



DementiaUK
Helping families face dementia

Capacity and decision-making



Dementia is a progressive condition which can affect a person's ability to make decisions. As dementia progresses, the person with the diagnosis might need family, friends or professionals to help them make decisions about their health, care, finances and living arrangements.

What is capacity?

Capacity is a legal term that refers to whether someone is able to make informed decisions. To have capacity, a person must be able to:

- understand the information relevant to the decision they are making
- retain that information for long enough to make the decision
- weigh up the information as part of their decision-making process
- communicate their decision to others. This doesn't have to be verbal – for example, nodding, blinking or hand gestures may all count

For a person with dementia, there may come a time when they no longer have the capacity to make informed decisions concerning

their health, care or finances. In this situation, family members, friends or professionals such as a doctor or social worker may need to make decisions for them.

If you are considering whether someone has capacity, you must always start with the assumption that they do. Bear in mind that capacity can change or fluctuate – for example, a person might lose capacity due to a period of illness but regain it once they have recovered.

Sometimes, a person with dementia may make decisions that you consider unwise or that you don't agree with, but this does not necessarily mean they lack capacity.

They may also have capacity to make some decisions – such as what to buy from the shops – but not others.

Who decides whether a person has capacity?

If you care for someone with dementia, you might have an opinion about whether they are able to make informed and safe decisions, but this is not a legal



assessment of capacity under the Mental Health Act 2005.

The Mental Health Act Code of Practice says that as a family carer, you can assess whether someone has capacity, but you must have ‘reasonable belief’ that the person lacks capacity and be able to describe your objective reasons for making that decision to the person themselves, family members or friends, and any professional or legal representative who queries it.

It is essential that you follow the Mental Capacity Act Code of Practice when making your assessment: see [gov.uk/government/publications/mental-capacity-act-code-of-practice](https://www.gov.uk/government/publications/mental-capacity-act-code-of-practice)

If you are in any doubt about a person’s capacity, it is strongly recommended that you ask a professional to carry out a Mental Capacity Assessment (MCA). This could be a GP or social worker in the case of decisions about health or care, for example, or a solicitor if there are legal or financial decisions to be made.

The MCA is a formal legal assessment based on the Mental Capacity Act 2005. It is particularly important to have a formal MCA if there are big decisions to be made – for example, whether the person should move into a care home or sell their own home.

What is a Mental Capacity Assessment (MCA)?

The person carrying out the assessment must follow the Mental Capacity Act Code of Practice.

There are five ‘statutory principles’:

- The person must be assumed to have capacity unless it is established that they do not have capacity
- The person must not be treated as unable to make a decision unless all practicable steps to help them do so have been taken without success
- The person is not to be treated as unable to make a decision simply because they make an unwise decision
- Any decision made for a person who lacks capacity must be in their best interests
- The decision must be made in the way that is least restrictive of the person’s rights and freedom

In an MCA assessment, the professional must consider two questions:

1. Does the person have an

impairment of, or a disturbance in the functioning of, their mind or brain?

2. Does that impairment or disturbance mean they are unable to make the specific decision in question?

If possible, the person’s capacity should be assessed over a series of meetings and at different times of day, as their ability to make decisions may vary depending on how physically and mentally tired they are.

It is important to note that an MCA only extends to the particular decision being made at that time – for instance, whether the person has the capacity to make a decision about receiving a medical treatment. If further decisions have to be made, a separate capacity assessment will need to be carried out for each.

If a professional, rather than a family member, friend or carer, makes the decision about a person’s capacity, they should record the details of the assessment in the person’s medical notes.



Planning for the future

There are two types of important document that can help with planning for a time when the person with dementia lacks capacity.

An Advance Care Plan (ACP) is a document in which the person sets out their wishes for their future medical and personal care, including long-term care like moving into a nursing home. It is

not legally binding but will help the people involved in the person's care to make decisions in their best interests.

Lasting power of attorney (LPA) is a legal process where the person appoints someone to be their 'attorney' and make decisions on their behalf, representing what their wishes would be.



There are two types of LPA:

- health and welfare
- property and financial affairs

The attorney may use the property and affairs LPA while the person with dementia still has capacity, with their agreement, but the health and welfare LPA can only be used when the person lacks capacity, and a formal assessment should be carried out first.

See Sources of support on p11 for information on ACP and LPA.

A person with dementia can only establish an ACP and LPA if they have capacity and the ability to make an informed decision about the contents of these documents, so it's important that they do this as soon as possible after their diagnosis.

This will make the process of organising suitable care and managing the person's finances less complicated and ensure their wishes are taken into consideration in any decisions that need to be made.

Who should make decisions for a person who lacks capacity?

When a person with dementia lacks capacity to make decisions, these decisions should be made in their best interests, through discussion with close family members and, where relevant, a trained health or social care professional who is involved in the person's care – for example, a social worker, GP or nurse.

Family and friends can only legally make decisions if they have been nominated as attorney for the person who has lost capacity, using an LPA.

Some decisions, such as selling the person's home or moving into residential care, can be very difficult to make and may cause disagreements with the person with dementia and/or between family members.

The best outcome is where everyone involved comes to a consensus about the best interests of the person with dementia. Where there is a lack of agreement or a dispute, the person can access

an Independent Mental Capacity Advocate (IMCA) to support them to communicate what they want to happen – see Sources of support on p11 for contact details.

Making a 'Best Interests decision'

When a person with dementia can no longer make informed decisions for themselves, their family and health and social care staff may have to make a 'Best Interests decision'.

A Best Interests meeting should be arranged to decide what is in the best interests of the person with dementia. This meeting should include the person with the diagnosis (where appropriate), their family, health and social care staff and any other person who is actively involved with supporting them.

Attempts should be made to involve the person with dementia as much as possible, and to find out their wishes and views regarding the decision to be made. The person's culture and beliefs should be taken into consideration in the decision-making process. If the

person has an LPA and/or ACP, these should be taken into account during the meeting and reflected in any decisions made.

Decisions made in the person's best interests should be the least restrictive option possible. For example, if the person wishes to go out regularly for walks but they are vulnerable and their safety would be at risk, the Best Interests decision would be to arrange for them to be accompanied on their walks, rather than deciding they cannot go out.

Deprivation of Liberty Safeguards (DoLS)

Deprivation of liberty refers to a person having their freedom restricted and being under continual supervision and control – for example, when they are in hospital or a care home.

Deprivation of Liberty Safeguards (DoLS) are an extension of the Mental Capacity Assessment and are designed to ensure that the restrictions in place to keep the person safe are appropriate and proportionate.

The local authority manages DoLS assessments and the individuals and organisations who carry them out.

It is only legal to deprive an individual of their liberty by placement in a care home or hospital if:

- it is in the person's best interests and necessary to protect them from harm
- there are no other alternative, less restrictive care options

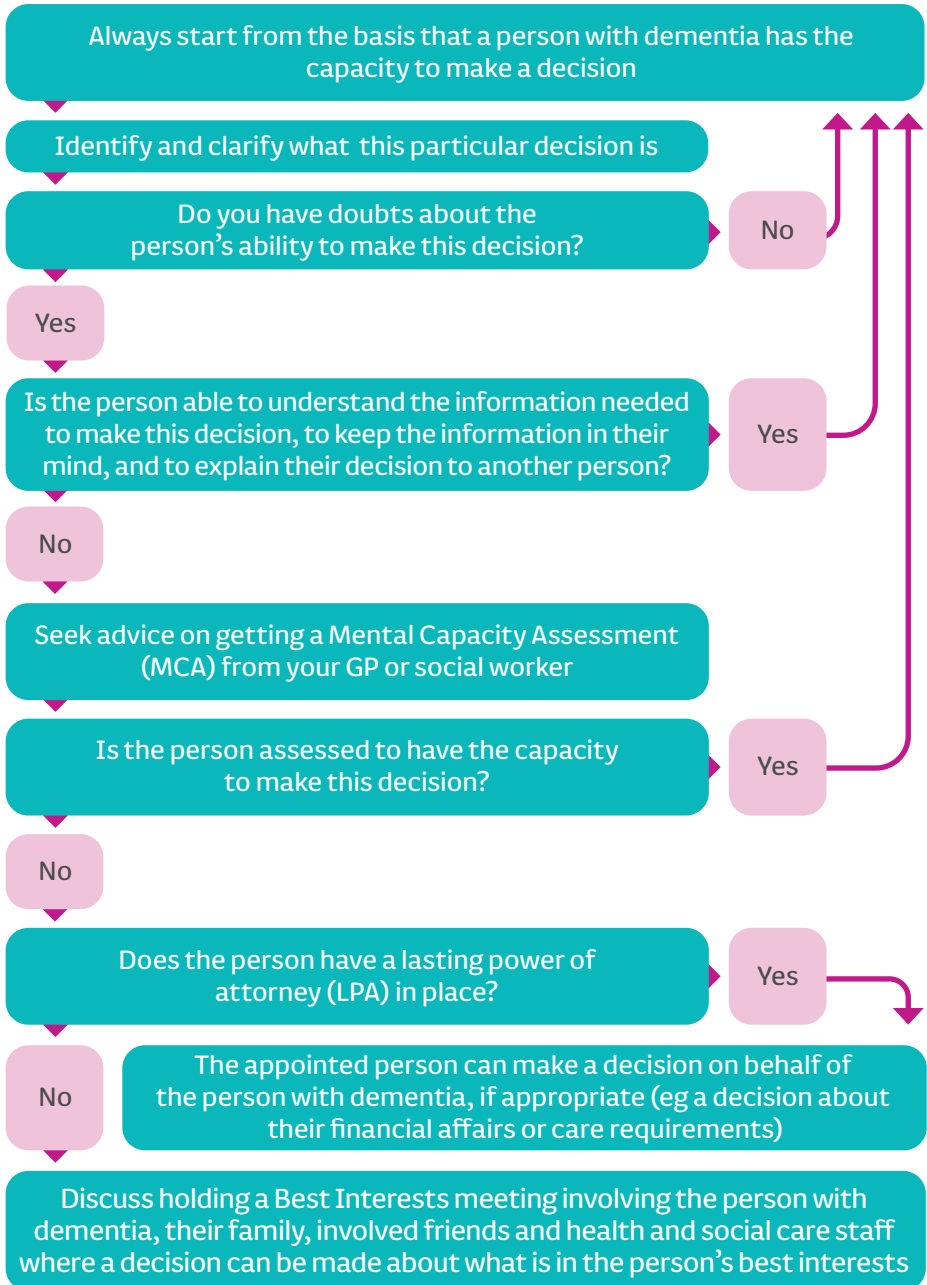
Before someone is deprived of liberty, a Mental Health Assessor needs to check whether the person lacks capacity. A Best Interests Assessor (usually a social worker, nurse, psychologist or occupational therapist) will then discuss with the Mental Health Assessor whether deprivation of liberty is in the person's best interests, and if so, grant authorisation.

The outcome can be challenged by anyone who feels that the wrong decision has been made.

For more information on DoLS see Sources of support on p11.



Assessing capacity flowchart



Sources of support

To speak to a dementia specialist Admiral Nurse about capacity and decision-making or any other aspect of dementia, please call our free Helpline on **0800 888 6678** (Monday–Friday 9am–9pm, Saturday and Sunday 9am–5pm) or email helpline@dementiauk.org

If you would prefer to book a phone or video call appointment with an Admiral Nurse, please visit dementiauk.org/closer-to-home

Dementia UK information

Advance Care Planning
dementiauk.org/advance-care-planning

Lasting power of attorney
dementiauk.org/lasting-power-of-attorney

Delirium (confusion)
dementiauk.org/delirium

Other resources

NHS information on the Mental Capacity Act
nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act

Making decisions: who decides when you can't?
gov.uk/government/publications/making-decisions-who-decides-when-you-cant

Independent Mental Capacity Advocates
gov.uk/government/publications/independent-mental-capacity-advocates

Mental Capacity Act Code of Practice
legislation.gov.uk/ukpga/2005/9/pdfs/ukpgacop_20050009_en.pdf

Deprivation of Liberty Safeguards (DoLS) at a glance
scie.org.uk/mca/dols/at-a-glance

The information in this booklet is written and reviewed by dementia specialist Admiral Nurses.

We are always looking to improve our resources, to provide the most relevant support for families living with dementia. If you have feedback about any of our leaflets, please email feedback@dementiauk.org

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For more information on how to support Dementia UK, please visit dementiauk.org/donate or call **0300 365 5500**.
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If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call **0800 888 6678** or email helpline@dementiauk.org

Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm



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