How are decisions made for me if I don’t have capacity?

This factsheet explains who makes decisions about your treatment and care if you are unable to make decisions for yourself and have not planned ahead by making an Advance Decision or Lasting Power of Attorney. It is applicable to people living in England and Wales. If you live in Scotland or Northern Ireland, or if you would like further information about your end-of-life rights and choices call our free Information Line on 0800 999 2434

What is ‘capacity’?

Mental capacity is the ability to make decisions for yourself about a particular matter. Having ‘capacity’ means having the ability to understand and retain information relating to the decision, understanding the consequences of any choice you make, taking that information into account, and being able to communicate your wishes.

You might 'lack capacity' because, for example, you have:

- dementia
- a mental health problem
- a brain injury
- a learning disability
- had a stroke
- been given end-of-life sedation

You might lose capacity to make a decision for a short time (for instance, if you are knocked unconscious) or for the indefinite future (for instance, if you are in a persistent vegetative state).

Whether or not you have capacity is assessed on a decision-by-decision basis. For example, you might have capacity to decide whether you want to be cared for in hospital or at home, but not have capacity to decide whether you want to refuse life-sustaining treatment.

Who decides if I have capacity?

On a day-to-day basis anyone, such as a family member, might need to decide whether you have the capacity to make a decision for yourself and there is no formal process for doing this. For example if you have dementia your partner
might need to decide if you have the capacity to remember to make yourself breakfast. For more complex decisions, like those about your medical treatment or where you are cared for, a health or social care professional will assess if you have capacity.

**What are my rights if I don’t have capacity?**

If your ability to make decisions for yourself is called into question there is a law in place to ensure that your rights are protected and upheld. This law is called The Mental Capacity Act.

**The Mental Capacity Act 2005**

The Mental Capacity Act 2005 (MCA) was created to protect and promote the right of individuals to make their own decisions. The Act is based on the following five key principles, which should underpin health and care professionals’ approach to decision-making.

1. Every adult has the right to make decisions for themselves, and people must be assumed to have capacity until it is proven otherwise.
2. People should be given all possible help and support to make their own decisions before anyone concludes that they lack capacity. This includes supporting people to communicate in different ways, such as making noises, or blinking, if they cannot speak properly.
3. It is every adult’s right to make a decision that seems unwise or strange to someone else. If a person makes such a decision it does not necessarily mean that they lack capacity.
4. Any decision that is made on behalf of a person who lacks capacity must be made in that person’s best interests.
5. People who lack capacity should not have their basic rights and freedoms restricted unnecessarily. This means that whenever a decision is made on someone else’s behalf the person making the decision must consider if a different decision or action would interfere less with the person’s rights and freedoms.

So how are decisions made if I can’t decide for myself?

There are ways you can plan in advance to ensure your wishes for treatment and care are followed if you lose the capacity to make your own decisions. One way is to make an Advance Decision to Refuse Treatment (Advance Decision), another is to appoint someone you trust to make decisions on your behalf by making a Lasting Power of Attorney for Health and Welfare (LPA). For more information on this see our factsheets Understanding Advance Decisions – England and Wales and Understanding Lasting Powers of Attorney for Health and Welfare – England and Wales.

If you cannot make a decision about your medical treatment, care or welfare and you have not made an Advance Decision or a LPA, then a health or social care professional, such as a doctor or social worker, will make a decision on your behalf. They are bound by law to make a decision that is in your ‘best interests’.

How does someone decide what is in my best interests?

The MCA states that anyone who makes a decision on your behalf must act in your best interests. There is no single definition of what this means but in order to decide what action is in your best interests the MCA provides a list of things that must be considered when a decision is taken. This list dictates that, amongst other things, the decision-maker must:

- Consider all the relevant information.
- Consider your wishes and feelings (this includes anything you have said to other people and things you have written down).
- Consider any values and beliefs you have that would be relevant to the decision.
- Take into account the views of your family members, carers and other relevant people.
- Not be motivated to bring about death when making decisions about life-sustaining treatment.

If you do not have the capacity to make a decision about your medical treatment your doctor will decide what treatment to give you. They are legally and ethically obliged to base their decision on what they believe is in your best interests, but there is no guarantee that their decision will reflect what you would actually want.
Will my family be consulted about my medical treatment?

For medical treatment decisions your doctor should speak to your family members and others close to you, but he/she does not legally have to follow what they say. This means that if you have not made an Advance Decision or Lasting Power of Attorney, the doctor has the final say about what treatments you receive. Your loved ones can challenge the doctor’s decision in the Court of Protection, but this can be costly and time-consuming, and ultimately the final decision will then lie with the judge.

Court Appointed Deputies

If you lack capacity but have not previously appointed an LPA for Health and Welfare, and there are ongoing decisions that need to be made about your health or care, then someone close to you can apply to the Court of Protection to be appointed as your Deputy. This means that they will have the legal power to make decisions about certain aspects of your personal welfare.

Deputies must be over 18 and are usually a family member or friend. The person who wishes to become your Deputy has to make an application to the Court of Protection. If their application is successful the Court will issue a court order that gives them authority to act on your behalf and explains which decisions they are legally allowed to make.

It is worth noting, however, that welfare Deputies are appointed relatively rarely. This is because the Mental Capacity Act states that if a serious decision needs to be made about a person’s welfare, then a decision by the Court of Protection is preferable to appointing a Deputy.

The Court will limit the Deputy’s decision-making power to specific issues, depending on your needs and the circumstances of the case. This is because the Deputy is appointed after you lose capacity and you therefore haven’t chosen this person yourself. A Deputy can only make a decision that they are authorised by the Court of Protection to make. So, for example, they cannot make a decision about your treatment if the Court has only given them the power to make a decision about your care arrangements.

A Deputy must always make decisions in your best interests, and is bound by law to do so. They must also take all steps possible to help you make a decision for yourself if you can.

To apply to become a Court Appointed Deputy there is an initial fee of £400. The application is the first part of a longer process. Once the court order is
issued there are continuing tasks and responsibilities that the Deputy has to complete.

The Office of the Public Guardian will support and supervise decisions that the Deputy makes, and the Deputy will have to submit reports to them on any action or decision that is taken on your behalf. Further fees have to be paid to cover the cost of this supervision. They are as follows:

- £100 for the Deputy Assessment fee. This is paid once to the Office of the Public Guardian to determine the level of supervision needed.
- An annual supervision fee of either £35 or £320. The amount will depend on how closely the Deputy needs to be supervised.

It is always better to create an LPA before you lose capacity. This is because the process of applying to be a Deputy can be lengthy and costly. The Deputy has to report on all decisions they make, which they would not have to do as an Attorney. Also their decision-making power is limited to certain decisions, and deputies can never be given the power to refuse life-sustaining treatment on your behalf.

For more information on Court Appointed Deputies contact Compassion in Dying or the Court of Protection.

What if I do not have anyone close to me to be involved in decisions?

The Mental Capacity Act created the **Independent Mental Capacity Advocate (IMCA) Service** to represent people who are unable to make important decisions about their health or welfare and have no family or friends who can be involved in the decision-making process.

It is the responsibility of your local authority or NHS organisation to make sure that IMCAs are available to represent people who lack capacity. The person or team responsible for your care (such as your social worker or hospital doctor) has a legal duty to ‘instruct’ (refer you to) an IMCA if:

- a decision needs to be made about serious medical treatment provided by the NHS; or
- it is proposed that you have a long-term stay in a care home (for longer than eight weeks) or in hospital (for longer than 28 days); or
- it is proposed that you move to different accommodation on a long-term basis;

and
- you are over 16 years old and lack capacity; and
there is nobody, apart from paid staff or professionals, who is willing and able to be consulted about the decision.

‘Serious medical treatment’ means anything that involves:

- giving new treatment; or
- stopping existing treatment; or
- withholding a possible treatment;

and where:
- there is a fine line between the benefits and the risks of the proposed treatment(s); or
- what is proposed would be likely to involve serious consequences.

The only time when it is okay not to instruct an IMCA is if an urgent decision is needed, for example when deciding whether to give treatment to save a person’s life.

The role of an IMCA is to support and protect the rights of particularly vulnerable people who have nobody else to speak for them. An IMCA will not be the person that makes the final decision, but it is their job to gather and present any information that will help the decision-maker (for example your social worker or hospital doctor) to take action that is in your best interests.

They will try to find out what your wishes and feelings are, and ensure your values or beliefs are taken into account when a decision is made. They should ask questions on your behalf, ensure that your rights are upheld, and check that the decision-maker has acted appropriately. They can also challenge any decisions made which they feel are not in your best interests.

What is the Court of Protection?

The Court of Protection was set up to protect people who are unable to make decisions about their personal health, welfare or finance. The Court has the power to make decisions about a person’s personal welfare and can decide whether to provide, withdraw or withhold medical treatment from a person who lacks capacity. It can also appoint a Deputy to make decisions on behalf of another person.

Address: The Royal Courts of Justice, Thomas Moore Building, , London, WC2A 2LL
Phone: 0300 456 0300
Email: courtofprotectionenquiries@hmcts.gsi.gov.uk
Web: www.gov.uk/court-of-protection
What is the Office of the Public Guardian (OPG)?

The OPG is part of the Ministry of Justice and has responsibilities for England and Wales. It supports the Public Guardian in the registration of Lasting Powers of Attorney (LPA), and the supervision of deputies appointed by the Court of Protection. It also helps Attorneys and Deputies to carry out their duties, and protects people who lack capacity to make decisions for themselves.

**Address:** PO Box 15118, Birmingham, B16 6GX
**Phone:** 0300 456 0300
**Email:** customerservices@publicguardian.gsi.gov.uk

How can we help?

- Compassion in Dying can send you a free Advance Decision form
- We provide information and support to make an Advance Decision or Lasting Power of Attorney for Health and Welfare
- We provide a free and comprehensive guide to *Your Rights at the End of Life*
- The following Compassion in Dying factsheets may be helpful:
  - *Understanding Advance Decisions – England and Wales*
  - *Understanding Lasting Powers of Attorney for Health and Welfare – England and Wales*

If you would like any of the factsheets mentioned here or want information about end-of-life rights more generally please call our free **Information Line** on **0800 999 2434** or visit our website [www.compassionindying.org.uk](http://www.compassionindying.org.uk).