



What you need to know  
about the Mental Capacity Act  
and end of life care

Second edition

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## Why is the Mental Capacity Act so important?

The Mental Capacity Act (2005) – the “MCA” – is about our human rights. It governs the way that decisions are made by or on behalf of adults who have impaired mental capacity to make decisions for themselves. It covers all types of decisions, including decisions about people’s personal welfare, health, care, finances and property. It sets out rights and duties that protect and empower people with impaired mental capacity and provides a framework to ensure that decisions about them are made in accordance with clear principles and processes.

The MCA became law in 2007. It supports and underpins good practice. Organisations working in health and care have a responsibility both to the people they care for and their employees to ensure that their staff understand and comply with it.

This guidance aims to help everybody – people approaching the end of life, families and carers, as well as health and social care staff working in all settings – to understand the MCA and how it affects decision-making at the end of life. It explains how people can use the MCA to express and protect their wishes about their future care.

## What does the MCA apply to?

The MCA covers:

- Decisions made by or on behalf of people aged **16 and over** who have impaired mental capacity. (There are a few exceptions: if somebody wants to make an advance decision to refuse treatment or give somebody else a Lasting Power of Attorney, they must be 18 or over. These are discussed in more detail on page 12)
- **All types of decision**, including decisions about money and property as well as health and social care
- **Everyone, including family and informal carers as well as professional care staff, who has to help adults with impaired capacity** to make decisions or make decisions on their behalf

The MCA covers **England and Wales**. Scotland and Northern Ireland have separate mental capacity laws. Although the principles are similar, the legislation is not identical, and this guidance does not cover those countries.

## Why might people have impaired mental capacity?

Having impaired mental capacity means that a person either can't make a decision for themselves or may need some help and support to make it.

Reasons why this might happen include:

- Dementia
- Learning disabilities
- Stroke or some neurological conditions
- Brain injury
- If people's consciousness and capacity are fluctuating or they are experiencing confusion and agitation through illness or frailty
- If people are on medications that can affect their cognitive function
- Mental health or psychiatric problems
- When people are reaching the end of their lives

## What's in the MCA?

These are some of the most important things to know:

- It sets out **legal frameworks** which must be followed:
  - to **assess people's mental capacity** to make a particular decision
  - to determine people's **best interests** if they can't make that decision themselves
- It emphasises that **care must be person-centred**; people should be seen as whole individuals, not defined or discriminated against by their condition or life circumstances
- If people can't make a decision for themselves, there's a **duty to consult** those who are close to them about their best interests
- The **things people have said or written down about what they want to happen** if they lose capacity to make a decision for themselves **must be taken into account** when deciding what their best interests are
- People can **refuse specific treatments** in advance if they want
- People can appoint others to make decisions on their behalf using a **Lasting Power of Attorney**
- There's a detailed **Code of Practice** alongside it. Professionals and paid staff have a duty to comply with the Code of Practice.
- It contains rules about **Deprivation of Liberty Safeguards** (sometimes referred to as "DOLS") to protect people with impaired mental health

Although this publication focuses on end of life and palliative care, the MCA applies to all care and treatment, and to all decisions about adults with impaired capacity. It has a very wide reach.

## Five key principles

Five key principles underpin the MCA. The first three relate to the process of supporting people and determining whether or not they have capacity to make a decision. The last two are about the decision-making process if they don't have capacity to decide for themselves.

### 1. **Presumption in favour of capacity**

*Everyone has the right to make their own decisions for themselves, and must be assumed to have capacity, unless it is established otherwise.*

### 2. **People should be supported to make their own decisions where possible**

*A person must not be treated as being unable to make a decision unless all practicable steps to help them to do so have been taken, without success.*

### 3. **People have the right to make unwise decisions**

*People are not to be treated as lacking capacity to make a decision just because they make a decision which others may think unwise or eccentric.*

### 4. **Best interests**

*Acts done or decisions made on behalf of a person established to be lacking capacity must be in their best interests.*

### 5. **People should be restricted as little as possible**

*Someone doing an act or taking a decision on behalf of someone who lacks capacity must consider whether it is possible to do it in a less restrictive way that impacts less on the person's rights and freedom of action.*

## Assessing a person's capacity to make a decision

All carers, professional and informal, need to assess a person's capacity before making a decision about their care, to make sure they do not have capacity to make it for themselves. If they decide that a person hasn't got capacity to make a particular decision, they'll need to be able to explain why if challenged. For most day to day decisions this can be done swiftly and informally, but specialist advice may be needed in difficult cases.

### Reminder: capacity and consent

If you think that somebody may have impaired capacity it is important to assess their capacity, rather than simply take them saying "yes" or a "no" at face value. You need to make sure that they are genuinely able to consent or refuse what is being suggested. If they don't have capacity to consent you need to consider their best interests.

The MCA tells people what they must and must not do when assessing a person's mental capacity:

### Identify the decision that needs to be made

**Capacity must be assessed on a decision-by-decision basis.** Unless someone is unconscious or has very severe impairment, their capacity should not be assessed on a "blanket" basis. For example, with some help, a person may be able to make decisions about where they want to sit, what they want to wear and eat, who they want to be with, and how they want to spend their day, but not have capacity to make complicated financial decisions.

### Don't discriminate

Lack of capacity must not be established simply by reference to somebody's age, appearance, condition or aspect of their behaviour. Don't make unjustified assumptions, but **engage with the person and assess them as an individual.**

## The 2-stage test

You need to ask two questions when deciding whether a person has capacity to make a particular decision:



1. **The functional question:** does the person have capacity to make the decision for themselves? The MCA says they cannot make the decision for themselves if they cannot do one or more of the following: understand relevant information; retain or remember the information; use or weigh the information to make the decision; or communicate by any means.



- If the answer is that they don't, then**
2. **The diagnostic question:** at the time the decision needs to be made, does the person have an impairment or disturbance of their mind or brain, *and* is that what is causing their lack of capacity?

## Support the person to make the decision themselves if possible

Remember the principle that you need to support the person to maximise their capacity to make the decision. Examples of how you might do this include:

- **Ask the person's usual carers** – for example their family or friends – what they have found is the best way to help the person to communicate
- **Write things down** for the person to read
- Use **simple language or pictures** to explain things
- Communication aids, for example **hearing aids**
- **Give people time and space** to think quietly
- Where necessary, **seek expert help**, for example from psychologists or speech therapists.





## Assessing capacity – some prompts

Think about the following questions when assessing someone's capacity and recording your reasons:

- What decision needs to be made?
- Does the person have an impairment or disturbance of the mind or brain?
- Is that so serious that it means the person cannot make the decision in question?
- What's the person's functional difficulty? Is about their memory, judgement, understanding or ability to communicate?
- What support has the person had to help them try to make the decision themselves?
- Do they still lack capacity, even with all practicable support?
- Does the decision need to be made now, or can it wait until the person's capacity improves?

## Making a best interests decision

If you have decided that a person does not have the capacity to make a decision, then you (or the person they have given a Lasting Power of Attorney to or a Court appointed deputy, if either of those applies) will have to make that decision for them in their best interests. The only exception to that is if the decision is about a particular treatment and the person has made an advance decision to refuse that specific treatment (see page 14).

As with assessing capacity, the MCA sets out what must and must not be done when assessing somebody's best interests:

- **Don't discriminate** or make unjustified assumptions about a person's best interests on the basis of their age, condition, behaviour or appearance. Instead, engage with the person as an individual; don't make assumptions about other people's quality of life.



- **Do take into account any circumstances that are relevant** to the decision that needs to be made. It's impossible for legislation to anticipate every circumstance that might be relevant. It's up to you to use your judgement to work out everything that's relevant and make sure you have taken that into account.
- **Think about whether and when the person might regain capacity** to make the decision. So, if the person fluctuates, with good and bad periods of mental function, wait until they regain capacity, and then ask them what they want to happen, unless the decision needs to be made urgently
- If possible, **involve the person in the decision-making**. Even though they do not have capacity to make the decision, they can still participate. Don't ignore them. They might be able to give important information and insights and tell you what they want or how they feel about what needs to be decided
- If the decision is about life-sustaining treatment, **you must not be motivated by a desire to bring about the person's death**. The MCA enables treatment such as artificial feeding to be withheld or withdrawn if that is in the person's best interests; it does not permit euthanasia.
- **Do take into account, so far as can be done, the person's wishes, feelings, beliefs, and values**, and in particular any written statement that they might have made whilst they had capacity. This means that any advance care plans or statements that the person has made must be taken into account and cannot be ignored.
- **Do consult, if possible, anybody that the person has nominated as well as anybody involved in caring for the person or interested in their welfare**. This means those who are close to the person, including relatives and friends. But remember: they must be consulted about what the person's best interests are, not what they want to happen.

## Reminder: consent and best interests

People who lack capacity must receive treatment if it is in their best interests for them to do so (unless they have made a binding advance decision to refuse it). Their inability to consent to treatment should not become a barrier to them getting treatment that they need.

For example, if it is in the best interests of someone with dementia that they receive a flu vaccination, or someone with Down's syndrome that they should receive chemotherapy, but they are unable to consent, they should still receive that treatment.

### Best interests – some prompts

- **Don't discriminate:** you mustn't make unjustified judgements or discriminate on the basis of the person's age, diagnosis, appearance or behaviour;
- Take **everything relevant** into account
- Make sure you **follow all the steps set out in the MCA** and take into account all the factors that you are required to (including the person's wishes, feelings, beliefs and values and the views of those close to or caring for them); and
- Make sure that you can **justify the decision as being in the person's best interests.**

**Remember:** The decision needs to be based on the person's best interests – not on what you'd want if you were in their situation.



# Who is responsible for making decisions about capacity and best interests?



Generally, **the person who is responsible is the person who has to carry out the decision.** For example, if the decision is about whether the person needs medication, the decision-maker is the person who has to administer the medication. The MCA says that decision-makers are legally protected if they reasonably believe that:

- The person did not have capacity to make the decision and
- What they did was in the person's best interests.

However, the **MCA also enables proxy decision-makers to be appointed.** Whilst they have capacity, people can make a Lasting Power of Attorney, to give somebody else authority to make decisions on their behalf. Or the court can appoint somebody as a deputy to make decisions.

## Lasting Powers of Attorney

It has always been possible to give somebody else a power of attorney to make decisions on your behalf about your property and money. The MCA extended that, so that it is now possible to give someone a power of attorney to make decisions about your health and welfare as well. This includes decisions about your health and social care.

These are called **Lasting Powers of Attorney** (LPAs). They replace the old enduring powers of attorney ("EPAs") which only covered property and money although pre-existing EPAs can still be used.

Important points about LPAs include:

- There are **two types**: health and personal welfare, and property and financial affairs
- **You can appoint more than one person as an attorney**, and the same person can be an attorney on both types
- You can also appoint different people to make different decisions

- The people you appoint under an LPA **must make decisions in your best interests**. They must follow the same processes and take the same things into account as everybody else who has to make a best interests decision
- LPAs must be completed in a **standard form and registered** (for a fee) at the Office of the Public Guardian before they can be activated
- A health and welfare LPA will only be **activated if the person who made it does not have capacity to make a decision**
- People who have been given an LPA can **only make decisions about life-sustaining treatment if the person has given them express power** to do so
- You **need to be 18 or over** to appoint someone under an LPA

## Deputies appointed by the court



If the Court of Protection decides it is in the best interests of somebody with impaired capacity, it can appoint deputies to make proxy decisions on that person's behalf. The **deputies must be appointed with as limited authority and for as short a time as possible**.

## Independent Mental Capacity Advocates (IMCAs)

The MCA enables some people to have advocacy support in specific circumstances. This comes from Independent Mental Capacity Advocates – IMCAs. IMCAs **are advocates, not decision-makers**. Their role is to support the person lacking capacity and make sure that the decision taken is in their best interests. IMCAs are only required in some situations. They **must** be instructed where the decision:

- Involves a person with impaired capacity who has no family or friends it would be appropriate to consult, only paid carers; and
- Is being taken by an NHS body or a Local Authority; and
- Is about either the person's long-term place of residence or serious medical treatment.

IMCAs **can** also be consulted in relation to care reviews where there is nobody else to be consulted, or adult protection cases.

Health and care organisations should ensure that their staff know how to contact their local IMCA service.

## Advance decisions to refuse treatment

The MCA makes it possible for a person to refuse in advance a specified treatment, should they lose the capacity to make that decision themselves at some point in the future. This is called an advance decision to refuse treatment. In the past these have sometimes been referred to as “living wills” or “advance directives”, but the MCA does not use those terms and they have no legal meaning.

If all the requirements of the MCA are met, an **advance decision to refuse treatment will be legally binding** and must be respected in the same way that it would be if the person had capacity and was refusing that treatment.

Important points about advance decisions to refuse treatment include:

- People **need to be 18 or over** to make an advance decision
- The advance decision **will not be used if the person still has capacity** to make the decision
- The **treatment to be refused must be specified**
- It is possible to refuse a specific treatment in all circumstances. But if you want to refuse treatment in some circumstances but not others, you must **specify the circumstances in which you are refusing it**
- **All the circumstances you specify must exist** at the time the treatment decision needs to be made. If any are absent it will not be binding
- **Advance decisions refusing life-sustaining treatment** must be in writing, signed, witnessed and contain a statement that the decision is to apply even if your life is at risk as a result
- You **can revoke an advance decision at any time**. That can be done verbally or in writing. If you do it verbally it is good practice for that to be noted on your medical records as well as all copies of the advance decision

- **Clinicians must assess** any apparent advance decision to refuse treatment to make sure that it meets all the requirements of the MCA and is legally binding in the circumstances that exist at the time
- If an advance decision to refuse treatment is not legally binding, that does not mean it can be ignored. It is still **evidence of your past wishes** and should be taken into account when assessing your best interests

If you are considering making an advance decision to refuse treatment you would be well advised to discuss this with your doctor to make sure that you understand the pros and cons of your decision.

## Empowering you – how can you use the MCA to protect your wishes?

There are a number of things you can do if you want to express and protect your preferences and choices about your future care, in anticipation that a time may come when you lose capacity to make particular decisions for yourself:

- **Discuss what you would want** with your family, friends and carers
- **Write down your wishes and preferences** in a plan – and let people know where it is
- **Nominate people you would like to be consulted** about your best interests if possible – you can also identify anybody that you don't want to be consulted. This is best done in writing.
- **Make an advance decision** to refuse specified treatments
- Appoint somebody to make decisions for you, using a **Lasting Power of Attorney**

As part of good care, people approaching the end of their lives should be offered opportunities to think about their future care with their medical team and (if they want) the people who are important to them, and have their wishes and preferences recorded. This is sometimes called **advance care planning**. It should be a process, not a one-off discussion.

The MCA provides the legal framework that supports advance care planning so that your wishes are respected. It empowers you by making sure that your wishes will be taken into account when decisions about your best interests are being made. If somebody decides not to follow your wishes when making a best interests decision, they will need to be able to explain why. It means that you must be supported to make your own decisions wherever possible.

## Empowering you – what does the MCA mean if you are a carer?

- It provides a framework of **protected decision-making** for all professional and informal carers, so that you can make a decision on that person's behalf. As long as you can show that you had good reason to believe that the person did not have capacity to make a decision, and that you believed that your decision was in their best interests, you will be protected.
- If a decision is being made about a person who lacks capacity, and you are close to them, or have an interest in their care, **you must be consulted** about their best interests where possible
- If you think that decisions are being made about that person which aren't in their best interests, **you can challenge** that
- If the person chooses to do it whilst they have capacity, you can be given a **Lasting Power of Attorney** to make decisions on their behalf
- You can **apply to the court** to be appointed as a deputy





## What else do you need to know about the MCA?

There are two organisations which support the MCA and help you use it:

- **Office of the Public Guardian (OPG)**

The OPG supports the Public Guardian, whose role is to protect people who may lack mental capacity from abuse. It also maintains a register of LPAs and court appointed deputies, and is responsible for supervising deputies.

- **Court of Protection**

The Court of Protection has been set up to rule on disputes relating to the MCA. For example, it can make decisions about whether someone has capacity to make a decision, or about their best interests. It can appoint deputies to make decisions on people's behalf or give someone the authority to make a one-off decision.

### **Code of Practice**

The MCA is supported by a Code of Practice, which is available online. All paid carers, as well as proxy decision-makers and IMCAs are under a statutory duty to "have regard" to it when acting in relation to a person who lacks capacity. That does not mean that the Code must be rigidly adhered to. It does mean that anybody who decides not to follow its guidance will need to be able to explain why if challenged.

Unpaid informal carers are not under a statutory duty in relation to the Code of Practice. However, they would be well advised to consult it when they need to.

### **Criminal sanctions**

The MCA introduced 2 new criminal offences to protect people with impaired capacity: ill-treatment and wilful neglect.

### **Deprivation of Liberty Safeguards (DOLS) and end of life care**

The MCA contains rules called Deprivation of Liberty Safeguards ("DOLS") which are intended to give **additional protection to people in care homes and hospitals** who lack capacity to make a particular decision, and have also been deprived of their liberty.



In 2014 the Supreme Court ruled (in the “Cheshire West case”<sup>1</sup>) that someone is being deprived of their liberty if they are under continuous or complete supervision and control, are not free to leave, and cannot consent to those arrangements. This ruling has caused considerable uncertainty, and means that some people receiving what many would regard as standard end of life care might come under the DOLS regime. In a more recent case, on intensive care (“the Ferreira case”<sup>2</sup>), suggested that most people who are being given immediately necessary life-saving treatment should not be considered to be deprived of their liberty even if – because of their injuries or illness – they cannot consent to staying in hospital and being subjected to continuous supervision and control. The Ferreira case concerned treatment in an intensive care unit, and it is not entirely clear whether it also applies to palliative or hospice care settings. At the time of preparation of this guidance, permission to appeal the decision was being sought from the Supreme Court.

The **Department of Health** recognised the potential for unnecessary distress to be caused by the inappropriate handling of DOLS processes in palliative and end of life care situations, and published a **guidance note** dated 22 October 2015<sup>3</sup>.

In 2017 the Law Commission published recommendations to scrap DOLs and replace them with “Liberty Protection Safeguards”. It also recommended other changes to the MCA. However, the **existing rules will remain in place unless and until the government decides to change the law.**

**Organisations and staff responsible for the care of dying people should be clear about the appropriate application of DOLS**, and be able to explain this clearly to the families and friends of dying people. This will require keeping abreast of the current legal situation, including the possibility of further legislation, as well as sensitive and clear communication.

.....  
1 P v Cheshire West and Chester Council and another and P and Q v Surrey County Council

2 R(Ferreira) v HM Senior Coroner for Inner South London & Ors [2017] EWCA Civ 31

3 DH Note on DOLS 22 October 2015 [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/485122/DH\\_Consolidated\\_Guidance.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/485122/DH_Consolidated_Guidance.pdf)

## Where else to look for help?

### **Dying Matters**

Dying Matters is a coalition set up by the National Council for Palliative Care to raise public awareness and change behaviours in relation to dying, death and bereavement. Its website contains information, leaflets, and films to help people have conversations and plan ahead for the end of life.

### **Office of the Public Guardian and the Court of Protection**

Information can be found via [www.gov.uk](http://www.gov.uk). This includes information about how to make a Lasting Power of Attorney, as well as examples of what valid Lasting Powers of Attorney look like.

### **Social Care Institute for Excellence**

SCIE is an independent charity working to improve care and support. Its website has information and films about the MCA.

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## Dying Matters

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