As their condition progresses, people with dementia may become unable to make some decisions for themselves. When this happens, the person is said to lack the ‘mental capacity’ to make the specific decision at that time.

The Mental Capacity Act is the law in England and Wales that protects and supports people who lack capacity to make a decision. It also outlines who can and should make decisions for them.

This factsheet explains what mental capacity is. It also explains the key principles or rules of the Mental Capacity Act. It looks at how the Act can be applied when people are planning for the future.

Northern Ireland has different laws around mental capacity. People who live in Northern Ireland can find relevant information in factsheet NI472, Enduring power of attorney and controllership.
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Mental Capacity Act 2005

The Mental Capacity Act covers important decision-making about a person’s property, financial affairs, and health and social care. It also covers everyday decision-making, such as decisions about what a person wears, what they eat and their personal care.

It does not cover decisions such as voting, making a will, marriage or divorce. For advice on these decisions, talk to a relevant professional or visit the government website (GOV.UK).

The Act can help people with dementia, their carers and professionals to make specific decisions and to plan for the future.

Decision-making and mental capacity

When a person has ‘mental capacity’ it means they are able to make a specific decision at a specific time. People who can’t do this are said to ‘lack capacity’ to make the specific decision. This might be due to an injury. Or they might have a learning disability, a mental illness, or a condition that affects their brain – such as dementia.

To have mental capacity a person must be able to:

- understand the information that is relevant to the decision they want to make
- keep the information in their mind long enough to make the decision
- weigh up the information that is available to make the decision
- communicate their decision in any way – including talking, using sign language, or through simple muscle movements such as blinking their eyes or squeezing someone’s hand.

When a person has dementia their mental capacity can change over time. It can also change in both the short term and the long term. For example, there might be days or even times of the day when the person can think more clearly. This means they may have capacity to make a decision at some times but lack capacity at other times.
A person may also have the capacity to make some decisions but not others. For example, a person may be able to decide that they want to go on holiday but not be able to make choices between transport or accommodation options. This is because some decisions involve having to take in more information, which may be harder for the person to process or understand. Some decisions, such as whether to move into a care home, also involve many factors to weigh up and this may also be harder for the person to consider. Therefore, you should not assume that a person lacks the mental capacity to choose simpler decisions such as what they want to wear or eat just because they can’t make difficult financial or medical decisions.

The principles of the Mental Capacity Act

The Mental Capacity Act is based on five key principles or rules which are mentioned throughout this factsheet. These are:

1. A person has the right to make decisions for themselves. You must assume that someone is able to make their own decisions, unless it is shown that they can’t do this.

2. A person should not be treated as being unable to make a decision unless they have been given all reasonable help and support to make and communicate their own decision.

3. A person should not be treated as being unable to make a decision just because other people think they have made a bad decision.

4. If a person lacks capacity, any decisions that other people make for them must be in the person’s best interests. (The Act includes a checklist that people must work through when they are deciding what is in the ‘best interests’ of someone who lacks capacity – see page 12.)

5. If a person lacks capacity, the people making the decision for them must consider the option that is the least restrictive to the person’s rights and freedoms.
Assessing capacity

You must always assume that a person is able to make a decision for themselves, until it is proved that they can’t.

A person’s capacity may be questioned if there is doubt about whether they can make a particular decision. This could happen if:

- the person’s behaviour or circumstances are making those around them doubt whether the person has capacity to make a particular decision
- a professional says they have doubts about the person’s ability to make the decision – this could be a social worker or the person’s GP
- the person has previously been unable to make a decision for themselves.

To work out whether a person has capacity to make a decision, the law says you must do a test (often called an assessment) to find out whether they have the ability to make the particular decision at the particular time.

Before the person is tested, they should be given as much help as possible to make the decision for themselves. Those who are supporting the person to make the decision should find the most helpful way to communicate with the person. This may mean trying to explain the information to them in a different way or helping them to understand the ideas that are involved in making the decision. It might help to break down information into small chunks. For more information about communication with a person with dementia see factsheet 500, Communicating.

Also note that not all decisions need to be made immediately. It is sometimes possible to delay a decision until a person has capacity to make it. However, this won’t be possible for every decision.
Who can assess capacity?
In general, whoever is with the person when a decision is being made will assess their capacity. However, this will differ depending on the decision that needs to be made – for example:

- Everyday decisions (such as what someone will eat or wear) – whoever is with them at the time can assess the person’s capacity to make the decision. This is likely to be the person’s family member, carer or care worker.

- More complicated decisions (such as where someone will live or decisions about treatment) – a professional will assess the person’s capacity to make the decision.

How is capacity assessed?
When a person has dementia, it’s likely that those around them will need to make this judgement more often as their condition progresses. The decision flowchart on page 7 shows the steps that someone should go through when they assess whether a person has capacity to make a decision. Family members or carers must believe that the person with dementia can’t make their own decision before taking action to make the decision for them.

If you need to decide whether a person has the mental capacity to make a specific decision, the decision flowchart will help. Also bear in mind that, in general, family members and carers know the person best. They can often tell when the person is or is not able to make a decision. Try to use your knowledge of the person to help you decide. You can also ask other people for advice – such as the person’s GP, community nurse or social worker.
Does the person have the mental capacity to make this decision?

Are you concerned that a person with dementia is unable to make a certain decision?

Yes

Can the person make the decision with help and support – for example, if they are given the right information, given more time, and communicated with appropriately?

No

Does the person meet all of the following requirements?

- They understand all the information they need to make the decision.
- They can keep the information in their mind for long enough to make the decision.
- They can weigh up the information that is available in order to make a decision.
- They can communicate the decision in some way – for example, squeezing someone’s hand or blinking their eyes.

No

For this decision, at this time, the person lacks capacity. This means they cannot make the decision for themselves and someone will need to make it for them. For decisions about everyday things such as food and clothes, this may be a carer or relative. For a more complex decision, for example about treatment, a health or social care professional may be involved.
Challenges to capacity assessments

The outcome of a capacity assessment is sometimes challenged. This can happen for the following reasons:

- If someone else feels that a person had the mental capacity to make a decision, but they were not allowed to do so.
- If someone feels the person did not have the capacity to make a decision, but they were allowed to make one.

The person can challenge a capacity assessment themselves, or it could be challenged by their family member, friend or even a professional.

If you want to challenge the outcome of a capacity assessment, start by speaking to the person who did the assessment. Ask why they made the decision they did and explain why you disagree with their assessment of the person's capacity. If this doesn’t help, you can ask for the decision to be reviewed, either by the person who first made the assessment or by the organisation involved. This may be social services or a hospital.

If you are still not satisfied, you can make a formal complaint. For example, if you disagree with a GP or a care home manager, the surgery or care home will have its own complaints procedure that you can follow. Ask them for information about how to make a complaint.

If you challenge a capacity assessment it could harm your relationship with the person who did the assessment. Therefore, before you challenge it, think about speaking to a local advice agency, a carers’ service or a solicitor. If you contact a solicitor make sure you ask them at the start of your conversation how much they will charge. You can also speak to Alzheimer’s Society by calling our support line on 0333 150 3456.

If someone challenges a capacity assessment that you have made, try to stay calm. Take your time to explain why you believe the person could or couldn’t make the decision for themselves. Carers and family members are not expected to write down each time they have to make a judgement about a person’s capacity and what their reasons were, especially when they are making decisions every day. However, if you are asked, you should be able to give examples to show why you made the decision.
This doesn’t happen often. Most family members and carers will never be challenged about the capacity assessments they make. But it is something you should think about when you are judging whether the person has capacity to make a decision. The law says you must have a ‘reasonable belief’ that the person lacks capacity, so you would need to show that you had this belief.

If you are assessing whether a person with dementia has capacity to make a major decision you might want to talk to a professional, such as a solicitor or a health or social care professional. Note that certain professionals may charge for advice. Major decisions could include the person wanting to make or change their will, or sell something they own (such as a property). It could also include decisions about their care and treatment.

**Making decisions**

If a capacity assessment shows that a person lacks the capacity to make a certain decision but the decision needs to be made at that time, it must be made for them.

**Who makes the decision?**

The type of decision that needs to be made will affect who should make the decision. If it is an everyday decision, it’s likely that someone who is there at the time can make the decision for the person with dementia. If it is a more complicated decision (particularly decisions about finances, care or treatment) you may have to speak to the person’s attorney or deputy (if they have one) or a professional who is involved in their care. For more information on these see ‘Lasting powers of attorney’ on page 13 and ‘If someone hasn’t planned ahead: Deputyship’ on page 15.

The following list has examples about who can make certain types of decisions for a person with dementia.

- Everyday decisions about washing, dressing, eating or activities – whoever is with the person at the time can make these decisions, such as a carer, family member or care worker.
Complicated decisions about finances or property – if the person has an attorney or deputy for property and financial affairs, they will make these decisions.

Decisions about where the person will live and receive care – if the person has an attorney or deputy for health and welfare, they can make the decision. If not, a professional such as a social worker or doctor will make the decision.

Decisions about life-sustaining treatment – if the person has appointed an attorney for health and welfare and given them this power, the attorney they may be able to make the decision. If the attorney can’t make the decision then it will be made by an appropriate doctor or consultant.

If there isn’t someone who knows the person with dementia well, the local authority (council) may appoint an independent mental capacity advocate (IMCA) to speak on the person’s behalf. This will happen when a major decision needs to be made, such as whether the person should move to a care home or have serious medical treatment. An IMCA is also sometimes involved if there is conflict between family members.

Making decisions in the person’s best interests

When a decision is made for a person who is not able to make that decision, it must always be made in the person’s ‘best interests’. This makes sure that the person’s rights are respected and that the decision is the best one for them.

A decision should never be made in the best interests of anyone other than the person themselves. For example, a decision should never be made to make things easier for a carer or professionals who are caring for the person.

A number of things should be considered for a decision to be made in a person’s best interests. These are listed in the best interests checklist on page 12.
Consultation rights and best interests decisions
The person has a right to be involved in decisions that are made about them (unless that’s inappropriate, for example if someone refuses to be consulted). This is very important. Just because someone can’t make the decision themselves, this does not mean that they won’t have preferences and feelings about what they would like to happen.

Family members, friends and carers also have a right to be consulted and involved in the decision, where appropriate. This is important and can be helpful because they often know the person best. They can say what they think is in the person’s best interests, as well as what the person’s preferences and views are.

There may be a ‘best interests meeting’ if the decision is more complicated, such as decisions about where the person will live. This isn’t always needed. However, when it is, a meeting can be a good way to consider all the different issues involved in the decision. This includes the views of the person and their family members. Sometimes family members or the person’s representatives will be invited to the best interests meeting. If family members disagree, the views from both sides of the argument should be taken into account.

At other times, family members won’t be invited to the best interests meeting. Often, the person themselves is not invited to attend. If the person and their family are not invited, their views should still be considered during the meeting. How this is done will depend on the situation – for example, they could offer their views in writing or through someone else, such as an IMCA. Or the person with dementia or their carer could meet with a professional before the meeting to share their views.
Best interests checklist

- Consider whether the person will have capacity later and whether the decision can be put off until then. This is crucial because a person with dementia may have good and bad days. They may be able to make the decision on another day.

- Encourage and support the person with dementia to take part in making the decision and to share their views, where possible.

- Consider the person’s past, present and future wishes and feelings.

- Take into account other people’s views, such as carers, friends, family members and any attorney or deputy the person may have.

- Note that decisions can’t simply be based on the person’s age, their behaviour or the fact that they have dementia (or any other condition).

- Take into account all the relevant circumstances when making a decision – for example, what things the person would have considered if they’d been able to make the decision themselves.

- If the decision involves life-sustaining treatment, there are other special issues that need to be considered. For example, checking whether the person has made an advance decision (see page 14), considering all the possible treatment options, and not being motivated by a desire to end a person’s life. If there is any doubt about the person’s best interests, the case should be referred to the Court of Protection for it to decide (see ‘Other useful organisations’ on page 16).
Planning ahead

The Mental Capacity Act created a number of ways for a person to plan ahead in case they can’t make decisions for themselves in the future. This means the person can make sure that what they want to happen will happen, even if they can’t decide or communicate their views in the future. Some ways that people can plan ahead are explained below. You don’t have to use any of these if you don’t want to.

Lasting powers of attorney

A Lasting power of attorney (LPA) enables a person to appoint someone they trust to make decisions for them in future if they can’t make a certain decision or decisions for themselves. The person (or people) they appoint will become their ‘attorney’. To make an LPA, a person needs to fill in a specific application form. This form needs to be signed and witnessed by various people before it is registered with the Office of the Public Guardian (see ‘Other useful organisations’ on page 16). An LPA must be registered before it can be used.

There are two types of LPA. They each relate to different decisions. A person can have both types of LPA, but to do this they will need to complete both forms. The two types of LPA are:

- LPA for property and financial affairs – this gives the attorney or attorneys the power to make decisions about things like selling the person’s house or managing their bank account.

- LPA for health and welfare – this gives the attorney or attorneys the power to make decisions about the person’s health and personal welfare, such as day-to-day care, medical treatment, or decisions about where they might live so that they can receive care and support, such as a care home.

For more information on how to make an LPA see factsheet 472, Lasting power of attorney.
You may also hear about Enduring power of attorney (EPA). These were used before LPAs were introduced under the Mental Capacity Act. If an EPA was made properly and signed before October 2007, it can still be registered and used. An EPA only allows the attorney to make decisions about a person’s finances and property. It does not cover health and welfare decisions.

If someone doesn’t have access to the internet or they don’t feel able to complete the LPA forms on a computer, Alzheimer’s Society offers a digital assistance service. Our trained volunteers can complete the forms for the person using the Office of the Public Guardian’s (OPG) online tool. For more information on this service call our support line on 0333 150 3456. The service doesn’t provide legal advice.

**Advance decisions**

The Mental Capacity Act also enables someone to create an advance decision to refuse treatment. This allows them to state the types of treatment they don’t want to have if they don’t have the mental capacity to decide this for themselves in the future. This may include refusing life-sustaining treatment.

A valid advance decision is legally binding. This means health professionals must follow it if the treatment and circumstances that are set out in the advance decision apply to the specific situation the person is in.

To be valid, an advance decision must be made in writing. It must also be signed and witnessed. It can help if the person has a conversation with their GP before they make an advance decision. This is to make sure that the advance decision covers what the person wants it to.

**Advance statements**

Another way that people can plan ahead is by creating an advance statement. This is where they can set out their wishes and preferences for the future, including both what they want and what they don’t want to happen. The statement could include their preferences about their care, where they will live, what they like or don’t like to eat, daytime activities they enjoy, and who they do and don’t want to visit them.
Advance statements can be made verbally or in writing. They are not legally binding. However, if someone is making a decision for a person who has made an advance statement, they must take the statement into account when they make the decision.

For more information about advance statements and advance decisions see booklet 1510, Planning ahead and factsheet 463, Advance decisions and advance statements.

If someone hasn’t planned ahead: Deputyship

If a person with dementia loses the ability to make some decisions and they haven’t made an LPA or EPA, it can become difficult for those who are trying to help them. This is especially true for financial decisions because only someone who has a legal power (such as an LPA, EPA or deputyship) can completely manage another person's finances. Therefore, if you are caring for a person who hasn’t made an LPA or EPA, you will need to apply to the Court of Protection to become their deputy in order to be able to manage their finances for them. Do note that it can take several months for this to be set up and the process is more expensive, with a higher cost for applying and ongoing fees after you’ve been appointed.

It is also possible to become a person's deputy for health and welfare decisions. You will need to show the court that the person needs to have a deputy. You can do this by showing that ongoing decisions need to be made about the person's welfare that only a deputy can make.

The court doesn’t appoint as many deputies for health and welfare. This is because professionals and family members can sometimes work together to make decisions in the person’s best interests so that deputyship is not needed.

For more information about deputyship and how to apply for it see factsheet 530, Deputyship.
Other useful organisations

Court of Protection
0300 456 4600
courtofprotectionenquiries@justice.gov.uk
www.gov.uk/court-of-protection

The Court of Protection helps people who have difficulty making their own decisions. It either makes a decision for the person or appoints someone else to do so.

Office of the Public Guardian
0300 456 0300 (customer services)
customerservices@publicguardian.gov.uk
www.gov.uk/opg

The Office of the Public Guardian supports and promotes decision-making for people in England and Wales who lack capacity or who would like to plan for their future within the framework of the Mental Capacity Act 2005. The Office of the Public Guardian has a range of useful information on the GOV.UK website, including the Mental Capacity Act Code of Practice.

Solicitors for the Elderly
0844 5676 173
admin@sfe.legal
https://sfe.legal

Solicitors for the Elderly is an independent, national organisation of lawyers who provide legal advice to older people. They can also help you to find a solicitor.
We are Alzheimer’s Society. We are a vital source of support and a powerful force for change for everyone affected by dementia. We provide help and hope.

For support and advice, call us on 0333 150 3456 or visit alzheimers.org.uk

People affected by dementia need our support more than ever. With your help we can continue to provide the vital services, information and advice they need.

To make a single or monthly donation, please call us on 0330 333 0804 or go to alzheimers.org.uk/donate