People with dementia often become unable to make some decisions for themselves as their condition progresses. When this happens, the person is said to ‘lack capacity’. The Mental Capacity Act is the law in England and Wales that protects and supports these people, and outlines who can and should make decisions on their behalf.

This factsheet explains what mental capacity is, outlines the key principles or rules of the Act, and looks at how it can be applied when planning for the future. Northern Ireland has different laws around mental capacity. For the relevant information for people in Northern Ireland see factsheet NI472, Enduring power of attorney and controllership.

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Mental Capacity Act 2005

The Mental Capacity Act covers important decision-making relating to an individual’s property, financial affairs, and health and social care. It also applies to everyday decisions, such as personal care, what to wear and what to eat. It can help people with dementia, their carers and professionals to make decisions, both now and in the future.

Decision-making and mental capacity

Mental capacity is the ability to make decisions for yourself. People who cannot do this are said to ‘lack capacity’. This might be due to injury, a learning disability, mental health problem or a condition such as dementia that may affect the way a person’s brain makes decisions.

To have capacity a person must be able to:

- understand the information that is relevant to the decision they want to make
- retain the information long enough to be able to make the decision
- weigh up the information available to make the decision
- communicate their decision by any possible means, including talking, using sign language, or through simple muscle movements such as blinking an eye or squeezing a hand.

It is important to be aware that the mental capacity of a person with dementia can change over time, both in the short and long term. As an example, there might be days or even times of the day when they are able to think more clearly than others, so a person may have capacity at some times and lack it at others.

A person may also have the capacity to make some decisions and not others, as some decisions require the person to understand more complex information, or weigh up more options, than others. You should not assume a person lacks capacity to choose what to wear or eat just because they cannot make difficult financial or medical decisions.
Issues around mental capacity can be complicated, however there is a very helpful, jargon-free Code of Practice available on the GOV.UK website that you might find useful.

The principles of the Mental Capacity Act

The Mental Capacity Act (MCA) is based on five key principles. These are mentioned throughout this factsheet, but are listed below for reference:

1. Every adult has the right to make decisions for themselves. It must be assumed that they are able to make their own decisions, unless it has been shown otherwise.

2. Every adult has the right to be supported to make their own decisions. All reasonable help and support should be given to assist a person to make their own decisions and communicate those decisions, before it can be assumed that they have lost capacity.

3. Every adult has the right to make decisions that may appear to be unwise or strange to others.

4. If a person lacks capacity, any decisions taken on their behalf must be in their best interests. (The act provides a checklist that all decision makers must work through when deciding what is in the best interests of the person who lacks capacity – see below.)

5. If a person lacks capacity, any decisions taken on their behalf must be the option least restrictive to their rights and freedoms.

Assessing capacity

It must always be assumed that everyone is able to make a decision for themselves, until it is proven that they cannot. The law says that the only way to establish this is to do a test or assessment to find out whether a person has the ability to make a particular decision at a particular time. It is important that before testing a person, they are given as much help as possible to make the decision for themselves. You might do this by trying to communicate the information in a different way, or helping them to understand the concepts involved.
This could include thinking about the forms of communication you use, breaking information down into small chunks, and thinking of different ways to describe things.

For more information about communication with a person with dementia see factsheet 500, Communicating.

It is also worth remembering that not all decisions have to be taken immediately. Sometimes, it may also be possible to put a decision off until the person has capacity to make it, however this will not be the case for every decision.

**Who can assess capacity?**

Generally, whoever is there when the decision is being made will assess the person’s capacity. However, this will vary depending on the decision that needs to be made:

- For everyday decisions, including what someone will eat or wear, whoever is there at the time can assess capacity, which is likely to be the person’s family, carer or care worker.

- For more complex decisions, such as where someone will live, or decisions about treatment, a professional will make the judgment – for example, a social worker or the person’s GP. This should be done in consultation with those closest to the person, such as their carer and relatives.

**How is capacity assessed?**

The decision flowchart below sets out the steps that someone should go through when assessing whether a person has capacity. It’s important that families or carers genuinely believe that the person with dementia cannot make a decision before taking action on their behalf.

The test of capacity outlined in this chart can be a very good guide to help people make this judgment. Generally, families and carers know the person best and so can often tell when the person is and is not able to make a decision. It is likely that they will have to make this judgment more as time goes on. If this is something you find yourself doing, there are ways to make this less daunting. Use the guidance, and use your knowledge of the person. You can seek advice from others, such as the GP, community nurse, or social worker, if you feel you need to.
Are you concerned that someone with dementia is unable to make a certain decision for themselves?

No

Yes

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

No

Yes

Let the person make their own decision

Check: does the person meet all of the following criteria?

- They understand all the information needed to make the decision.
- They can retain the information for long enough to make the decision.
- They can weigh up the information available in order to make a decision.
- They can communicate the decision by some means – for example, squeezing a hand, blinking an eye.

No

Yes

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

Sometimes the outcome of a capacity assessment will be challenged. This can happen if someone feels the person had the capacity to make a decision themselves but was not allowed to, or did not have the capacity to make a decision but was allowed to. It may be the person themselves that challenges this, a relative or friend, or even a professional.

If you wish to challenge the outcome of a capacity assessment, it is best to start by speaking to the person that carried out the assessment. Ask them for their reasons and explain why you disagree. If this does not help, you can ask for the decision to be reviewed, either by the person that made the initial assessment, or by the organisation or body involved – for example, social services or a hospital. If you are still dissatisfied, you could put in a formal complaint. For example, if it is a GP or a care home manager that you disagree with, the surgery or care home will have its own complaints procedure that you can follow.

You may want to seek help before challenging a capacity assessment, as there is a risk of damaging a relationship. You may want to talk with a local advice agency, Alzheimer’s Society, a carers’ service or a solicitor.

If you find yourself challenged over a capacity assessment, stay calm and focused on your reasons. Take your time to explain your reasons for believing that the person could or could not make the decision for themselves. Carers and families are not expected to keep notes of each time they have had to make a judgment about a person’s capacity and what their reasons were, especially when making decisions they make every day. Instead, if asked you should be able to outline examples showing why you came to your conclusion. This doesn’t happen often, and most families and carers will never be challenged about the assessments they make, but it is something to consider when making these judgments. If it is a major decision that is being considered, you might want to talk to a solicitor – for example, if the person with dementia wants to make or change a will, or dispose of some of their assets.
Making decisions

If a capacity assessment has been carried out and it has been decided that the person lacks the capacity to make a certain decision, it must be made for them, if the decision needs to be made at that time. Who makes the decision will depend upon the circumstances, and there are a number of things that any decision maker must consider.

Who makes the decision?

The person who makes the decision will depend upon the type of decision that needs to be made. If it is an everyday decision, it is likely that the person there at the time can make it on behalf of the person with dementia. If it is more complex, particularly decisions about finances, care or treatment, you may have to consult with either the person’s attorney or deputy (if they have one) or a professional involved in their care.

- Everyday decisions about washing, dressing, eating or activities – whoever is with the person at the time can make these decisions, eg the carer, family or care worker.
- Decisions about the person’s finances or property – their attorney or deputy for property and financial affairs will make these decisions. For more information see ‘Lasting power of attorney’ and ‘When someone hasn’t planned ahead: Deputyship’, below.
- Decisions about where the person will live and receive care – if they have 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 relating to life-sustaining treatment – if the person appointed an attorney for health and welfare and gave them this power then they may be able to make the decision, if not then it will be an appropriate doctor or consultant.

If there isn’t someone who knows the person with dementia well, then the local authority (council) may appoint an independent mental capacity advocate (IMCA) to speak on behalf of the person with dementia. This happens when major decisions are being considered, such as moving to a care home or whether to have serious medical treatment. Sometimes, an
IMCA may also be asked to be involved if there is conflict between family members.

**Making decisions in the person’s best interests**

When a decision is made on behalf of a person who lacks the ability to make it themselves, it must always be made in the person’s best interests. This ensures that:

- their rights are respected, and
- the decision is the best one for them.

It should never be made in the best interests of the person making the decision. For example, it should never be made to make things easier for the carer or professionals involved.

In doing this, there are a number of things that should be considered. The best interests checklist opposite outlines these.

For practical information about making decisions and taking action on behalf of a person who lacks capacity see factsheet 484, *Making decisions and managing difficult situations*. This factsheet looks at various common situations and how decisions can be made.

**Consultation rights and best interest decisions**

The best interests checklist shows the rights that the person and those close to them have in decision-making:

- When appropriate, the person has a right to be involved in decisions made about them. This is crucial as just because someone cannot make the decision themselves, this does not mean that they don’t still have preferences and feelings about what they would like.
- Family, friends, and carers also have a right to be consulted and involved in the decision, where appropriate. This is vital as they often know the person best and can share what they feel is in the person’s best interests, as well as what the person’s preferences and views are.
Sometimes, especially when making more complex decisions such as where someone will live, there may be a ‘best interests meeting’. This isn’t always necessary, but when it is it can be a very good way of considering all the different factors involved in the decision, including the views of the person and their family. Sometimes family or representatives of the person will be invited, but at other times they won’t. Where they aren’t, their views should still be considered in the meeting. How this is done is dependent on the situation – for example, views could be submitted in writing, or via someone else such as an IMCA. Alternatively, the person or their carer could meet with a professional before the meeting is held to share their views.

**Best interests checklist**

- Decisions cannot simply be based on the person’s age, dementia or other condition, or their behaviour.
- All the relevant circumstances should be taken into account when making a decision. For example, looking at what the person would have considered if they were able to make the decision themselves.
- The person with dementia should be encouraged and enabled to take part in the decision and share their views, where possible.
- It should be considered whether the person will regain capacity later, and if the decision can be put off until then. This is crucial as a person with dementia may have good and bad days and they may be able to make the decision on another day.
- The person’s past, present and future wishes and feelings should be taken into account.
- The views of other people, such as carers, friends, family and any attorney or deputy, should be taken into account.
- If the decision involves life-sustaining treatment, there are other special considerations to take into account. For example, checking whether there is an advance decision (see ‘Advance decisions’ below), considering all the treatment options available and not being motivated by a desire to end a person’s life. If there is any doubt over the person’s best interests, the case should be referred to the Court of Protection for it to decide.
Planning ahead

The Act created a number of ways that someone can plan for their future in case they cannot make decisions for themselves. This is empowering as it means that someone can ensure that what they want to happen will still happen, even when they cannot decide or communicate these views. 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 someone to choose who they would wish to make decisions for them in future, if they become unable to make decisions themselves. The person or persons they appoint will then become their ‘attorney’. To make an LPA, someone needs to complete a specific application form and this needs to be signed and witnessed by various people before being registered with the Office of the Public Guardian (see ‘Other useful organisations’ below). It must be registered before it can be used.

There are two different types of LPA, each relating to different decisions. Someone can have both types, but will need to complete both sets of forms. The two types are:

- LPA for property and financial affairs – this gives the attorney or attorneys the power to make decisions about the person’s financial and property matters, such as selling a house or managing a 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 where they should live. One of its most important uses is around making the decision to move to a care home or to a new care home.

For more information on how to make an LPA see factsheet 472, Lasting power of attorney.

You may also come across, or have made, an Enduring power of attorney (EPA). This was the previous system, before LPAs were introduced under the Mental Capacity Act. As long as they were made properly and signed before October 2007, they can still be registered and used. However, an
EPA only enables the attorney to make decisions about a person’s finances and property. It does not cover health and welfare decisions.

**Advance decisions**
The MCA also enables someone to create an advance decision to refuse treatment. This allows someone to state the types of treatment that they do not want, should they lack the mental capacity to decide this for themselves in the future. This may include refusal of life-sustaining treatment. Valid advance decisions are legally binding and must be followed by health professionals, provided the treatment and circumstances set out by the advance decision apply to the situation in question.

To be valid, an advance decision must be made in writing, and must be signed and witnessed. The document contains a several pieces of information, and it can help to have a conversation with the GP before making an advance decision, in order to ensure that it covers what the person wants it to.

For more information about advance decisions, as well as a template advance decision form, see factsheet 463, *Advance decisions and advance statements*.

**Advance statements**
Another way someone can plan for their future is by creating an advance statement. This is where they set out their wishes and preferences, including preferences about care, where they will live, what they like to eat or dislike, and even daytime activities and who they do and don’t wish to visit them.

Advance statements can either be made in writing or verbally. They are not legally binding, but must be taken into account when decisions are made on behalf of a person who cannot make the decisions for themselves. They are a good way of enabling someone to express their wishes for the future, including both what they do and don’t want.

For more information about advance statements see factsheet 463, *Advance decisions and advance statements*. 
When someone hasn’t planned ahead: Deputyship

Not everyone will have created an LPA. If someone with dementia loses the ability to make some decisions without having made an LPA or EPA, it can become difficult for those trying to help. This is especially true for financial decisions, as only someone with a legal power (eg LPA, EPA or deputyship) can completely manage another person’s finances. Therefore, if someone 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 that person’s finances on their behalf.

It is also possible to become a person’s deputy for health and welfare decisions. You will need to show the court that deputyship is needed, by demonstrating that there is a need for continuous welfare decisions to be made that only the deputy can make.

Sometimes, instead of applying to become the person’s deputy, professionals and family members can work together to make decisions in the person’s best interests, and so deputyship is not needed.

For more information about deputyship and how to apply see factsheet 530, Becoming a deputy for a person with dementia.

Other useful organisations

Court of Protection
First Avenue House
42–49 High Holborn
London WC1A 9JA

0300 456 4600
020 7664 7755 (Textphone)
www.gov.uk/court-of-protection

The Court of Protection helps people who have difficulty making their own decisions by making the decisions for the person or appointing someone else to do so.
Office of the Public Guardian
PO Box 16185
Birmingham B2 2WH

0300 456 0300 (customer services)
customerservices@publicguardian.gsi.gov.uk
www.gov.uk/opg

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

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Factsheet 460LP
Last updated: October 2015
Next review due: October 2018
Reviewed by: Jill Manthorpe, Professor of Social Work, King’s College, London; Director, Solicitors For the Elderly and Karon Walton, Tollers LLP
This factsheet has also been reviewed by people affected by dementia.
A list of sources is available on request.

Alzheimer’s Society National Dementia Helpline
England, Wales and Northern Ireland:
0300 222 1122
9am–8pm Monday–Wednesday
9am–5pm Thursday–Friday
10am–4pm Saturday–Sunday

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