also affect someone's ability to make decisions. Examples include acute illness, severe pain, the effect of medication, or distress after a death or shock. More guidance on how to support someone with fluctuating or temporary capacity to make a decision can be found in chapter 3, particularly paragraphs 3.12–3.16. More information about factors that may indicate that a person may regain or develop capacity in the future can be found at paragraph 5.28.
- 4.27 As in any other situation, an assessment must only examine a person's capacity to make a particular decision when it needs to be made. It may be possible to put off the decision until the person has the capacity to make it (see also guidance on best interests in chapter 5).

### **Ongoing conditions that may affect capacity**

- 4.28 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.
- 4.29 Again, it is important to review capacity from time to time, as people can improve their decision-making capabilities. In particular, someone with an ongoing condition may become able to make some, if not all, decisions. Some people (for example, people with learning disabilities) will learn new skills throughout their life, improving their capacity to make certain decisions. So assessments should be reviewed from time to time. Capacity should always be reviewed:
- whenever a care plan is being developed or reviewed
  - at other relevant stages of the care planning process, and
  - as particular decisions need to be made.

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<sup>4</sup> This was demonstrated in the case *Re AK (Adult Patient) (Medical Treatment: Consent)* [2001] 1 FLR 129

4.30 It is important to acknowledge the difference between:

- unwise decisions, which a person has the right to make (chapter 2, principle 3), and
- decisions based on a lack of understanding of risks or inability to weigh up the information about a decision.

Information about decisions the person has made based on a lack of understanding of risks or inability to weigh up the information can form part of a capacity assessment – particularly if someone repeatedly makes decisions that put them at risk or result in harm to them or someone else.

### **Scenario: Ongoing conditions**

Paul had an accident at work and suffered severe head injuries. He was awarded compensation to pay for care he will need throughout his life as a result of his head injury. An application was made to the Court of Protection to consider how the award of compensation should be managed, including whether to appoint a deputy to manage Paul's financial affairs. Paul objected as he believed he could manage his life and should be able to spend his money however he liked.

He wrote a list of what he intended to spend his money on. This included fully-staffed luxury properties and holiday villas, cars with chauffeurs, jewellery and various other items for himself and his family. But spending money on all these luxury items would not leave enough money to cover the costs of his care in future years.

The court judged that Paul had capacity to make day-to-day financial decisions, but he did not understand why he had received compensation and what the money was supposed to be used for. Nor did he understand how buying luxuries now could affect his future care. The court therefore decided Paul lacked capacity to manage large amounts of money and appointed a deputy to make ongoing financial decisions relating to his care. But it gave him access to enough funds to cover everyday needs and occasional treats.

### **What other legal tests of capacity are there?**

4.31 The Act makes clear that the definition of 'lack of capacity' and the two-stage test for capacity set out in the Act are 'for the purposes of this Act'. This means that the definition and test are to be used in situations covered by this Act. Schedule 6 of the Act also amends existing laws to ensure that the definition and test are used in other areas of law not covered directly by this Act.

For example, Schedule 6, paragraph 20 allows a person to be disqualified from jury service if they lack the capacity (using this Act's definition) to carry out a juror's tasks.

4.32 There are several tests of capacity that have been produced following judgments in court cases (known as common law tests).<sup>5</sup> These cover:

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<sup>5</sup> For details, see British Medical Association & Law Society, *Assessment of Mental Capacity: Guidance for Doctors and Lawyers* (Second edition) (London: BMJ Books, 2004)

- capacity to make a will<sup>6</sup>
- capacity to make a gift<sup>7</sup>
- capacity to enter into a contract<sup>8</sup>
- capacity to litigate (take part in legal cases),<sup>9</sup> and
- capacity to enter into marriage.<sup>10</sup>

4.33 The Act's new definition of capacity is in line with the existing common law tests, and the Act does not replace them. When cases come before the court on the above issues, judges can adopt the new definition if they think it is appropriate. The Act will apply to all other cases relating to financial, healthcare or welfare decisions.

## When should capacity be assessed?

4.34 Assessing capacity correctly is vitally important to everyone affected by the Act. Someone who is 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. Also, if a person lacks capacity to make specific decisions, that person might make decisions they do not really understand. Again, this could cause harm or put the person at risk. So it is important to carry out an assessment when a person's capacity is in doubt. It is also important that the person who does an assessment can justify their conclusions. Many organisations will provide specific professional guidance for members of their profession.<sup>11</sup>

4.35 There are a number of reasons why people may question a person's capacity to make a specific decision:

- the person's behaviour or circumstances cause doubt as to whether they have the capacity to make a decision

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<sup>6</sup> *Banks v Goodfellow* (1870) LR 5 QB 549

<sup>7</sup> *Re Beaney (deceased)* [1978] 2 All ER 595

<sup>8</sup> *Boughton v Knight* (1873) LR 3 PD 64

<sup>9</sup> *Masterman-Lister v Brutton & Co and Jewell & Home Counties Dairies* [2003] 3 All ER 162 (CA)

<sup>10</sup> *Sheffield City Council v E & S* [2005] 1 FLR 965

<sup>11</sup> See for example, British Medical Association & Law Society, *Assessment of Mental Capacity: Guidance for Doctors and Lawyers* (Second edition) (London: BMJ Books, 2004); the Joint Royal Colleges Ambulance Service Liaison Committee Clinical Practice Guidelines (JRCALC, available online at [www2.warwick.ac.uk/fac/med/research/hsri/emergencycare/jrcalc\\_2006/clinical\\_guidelines\\_2006.pdf](http://www2.warwick.ac.uk/fac/med/research/hsri/emergencycare/jrcalc_2006/clinical_guidelines_2006.pdf)) and British Psychological Society, *Guidelines on assessing capacity* (BPS, 2006 available online at [www.bps.org.uk](http://www.bps.org.uk))

- somebody else says they are concerned about the person's capacity, or
  - the person has previously been diagnosed with an impairment or disturbance that affects the way their mind or brain works (see paragraphs 4.11–4.12 above), and it has already been shown they lack capacity to make other decisions in their life.
- 4.36 The starting assumption must be that the person has the capacity to make the specific decision. If, however, anyone thinks a person lacks capacity, it is important to then ask the following questions:
- 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, an advocate or someone to help with communication)?
- 4.37 Chapter 3 describes ways to deal with these questions and suggest steps which may help people make their own decisions. If all practical and appropriate steps fail, an assessment will then be needed of the person's capacity to make the decision that now needs to be made.

### **Who should assess capacity?**

- 4.38 The person who assesses an individual's capacity to make a decision will usually be the person who is directly concerned with the individual at the time the decision needs to be made. This means that different people will be involved in assessing someone's capacity to make different decisions at different times.

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. Then a district nurse might assess if the person can consent to have a dressing changed.

- 4.39 For acts of care or treatment (see chapter 6), the assessor must have a 'reasonable belief' that the person lacks capacity to agree to the action or decision to be taken (see paragraphs 4.44–4.45 for a description of reasonable belief).
- 4.40 If a doctor or healthcare professional proposes treatment or an examination, they must assess the person's capacity to consent. In settings such as a hospital, this can involve the multi-disciplinary team (a team of people from

different professional backgrounds who share responsibility for a patient). But ultimately, it is up to the professional responsible for the person's treatment to make sure that capacity has been assessed.

- 4.41 For a legal transaction (for example, making a will), a solicitor or legal practitioner must assess the client's capacity to instruct them. They must assess whether the client has the capacity to satisfy any relevant legal test. In cases of doubt, they should get an opinion from a doctor or other professional expert.
- 4.42 More complex decisions are likely to need more formal assessments (see paragraph 4.54 below). 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. But 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.
- 4.43 Any assessor should have the skills and ability to communicate effectively with the person (see chapter 3). If necessary, they should get professional help to communicate with the person.

#### **Scenario: Getting help with assessing capacity**

Ms Dodd suffered brain damage in a road accident and is unable to speak. At first, her family thought she was not able to make decisions. But they soon discovered that she could choose by pointing at things, such as the clothes she wants to wear or the food she prefers. Her behaviour also indicates that she enjoys attending a day centre, but she refuses to go swimming. Her carers have assessed her as having capacity to make these decisions.

Ms Dodd needs hospital treatment but she gets distressed when away from home. Her mother feels that Ms Dodd is refusing treatment by her behaviour, but her father thinks she lacks capacity to say no to treatment that could improve her condition.

The clinician who is proposing the treatment will have to assess Ms Dodd's capacity to consent. He gets help from a member of staff at the day centre who knows Ms Dodd's communication well and also discusses things with her parents. Over several meetings the clinician explains the treatment options to Ms Dodd with the help of the staff member. The final decision about Ms Dodd's capacity rests with the clinician, but he will need to use information from the staff member and others who know Ms Dodd well to make this assessment.

#### **What is 'reasonable belief' of lack of capacity?**

- 4.44 Carers (whether family carers or other carers) and care workers do not have to be experts in assessing capacity. But to have protection from liability when providing care or treatment (see chapter 6), they must have a 'reasonable belief' that the person they care for lacks capacity to make relevant decisions about their care or treatment (section 5 (1)). To have this reasonable belief, they must have taken 'reasonable' steps to establish that the person lacks capacity to make a decision or consent to an act at the time the decision or

consent is needed. They must also establish that the act or decision is in the person's best interests (see chapter 5).

They do not usually need to follow formal processes, such as involving a professional to make an assessment. However, if somebody challenges their assessment (see paragraph 4.63 below), they 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.

4.45 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 who have no formal qualifications. See paragraph 4.36 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 prove otherwise?
- Does the person have a previous diagnosis of disability or mental disorder? Does 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 take 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.

### **What other factors might affect an assessment of capacity?**

4.46 It is important to assess people when they are in the best state to make the decision, if possible. Whether this is possible will depend on the nature and urgency of the decision to be made. Many of the practical steps suggested in chapter 3 will help to create the best environment for assessing capacity. The assessor must then carry out the two stages of the test of capacity (see paragraphs 4.11–4.25 above).

- 4.47 In many cases, it may be clear that the person has an impairment or disturbance in the functioning of their mind or brain which could affect their ability to make a decision. For example, there might be a past diagnosis of a disability or mental disorder, or there may be signs that an illness is returning. Old assumptions about an illness or condition should be reviewed. Sometimes an illness develops gradually (for example, dementia), and it is hard to know when it starts to affect capacity. Anyone assessing someone's capacity may need to ask for a medical opinion as to whether a person has an illness or condition that could affect their capacity to make a decision in this specific case.

### **Scenario: Getting a professional opinion**

Mr Elliott is 87 years old and lives alone. He has poor short-term memory, and he often forgets to eat. He also sometimes neglects his personal hygiene. His daughter talks to him about the possibility of moving into residential care. She decides that he understands the reasons for her concerns as well as the risks of continuing to live alone and, having weighed these up, he has the capacity to decide to stay at home and accept the consequences.

Two months later, Mr Elliott has a fall and breaks his leg. While being treated in hospital, he becomes confused and depressed. He says he wants to go home, but the staff think that the deterioration in his mental health has affected his capacity to make this decision at this time. They think he cannot understand the consequences or weigh up the risks he faces if he goes home. They refer him to a specialist in old age psychiatry, who assesses whether his mental health is affecting his capacity to make this decision. The staff will then use the specialist's opinion to help their assessment of Mr Elliott's capacity.

- 4.48 Anyone assessing someone's capacity must not assume that a person lacks capacity simply because they have a particular diagnosis or condition. There must be proof that the diagnosed illness or condition affects the ability to make a decision when it needs to be made. The person assessing capacity should ask the following questions:

- Does the person have a general understanding of what decision they need to make and why they need to make it?
- Do they understand the likely consequences of making, or not making, this decision?
- Can they understand and process information about the decision? And can they use it to help them make a decision?

In borderline cases, or where there is doubt, the assessor must be able to show that it is more likely than not that the answer to these questions is 'no'.

### **What practical steps should be taken when assessing capacity?**

- 4.49 Anyone assessing someone's capacity will need to decide which of these steps are relevant to their situation.
- They should make sure that they understand the nature and effect of the decision to be made themselves. They may need access to relevant documents and background information (for example, details of the

person's finances if assessing capacity to manage affairs). See chapter 16 for details on access to information.

- They may need other relevant information to support the assessment (for example, healthcare records or the views of staff involved in the person's care).
- Family members and close friends may be able to provide valuable background information (for example, the person's past behaviour and abilities and the types of decisions they can currently make). But their personal views and wishes about what they would want for the person must not influence the assessment.
- They should again 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, did you understand what I just said?). They are not enough to assess the person's capacity to make a decision. But there may be no alternative in cases where there are major communication difficulties. In these cases, check the response by asking questions again in a different way.
- Skills and behaviour do not necessarily reflect the person's capacity to make specific decisions. The fact that someone has good social or language skills, polite behaviour or good manners doesn't necessarily mean they understand the information or are able to weigh it up.
- Repeating these steps can help confirm the result.

4.50 For certain kinds of complex decisions (for example, making a will), there are specific legal tests (see paragraph 4.32 above) in addition to the two-stage test for capacity. In some cases, medical or psychometric tests may also be helpful tools (for example, for assessing cognitive skills) in assessing a person's capacity to make particular decisions, but the relevant legal test of capacity must still be fulfilled.

### **When should professionals be involved?**

4.51 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 will simply involve contacting the person's general practitioner (GP) or family 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. In some cases, a multi-disciplinary approach is best. This means combining the skills and expertise of different professionals.



4.52 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 get 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.

4.53 Professional involvement might be needed 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, 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 vulnerable adult who may lack capacity to make decisions that protect them
- a person repeatedly makes decisions that put them at risk or could result in suffering or damage.

### **Scenario: Involving professional opinion**

Ms Ledger is a young woman with learning disabilities and some autistic spectrum disorders. Recently she began a sexual relationship with a much older man, who is trying to persuade her to move in with him and come off the pill. There are rumours that he has been violent towards her and has taken her bankbook.

Ms Ledger boasts about the relationship to her friends. But she has admitted to her key worker that she is sometimes afraid of the man. Staff at her sheltered accommodation decide to make a referral under the local adult protection procedures. They arrange for a clinical psychologist to assess Ms Ledger's understanding of the relationship and her capacity to consent to it.

4.54 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, in which case an expert should be asked for an opinion<sup>12</sup>
- to establish whether a person who might be involved in a legal case needs the assistance of the Official Solicitor or other litigation friend (somebody to represent their views to a court and give instructions to their legal representative) and there is doubt about the person's capacity to instruct a solicitor or take part in the case<sup>13</sup>
- whenever the Court of Protection has to decide if a person lacks capacity in a certain matter
- if the courts are required to make a decision about a person's capacity in other legal proceedings<sup>14</sup>
- if there may be legal consequences of a finding of capacity (for example, deciding on financial compensation following a claim for personal injury).

### **Are assessment processes confidential?**

- 4.55 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. But sometimes information may be disclosed without the consent of the person who the information concerns (for example, to protect the person or prevent harm to other people).<sup>15</sup>
- 4.56 Anyone assessing someone's capacity needs accurate information concerning the person being assessed that is relevant to the decision the person has to make. So professionals should, where possible, make relevant information available. They should make every effort to get the person's permission to reveal relevant information. They should give a full explanation of why this is necessary, and they should tell the person about the risks and consequences of revealing, and not revealing information. If the person is unable to give permission, the professional might still be allowed to provide information that will help make an accurate assessment of the person's capacity to make the specific decision. Chapter 16 has more detail on how to access information.

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<sup>12</sup> *Kenward v Adams*, The Times, 29 November 1975

<sup>13</sup> Civil Procedure Rules 1998, r 21.1

<sup>14</sup> *Masterman-Lister v Brutton & Co and Jewell & Home Counties Dairies* [2002] EWCA Civ 1889, CA at 54

<sup>15</sup> For example, in the circumstances discussed in *W v Egdell and others* [1990] 1 All ER 835 at 848; *S v Plymouth City Council and C*, [2002] EWCA Civ 388) at 49

## What if someone refuses to be assessed?

- 4.57 There may be circumstances in which a person whose capacity is in doubt refuses to undergo an assessment of capacity or refuses to be examined by a doctor or other professional. In these circumstances, it might help to explain to someone refusing an assessment why it is needed and what the consequences of refusal are. But threats or attempts to force the person to agree to an assessment are not acceptable.
- 4.58 If the person lacks capacity to agree or refuse, the assessment can normally go ahead, as long as the person does not object to the assessment, and it is in their best interests (see chapter 5).
- 4.59 Nobody can be forced to undergo an assessment of capacity. If someone refuses to open the door to their home, it cannot be forced. If there are serious worries about the person's mental health, it may be possible to get a warrant to force entry and assess the person for treatment in hospital – but the situation must meet the requirements of the Mental Health Act 1983 (section 135). But simply refusing an assessment of capacity is in no way sufficient grounds for an assessment under the Mental Health Act 1983 (see chapter 13).

## Who should keep a record of assessments?

- 4.60 Assessments of capacity to take day-to-day decisions or consent to care require no formal assessment procedures or recorded documentation. Paragraphs 4.44–4.45 above 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.

### Professional records

- 4.61 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 findings in the relevant professional records.
- A doctor or healthcare professional proposing treatment should carry out an assessment of the person's capacity to consent (with a multi-disciplinary team, if appropriate) and record it in the patient's clinical notes.
  - Solicitors 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 it on the client's file.
  - 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. This includes:
    - Person Centred Planning for people with learning disabilities
    - the Care Programme Approach for people with mental illness
    - the Single Assessment Process for older people in England, and
    - the Unified Assessment Process in Wales.

## **Formal reports or certificates of capacity**

4.62 In some cases, a more detailed report or certificate of capacity may be required, for example,

- for use in court or other legal processes
- as required by Regulations, Rules or Orders made under the Act.

## **How can someone challenge a finding of lack of capacity?**

4.63 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 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.

4.64 The assessor must show they have applied the principles of the Mental Capacity Act (see chapter 2). Attorneys, deputies and professionals will need to show that they have also followed guidance in this chapter.

4.65 It might be possible to get a second opinion from an independent professional or another expert in assessing capacity. Chapter 15 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 of Protection. The Court of Protection can rule on whether a person has capacity to make the decision covered by the assessment (see chapter 8).

## 5 What does the Act mean when it talks about ‘best interests’?

One of the key principles of the Act is that any act done for, or any decision made on behalf of a person who lacks capacity must be done, or made, in that person’s *best interests*. That is the same whether the person making the decision or acting is a family carer, a paid care worker, an attorney, a court-appointed deputy, or a healthcare professional, and whether the decision is a minor issue – like what to wear – or a major issue, like whether to provide particular healthcare.

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.

There are exceptions to this, including circumstances where a person has made an advance decision to refuse treatment (see chapter 9) and, in specific circumstances, the involvement of a person who lacks capacity in research (see chapter 11). But otherwise the underpinning principle of the Act is that all acts and decisions should be made in the best interests of the person without capacity.

Working out what is in someone else’s best interests may be difficult, and the Act requires people to follow certain steps to help them work out 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. As long as the person who acts or makes the decision has followed the steps to establish whether a person has capacity, and done everything they reasonably can to work out what someone’s best interests are, the law should protect them.

This chapter explains what the Act means by ‘best interests’ and what things should be considered when trying to work out what is in someone’s best interests. It also highlights some of the difficulties that might come up in working out what the best interests of a person who lacks capacity to make the decision actually are.

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.

### Quick summary

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

#### *Encourage participation*

- do whatever is possible to permit and encourage the person to take part, or to improve their ability to take part, in making the decision

#### *Identify all relevant circumstances*

- try to identify all the things that the person who lacks capacity would take into account if they were making the decision or acting for themselves

### *Find out the person's views*

- try to find out the views of the person who lacks capacity, including:
  - the person's past and present wishes and feelings – these may have been expressed verbally, in writing or through behaviour or habits.
  - any beliefs and values (e.g. religious, cultural, moral or political) that would be likely to influence the decision in question.
  - any other factors the person themselves would be likely to consider if they were making the decision or acting for themselves.

### *Avoid discrimination*

- not make assumptions about someone's best interests simply on the basis of the person's age, appearance, condition or behaviour.

### *Assess whether the person might regain capacity*

- consider whether the person is likely to regain capacity (e.g. after receiving medical treatment). If so, can the decision wait until then?

### *If the decision concerns life-sustaining treatment*

- not be motivated in any way by a desire to bring about the person's death. They should not make assumptions about the person's quality of life.

### *Consult others*

- if it is practical and appropriate to do so, consult other people for their views about the person's best interests and to see if they have any information about the person's wishes and feelings, beliefs and values. In particular, try to consult:
  - anyone previously named by the person as someone to be consulted on either the decision in question or on similar issues
  - anyone engaged in caring for the person
  - close relatives, friends or others who take an interest in the person's welfare
  - any attorney appointed under a Lasting Power of Attorney or Enduring Power of Attorney made by the person
  - any deputy appointed by the Court of Protection to make decisions for the person.
- For decisions about major medical treatment or where the person should live and where there is no-one who fits into any of the above categories, an Independent Mental Capacity Advocate (IMCA) must be consulted. (See chapter 10 for more information about IMCAs.)
- When consulting, remember that the person who lacks the capacity to make the decision or act for themselves still has a right to keep their affairs private – so it would not be right to share every piece of information with everyone.

### *Avoid restricting the person's rights*

- see if there are other options that may be less restrictive of the person's rights.

*Take all of this into account*

- weigh up all of these factors in order to work out what is in the person's best interests.

## **What is the best interests principle and who does it apply to?**

5.1 The best interests principle underpins the Mental Capacity Act. It is set out in section 1(5) of the Act.

'An act done, or decision made, under this Act for or on behalf of a person who lacks capacity must be done, or made, in his best interests.'

The concept has been developed by the courts in cases relating to people who lack capacity to make specific decisions for themselves, mainly decisions concerned with the provision of medical treatment or social care.

5.2 This principle covers all aspects of financial, personal welfare and healthcare decision-making and actions. It applies to anyone making decisions or acting under the provisions of the Act, including:

- family carers, other carers and care workers
- healthcare and social care staff
- attorneys appointed under a Lasting Power of Attorney or registered Enduring Power of Attorney
- deputies appointed by the court to make decisions on behalf of someone who lacks capacity, and
- the Court of Protection.

5.3 However, as chapter 2 explained, the Act's first key principle is that people must be assumed to have capacity to make a decision or act for themselves unless it is established that they lack it. That means that working out a person's best interests is only relevant when that person has been assessed as lacking, or is reasonably believed to lack, capacity to make the decision in question or give consent to an act being done.

People with capacity are able to decide for themselves what they want to do. When they do this, they might choose an option that other people don't think is in their best interests. That is their choice and does not, in itself, mean that they lack capacity to make those decisions.

### **Exceptions to the best interests principle**

5.4 There are two circumstances when the best interests principle will not apply. The first is where someone has previously made an advance decision to refuse medical treatment while they had the capacity to do so. Their advance decision should be respected when they lack capacity, even if others think that the decision to refuse treatment is not in their best interests (guidance on advance decisions is given in chapter 9).

The second concerns the involvement in research, in certain circumstances, of someone lacking capacity to consent (see chapter 11).

## What does the Act mean by best interests?

- 5.5 The term 'best interests' is not actually defined in the Act. This is because so many different types of decisions and actions are covered by the Act, and so many different people and circumstances are affected by it.
- 5.6 Section 4 of the Act explains how to work out the best interests of a person who lacks capacity to make a decision at the time it needs to be made. This section sets out a checklist of common factors that must always be considered by anyone who needs to decide what is in the best interests of a person who lacks capacity in any particular situation. This checklist is only the starting point: in many cases, extra factors will need to be considered.
- 5.7 When working out what is in the best interests of the person who lacks capacity to make a decision or act for themselves, decision-makers must take into account all relevant factors that it would be reasonable to consider, not just those that they think are important. They must not act or make a decision based on what they would want to do if they were the person who lacked capacity.

### Scenario: Whose best interests?

Pedro, a young man with a severe learning disability, 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 Pedro an occasional general anaesthetic so that a dentist can clean his teeth and fill any cavities. 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 Pedro'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 Pedro's best interests.

Having talked to others, the dentist tries to find ways of involving Pedro in the decision, with the help of his key worker and an advocate, to try 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 tries to find out if any other forms of dental care would be better, such as a mouthwash or dental gum.

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

- a proper investigation to be carried out under anaesthetic so that immediate treatment can be provided
- options for his future dental care to be reviewed by the care team, involving Pedro as far as possible.

### Who can be a decision-maker?

- 5.8 Under the Act, many different people may be required to make decisions or act on behalf of someone who lacks capacity to make decisions for



themselves. The person making the decision is referred to throughout this chapter, and in other parts of the Code, as the 'decision-maker', and it is the decision-maker's responsibility to work out what would be in the best interests of the person who lacks capacity.

- For most day-to-day actions or decisions, the decision-maker will be the carer most directly involved with the person at the time.
- Where the decision involves the provision of medical treatment, the doctor or other member of healthcare staff responsible for carrying out the particular treatment or procedure is the decision-maker.
- Where nursing or paid care is provided, the nurse or paid carer will be the decision-maker.
- If a Lasting Power of Attorney (or Enduring Power of Attorney) has been made and registered, or a deputy has been appointed under a court order, the attorney or deputy will be the decision-maker, for decisions within the scope of their authority.

5.9 What this means is that a range of different decision-makers may be involved with a person who lacks capacity to make different decisions.

5.10 In some cases, the same person may make different types of decision for someone who lacks capacity to make decisions for themselves. For instance, a family carer may carry out certain acts in caring for the person on a day-to-day basis, but if they are also an attorney, appointed under a Lasting Power of Attorney (LPA), they may also make specific decisions concerning the person's property and affairs or their personal welfare (depending on what decisions the LPA has been set up to cover).

5.11 There are also times when a joint decision might be made by a number of people. For example, when a care plan for a person who lacks capacity to make relevant decisions is being put together, different healthcare or social care staff might be involved in making decisions or recommendations about the person's care package. Sometimes these decisions will be made by a team of healthcare or social care staff as a whole. At other times, the decision will be made by a specific individual within the team. A different member of the team may then implement that decision, based on what the team has worked out to be the person's best interests.

5.12 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.

### **Scenario: Coming to a joint decision**

Jack, a young man with a brain injury, lacks capacity to agree to a rehabilitation programme designed to improve his condition. But the healthcare and social care staff who are looking after him believe that he clearly needs the programme, and have obtained the necessary funding from the Primary Care Trust.

However, Jack's family want to take him home from hospital as they believe they can provide better care for him at home.

A 'best interests' case conference is held, involving Jack, his parents and other family members and the relevant professionals, in order to decide what course of action would be in the Jack's best interests.

A plan is developed to enable Jack to live at home, but attend the day hospital every weekday. Jack seems happy with the proposals and both the family carers and the healthcare and social care staff are satisfied that the plan is in his best interests.

## **What must be taken into account when trying to work out someone's best interests?**

5.13 Because every case – and every decision – is different, the law can't set out all the factors that will need to be taken into account in working out someone's best interests. But section 4 of the Act sets out some common factors that must always be considered when trying to work out someone's best interests. These factors are summarised in the checklist here:

- Working out what is in someone's best interests cannot be based simply on someone's age, appearance, condition or behaviour. (see paragraphs 5.16–5.17).
- All relevant circumstances should be considered when working out someone's best interests (paragraphs 5.18–5.20).
- Every effort should be made to encourage and enable the person who lacks capacity to take part in making the decision (paragraphs 5.21–5.24).
- 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 (paragraphs 5.25–5.28).
- Special considerations apply to decisions about life-sustaining treatment (paragraphs 5.29–5.36).
- The person's past and present wishes and feelings, beliefs and values should be taken into account (paragraphs 5.37–5.48).
- The views of other people who are close to the person who lacks capacity should be considered, as well as the views of an attorney or deputy (paragraphs 5.49–5.55).

It's important not to take shortcuts in working out best interests, and a proper and objective assessment must be carried out on every occasion. If the decision is urgent, 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. Not all the factors in the checklist will be relevant to all types of decisions or actions, and in many cases other factors will have to be considered as well, even though some of them may then not be found to be relevant.

5.14 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.

5.15 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 of that person for each relevant decision, setting out:

- how the decision about the person's best interests was reached
- 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.

This record should remain on the person's file.

For major decisions based on the best interests of a person who lacks capacity, it may also be useful for family and other carers to keep a similar kind of record.

### **What safeguards does the Act provide around working out someone's best interests?**

5.16 Section 4(1) states that anyone working out someone's best interests must not make unjustified assumptions about what their best interests might be simply on the basis of the person's age, appearance, condition or any aspect of their behaviour. In this way, 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.

5.17 '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.

#### **Scenario: Following the checklist**

Martina, an elderly woman with dementia, is beginning to neglect her appearance and personal hygiene and has several times been found wandering in the street unable to find her way home. Her care workers are concerned that Martina no longer has capacity to make appropriate decisions relating to her daily care. Her daughter is her personal welfare attorney and believes the time has come to act under the Lasting Power of Attorney (LPA).

She assumes it would be best for Martina to move into a care home, since the staff would be able to help her wash and dress smartly and prevent her from wandering.

However, it cannot be assumed *simply on the basis of her age, condition, appearance or behaviour* either that Martina lacks capacity to make such a decision or that such a move would be in her best interests.

Instead, steps must be taken to assess her capacity. If it is then agreed that Martina lacks the capacity to make this decision, all the relevant factors in the

best interests' checklist must be considered to try to work out what her best interests would be.

Her daughter must therefore consider:

- Martina's past and present wishes and feelings
- the views of the people involved in her care
- any alternative ways of meeting her care needs effectively which might be less restrictive of Martina's rights and freedoms, such as increased provision of home care or attendance at a day centre.

By following this process, Martina's daughter can then take decisions on behalf of her mother and in her best interests, when her mother lacks the capacity to make them herself, on any matters that fall under the authority of the LPA.

### **How does a decision-maker work out what 'all relevant circumstances' are?**

5.18 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 in the 'checklist'. Clearly, 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. So relevant circumstances are defined in section 4(11) of the Act as those:

'(a) of which the person making the determination is aware, and

(b) which it would be reasonable to regard as relevant.'

5.19 The relevant circumstances will of course vary from case to case. 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.<sup>16</sup> But 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.

5.20 Financial decisions are another area where the relevant circumstances will vary. For example, if a person had received a substantial sum of money as compensation for an accident resulting in brain injury, the decision-maker would have to consider a wide range of circumstances when making decisions about how the money is spent or invested, such as:

- whether the person's condition is likely to change
- whether the person needs professional care, and

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<sup>16</sup> *An Hospital NHS Trust v S* [2003] EWHC 365 (Fam), paragraph 47

- whether the person needs to live somewhere else to make it easier for them.

These kinds of issues can only be decided on a case-by-case basis.

## **How should the person who lacks capacity be involved in working out their best interests?**

- 5.21 Wherever possible, the person who lacks capacity to make a decision should still be involved in the decision-making process (section 4(4)).
- 5.22 Even if the person lacks capacity to make the decision, they may have views on matters affecting the decision, and on what outcome would be preferred. Their involvement can help work out what would be in their best interests.
- 5.23 The decision-maker should make sure that all practical means are used 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 to help the person improve their ability to participate.
- 5.24 Consulting the person who lacks capacity will involve taking time to explain what is happening and why a decision needs to be made. Chapter 3 includes a number of practical steps to assist and enable decision-making which may also be helpful in encouraging greater participation. These include:
- using simple language and/or illustrations or photographs to help the person understand the options
  - asking them about the decision at a time and location where the person feels most relaxed and at ease
  - breaking the information down into easy-to-understand points
  - using specialist interpreters or signers to communicate with the person.

This may mean that other people are required to communicate with the person to establish their views. For example, a trusted relative or friend, a full-time carer or an advocate may be able to help the person to express wishes or aspirations or to indicate a preference between different options.

More information on all of these steps can be found in chapter 3.

### **Scenario: Involving someone in working out their best interests**

The parents of Amy, a young woman with learning difficulties, are going through a divorce and are arguing about who should continue to care for their daughter. Though she cannot understand what is happening, attempts are made to see if Amy can give some indication of where she would prefer to live.

An advocate is appointed to work with Amy to help her understand the situation and to find out her likes and dislikes and matters which are important to her. With the advocate's help, Amy is able to participate in decisions about her future care.

## How do the chances of someone regaining and developing capacity affect working out what is in their best interests?

5.25 There are some situations where decisions may be deferred, if someone who currently lacks capacity may regain the capacity to make the decision for themselves. Section 4(3) of the Act requires the decision-maker to consider:

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

It may then be possible to put off the decision until the person can make it for themselves.

5.26 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.

5.27 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 for themselves in the future.

### **Scenario: Taking a short-term decision for someone who may regain capacity**

Mr Fowler has suffered a stroke leaving him severely disabled and unable to speak. Within days, he has shown signs of improvement, so with intensive treatment there is hope he will recover over time. But at present both his wife and the hospital staff find it difficult to communicate with him and have been unable to find out his wishes.

He has always looked after the family finances, so Mrs Fowler suddenly discovers she has no access to his personal bank account to provide the family with money to live on or pay the bills. Because the decision can't be put off while efforts are made to find effective means of communicating with Mr Fowler, an application is made to the Court of Protection for an order that allows Mrs Fowler to access Mr Fowler's money.

The decision about longer-term arrangements, on the other hand, can be delayed until alternative methods of communication have been tried and the extent of Mr Fowler's recovery is known.

5.28 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 in time (for example, where it is caused by the effects of medication or alcohol, or following a sudden shock)

- 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) so it may be possible to arrange for the decision to be made during a time when they do have capacity
- a person previously unable to communicate may learn a new form of communication (see chapter 3).

## **How should someone's best interests be worked out when making decisions about life-sustaining treatment?**

- 5.29 A special factor in the checklist applies to decisions about treatment which is necessary to keep the person alive ('life-sustaining treatment') and this is set out in section 4(5) of the Act. 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.
- 5.30 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 prescribed. 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.
- 5.31 All reasonable steps which are in the person's best interests should be taken to prolong their life. There will be a limited number of cases where treatment is futile, overly burdensome to the patient or where there is no prospect of recovery. In circumstances such as these, it may be that an assessment of best interests leads to the conclusion that it would be in the best interests of the patient to withdraw or withhold life-sustaining treatment, even if this may result in the person's death. The decision-maker must make a decision based on the best interests of the person who lacks capacity. They must not be motivated by a desire to bring about the person's death for whatever reason, even if this is from a sense of compassion. Healthcare and social care staff should also refer to relevant professional guidance when making decisions regarding life-sustaining treatment.
- 5.32 As with all decisions, before deciding to withdraw or withhold life sustaining treatment, the decision-maker must consider the range of treatment options available to work out what would be in the person's best interests. All the factors in the best interests checklist should be considered, and in particular, the decision-maker should consider any statements that the person has previously made about their wishes and feelings about life-sustaining treatment.
- 5.33 Importantly, section 4(5) cannot 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, even where the

person's death is foreseen. Doctors must apply the best interests' checklist and use their professional skills to decide whether life-sustaining treatment is in the person's best interests. If the doctor's assessment is disputed, and there is no other way of resolving the dispute, ultimately the Court of Protection may be asked to decide what is in the person's best interests.

- 5.34 Where a person has made a written statement in advance that requests particular medical treatments, such as artificial nutrition and hydration (ANH), 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 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.
- 5.35 If someone has made an advance decision to refuse life-sustaining treatment, specific rules apply. More information about these can be found in chapter 9 and in paragraph 5.45 below.
- 5.36 As mentioned in paragraph 5.33 above, where there is any doubt about the patient's best interests, an application should be made to the Court of Protection for a decision as to whether withholding or withdrawing life-sustaining treatment is in the patient's best interests.

### **How do a person's wishes and feelings, beliefs and values affect working out what is in their best interests?**

- 5.37 Section 4(6) of the Act requires the decision-maker to consider, as far as they are 'reasonably ascertainable':

'(a) the person's past and present wishes and feelings (and in particular, any relevant written statements made by him when he had capacity),

(b) the beliefs and values that would be likely to influence his decision if he had capacity, and

(c) the other factors that he would be likely to consider if he were able to do so.'

Paragraphs 5.38–5.48 below give further guidance on each of these factors.

- 5.38 In setting out the requirements for working out a person's 'best interests', section 4 of the Act puts the person who lacks capacity at the centre of the decision to be made. Even if they cannot make the decision, their wishes and feelings, beliefs and values should be taken fully into account – whether expressed in the past or now. But their wishes and feelings, beliefs and values will not necessarily be the deciding factor in working out their best interests. Any such assessment must consider past and current wishes and feelings, beliefs and values alongside all other factors, but the final decision must be based entirely on what is in the person's best interests.



## **Scenario: Considering wishes and feelings as part of best interests**

Andre, a young man with severe learning disabilities who does not use any formal system of communication, cuts his leg while outdoors. There is some earth in the wound. A doctor wants to give him a tetanus jab, but Andre appears scared of the needle and pushes it away. Assessments have shown that he is unable to understand the risk of infection following his injury, or the consequences of rejecting the injection.

The doctor decides that it is in the Andre's best interests to give the vaccination. She asks a nurse to comfort Andre, and if necessary, restrain him while she gives the injection. She has objective reasons for believing she is acting in Andre's best interests, and for believing that Andre lacks capacity to make the decision for himself. So she should be protected from liability under section 5 of the Act (see chapter 6).

### **What is 'reasonably ascertainable'?**

- 5.39 How much someone can learn about a person's past and present views will depend on circumstances and the time available. 'Reasonably ascertainable' means considering all possible information 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 his friends, family or carers (see chapter 3 for guidance on helping communication).

### **What role do a person's past and present wishes and feelings play?**

- 5.40 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. An advocate could help the person make choices and express their views.
- 5.41 The person may have held strong views in the past which could have a bearing on the decision now to be made. All reasonable efforts must be made to find out whether the person has expressed views in the past that will shape the decision to be made. This could have been through verbal communication, writing, behaviour or habits, or recorded in any other way (for example, home videos or audiotapes).
- 5.42 Section 4(6)(a) places special emphasis on written statements the person might have made before losing capacity. These could provide a lot of information about a person's wishes. For example, these statements could include information about 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.
- 5.43 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.
- 5.44 A doctor should take written statements made by a person before losing

capacity which request specific treatments as seriously as those made by people who currently have capacity to make treatment decisions. But they would not have to follow a written request if they think the specific treatment would be clinically unnecessary or not appropriate for the person's condition, so not in the person's best interests.

- 5.45 It is important to note the distinction between a written statement expressing treatment preferences and a statement which constitutes an advance decision to refuse treatment. This is covered by section 24 of the Act, and it has a different status in law. Doctors cannot ignore a written statement that is a valid advance decision to refuse treatment. An advance decision to refuse treatment must be followed if it meets the Act's requirements and applies to the person's circumstances. In these cases, the treatment must not be given (see chapter 9 for more information). If there is not a valid and applicable advance decision, treatment should be provided based on the person's best interests.

### **What role do beliefs and values play?**

- 5.46 Everybody's values and beliefs 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, for example. Evidence of a person's beliefs and values can be found in things like their:

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

Some people set out their values and beliefs in a written statement while they still have capacity.

### **Scenario: Considering beliefs and values**

Anita, a young woman, suffers serious brain damage during a car accident. The court appoints her father as deputy to invest the compensation she received. As the decision-maker he must think about her wishes, beliefs and values before deciding how to invest the money.

Anita had worked for an overseas charity. Her father talks to her former colleagues. They tell him how Anita's political beliefs shaped her work and personal beliefs, so he decides not to invest in the bonds that a financial adviser had recommended, because they are from companies Anita would not have approved of. Instead, he employs an ethical investment adviser to choose appropriate companies in line with her beliefs.

### **What other factors should a decision-maker consider?**

- 5.47 Section 4(6)(c) of the Act requires decision-makers to consider any other factors the person who lacks capacity would consider if they were able to do

so. This might include the effect of the decision on other people, obligations to dependants or the duties of a responsible citizen.

- 5.48 The Act allows actions that benefit other people, as long as they are in the best interests of the person who lacks capacity to make the decision. For example, having considered all the circumstances of the particular case, a decision might be made to take a blood sample from a person who lacks capacity to consent, to check for a genetic link to cancer within the family, because this might benefit someone else in the family. But it might still be in the best interests of the person who lacks capacity. ‘Best interests’ goes beyond the person’s medical interests.

For example, courts have previously ruled that possible wider benefits to a person who lacks capacity to consent, such as providing or gaining emotional support from close relationships, are important factors in working out the person’s own best interests.<sup>17</sup> If it is likely that the person who lacks capacity would have considered these factors themselves, they can be seen as part of the person’s best interests.

### **Who should be consulted when working out someone’s best interests?**

- 5.49 The Act places a duty on the decision-maker to consult other people close to a person who lacks capacity, where practical and appropriate, on decisions affecting the person and what might be in the person’s best interests. This also applies to those involved in caring for the person and interested in the person’s welfare. Under section 4(7), the decision-maker has a duty to take into account the views of the following people, where it is practical and appropriate to do so:

- anyone the person has previously named as someone they want to be consulted
- anyone involved in caring for the person
- anyone interested in their welfare (for example, family carers, other close relatives, or an advocate already working with the person)
- an attorney appointed by the person under a Lasting Power of Attorney, and
- a deputy appointed for that person by the Court of Protection.

- 5.50 If there is no-one to speak to about the person’s best interests, in some circumstances the person may qualify for an Independent Mental Capacity Advocate (IMCA). For more information on IMCAs, see chapter 10.

- 5.51 Decision-makers must show they have thought carefully about who to speak to. If it is practical and appropriate to speak to the above people, they must do so and must take their views into account. They must be able to explain why they did not speak to a particular person – it is good practice to have a clear

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<sup>17</sup> See for example *Re Y (Mental Incapacity: Bone marrow transplant)* [1996] 2 FLR 787; *Re A (Male Sterilisation)* [2000] 1 FLR 549

record of their reasons. It is also good practice to give careful consideration to the views of family carers, if it is possible to do so.

5.52 It is also good practice for healthcare and social care staff 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 healthcare and social care staff go against the views of somebody who has been consulted while working out the person's best interests.

5.53 The decision-maker should try to find out:

- what the people consulted think is in the person's best interests in this matter, and
- if they can give information on the person's wishes and feelings, beliefs and values.

5.54 This information may be available from somebody the person named before they lost capacity as someone they wish to be consulted. People who are close to the person who lacks capacity, such as close family members, are likely to know them best. They may also be able to help with communication or interpret signs that show the person's present wishes and feelings. Everybody's views are equally important – even if they do not agree with each other. They must be considered alongside the views of the person who lacks capacity and other factors. See paragraphs 5.62–5.69 below for guidance on dealing with conflicting views.

### **Scenario: Considering other people's views**

Lucia, a young woman with severe brain damage, is cared for at home by her parents and attends a day centre a couple of days each week. The day centre staff would like to take some of the service users on holiday. They speak to Lucia's parents as part of the process of assessing whether the holiday would be in her best interests.

The parents think that the holiday would be good for her, but they are worried that Lucia gets very anxious if she is surrounded by strangers who don't know how to communicate with her. Having tried to seek Lucia's views and involve her in the decision, the staff and parents agree that a holiday would be in her best interests, as long as her care assistant can go with her to help with communication.

5.55 Where an attorney has been appointed under a Lasting Power of Attorney or Enduring Power of Attorney, or a deputy has been appointed by a court, they must make the decisions on any matters they have been appointed to deal with. Attorneys and deputies should also be consulted, if practical and appropriate, on other issues affecting the person who lacks capacity.

For instance, an attorney who is appointed only to look after the person's property and affairs may have information about the person's beliefs and values, wishes and feelings, that could help work out what would be in the person's best interests regarding healthcare or treatment decisions. (See chapters 7 and 8 for more information about the roles of attorneys and deputies.)

## **How can decision-makers respect confidentiality?**

- 5.56 Decision-makers must balance the duty to consult other people with the right to confidentiality of the person who lacks capacity. So if confidential information is to be discussed, they should only seek the views of people who it is appropriate to consult, where their views are relevant to the decision to be made and the particular circumstances.
- 5.57 There may be occasions where it is in the person's best interests for personal information (for example, about their medical condition, if the decision concerns the provision of medical treatment) to be revealed to the people consulted as part of the process of working out their best interests (further guidance on this is given in chapter 16). Healthcare and social care staff who are trying to determine a person's best interests must follow their professional guidance, as well as other relevant guidance, about confidentiality.

## **When does the best interests principle apply?**

- 5.58 Section 1(5) of the Act confirms that the principle applies to any act done, 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.

### **Reasonable belief about a person's best interests**

- 5.59 Section 4(9) confirms 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, then – provided they have followed the checklist in section 4 – they will have complied with the best interests principle set out in the Act. Coming to an incorrect conclusion about a person's capacity or best interests does not necessarily mean that the decision-maker would not get protection from liability (this is explained in chapter 6). But they must be able to show 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 they made their decision or took action.
- 5.60 Where there is a need for a court 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 (for example, psychiatrists or social workers). But in most day-to-day situations, there is no need for such formality. In emergency situations, it may not be practical or possible to gather formal evidence.
- 5.61 Where the court is not involved, people are still expected to have reasonable grounds for believing that they are acting in somebody's best interests. This does not mean that decision-makers can simply impose their own views. They must have objective reasons for their decisions – and they must be able to demonstrate them. They must be able to show they have considered all relevant circumstances and applied all elements of the best interests checklist.

### **Scenario: Demonstrating reasonable belief**

Mrs Prior is mugged and knocked unconscious. She is brought to hospital without any means of identification. She has head injuries and a stab wound, and has lost a lot of blood. In casualty, a doctor arranges an urgent blood

transfusion. Because this is necessary to save her life, the doctor believes this is in her best interests.

When her relatives are contacted, they say that Mrs Prior's beliefs meant that she would have refused all blood products. But since Mrs Prior's handbag had been stolen, the doctor had no idea who the woman was nor what her beliefs were. He needed to make an immediate decision and Mrs Prior lacked capacity to make the decision for herself. Therefore he had reasonable grounds for believing that his action was in his patient's best interests – and so was protected from liability.

Now that the doctor knows Mrs Prior's beliefs, he can take them into account in future decisions about her medical treatment if she lacks capacity to make them for herself. He can also consult her family, now that he knows where they are.

### **What problems could arise when working out someone's best interests?**

- 5.62 It is important that the best interests principle and the statutory checklist are flexible. Without flexibility, it would be impossible to prioritise factors in different cases – and it would be difficult to ensure that the outcome is the best possible for the person who lacks capacity to make the particular decision. Some cases will be straightforward. Others will require decision-makers to balance the pros and cons of all relevant factors.<sup>18</sup> But this flexibility could lead to problems in reaching a conclusion about a person's best interests.

### **What happens when there are conflicting concerns?**

- 5.63 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.
- 5.64 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.

### **Scenario: Dealing with disagreement**

Some time ago, Mr Graham made a Lasting Power of Attorney (LPA) appointing his son and daughter as joint attorneys to manage his finances and property. He now has Alzheimer's disease and has moved into private

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<sup>18</sup> *Re A (Male Sterilisation)* [2000] 1 FLR 549

residential care. The son and daughter have to decide what to do with Mr Graham's house.

His son thinks it is in their father's best interests to sell it and invest the money for Mr Graham's future care. But his daughter thinks it is in Mr Graham's best interests to keep the property, because he enjoys visiting and spending time in his old home.

After making every effort to get Mr Graham's views, the family meets to discuss all the issues involved. After hearing other family views, the attorneys agree that it would be in their father's best interests to keep the property for so long as he is able to enjoy visiting it.

### **Family, partners and carers who are consulted**

- 5.65 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.
- 5.66 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.
- 5.67 People with conflicting interests should not be cut out of the process (for example, 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, and
  - what their relationship is.

### **Scenario: Settling disagreements**

Robert is 19 and has learning disabilities and autism. He is about to leave his residential special school. His parents want Robert to go to a specialist unit run by a charitable organisation, but he has been offered a place in a local supported living scheme. The parents don't think Robert will get appropriate care there.

The school sets up a 'best interests' meeting. People who attend include Robert, his parents, teachers from his school and professionals involved in preparing Robert's care plan. Robert's parents and teachers know him best. They set out their views and help Robert to communicate where he would like to live.

Social care staff identify some different placements within the county. Robert visits these with his parents. After further discussion, everyone agrees that a community placement near his family home would be in Robert's best interests.

## **Settling disputes about best interests**

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

- Involve an advocate to act on behalf of the person who lacks capacity to make the decision (see paragraph 5.69 below).
- Get a second opinion.
- Hold a formal or informal 'best interests' case conference.
- Attempt some form of mediation (see chapter 15).
- Pursue a complaint through the organisation's formal procedures.

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. Chapter 8 provides more information about the Court of Protection.

## **Advocacy**

5.69 An advocate might be useful in providing support for the person who lacks capacity to make a decision in the process of working out their best interests, if:

- the person who lacks capacity has no close family or friends to take an interest in their welfare, and they do not qualify for an Independent Mental Capacity Advocate (see chapter 10)
- 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 person who lacks capacity is already in contact with an advocate
- the proposed course of action may lead to the use of restraint or other restrictions on the person who lacks capacity
- there is a concern about the protection of a vulnerable adult.