

Mental capacity and decision-making



2 Dementia UK

Dementia is a progressive condition, and it is likely that over time, a person with the condition will lose the mental capacity to make decisions about their health, care, finances and living arrangements, and will need family, friends or professionals to help.

Capacity is a legal term that refers to whether someone is capable of making 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 it up as part of their decision-making process
- communicate their decision to others – this does not have to be verbal; for example, nodding, blinking or hand gestures may all count

People with dementia often reach a point where they can no longer do these things, and therefore do not have the capacity to make informed decisions about their health, care or finances. In this situation, family members, friends or professionals such as a doctor, social worker or solicitor 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. Sometimes, a person with dementia may make decisions that you consider unwise or that you do not agree with, but this does not necessarily mean they lack capacity.

Bear in mind that capacity can change or fluctuate – for example, a person might lose capacity due to a period of illness like delirium (sudden, intense confusion) but regain it once they have recovered.



They may also have capacity to make some decisions (such as what to buy from the shops) but not others (such as whether they need professional care at home).

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 Capacity Act 2005.

The Mental Capacity 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 objectively describe your reasons to the person themselves, family members or friends, and any professional or legal representative who queries it.

4 Dementia UK

It is essential that you follow the Mental Capacity Act Code of Practice when making your assessment, which says:

- 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

For more information on the Mental Capacity Act 2005, please see Sources of support on p11.

What is a mental capacity assessment?

A mental capacity assessment (MCA) is a formal legal assessment based on the Mental Capacity Act 2005. It is particularly important to carry out an MCA if there are major decisions to be made – for example, whether the person should move into a care home or sell their own home.

If you are in any doubt about a person's capacity, it is strongly recommended that you ask a professional to carry out an MCA. For example, this could be a GP or social worker for decisions about health or care; or a solicitor for legal or financial decisions.

In an MCA, the professional must consider two questions:

1. Does the person have an impairment or 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?

It is important to note that an MCA only covers the particular decision being made at that time – for instance, whether the person should receive an immediate medical treatment. If further decisions have to be made, there should be a separate MCA for each.

If a professional, rather than a family member, friend or carer, makes the decision about a person's capacity, they should keep a written record of the assessment and outcome, for example in their medical notes.

Planning for the future

When a person is diagnosed with dementia, they should be encouraged to start thinking about their future plans as soon as possible, while they still have capacity.

If the person has only recently been diagnosed, or if they have young onset dementia (where symptoms develop before the age of 65), there may not seem to be much urgency to make formal plans for their future. But it is impossible to predict how quickly dementia will progress, so it is important that they do this as soon as possible. This will make the process of managing their care and finances less complicated and ensure their wishes are considered in any decisions that need to be made.

There are certain 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 setting out the person's

6 Dementia UK

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.

An advance decision, also known as an advance decision to refuse treatment (ADRT) or a living Will, is where a person decides to refuse certain medical treatments in the future if they cannot communicate their wishes at that time. It includes life-sustaining treatment like CPR, ventilation and antibiotics. If this is drawn up correctly and properly witnessed, it is legally binding. Please see Sources of support on p11 for more information.

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

Without an LPA, you may not legally be allowed to make decisions on the person's behalf – even if you are their next of kin. You may have to apply to the Court of Protection to become the person's 'deputy', which can be a complicated process.

Please see Sources of support on p10 for information on ACP and LPA.

A Will is important for everyone to ensure their money and other assets like property are left to the people and causes of their choosing after their death. Dementia UK has free Will-writing offers



for anyone wishing to make or amend a Will – please see Sources of support on p10.

If the person with dementia does not have a Will and has lost capacity to make one, or if changes need to be made to their current Will, someone else can do this on their behalf – but only if the person is unable to understand:

- what making or changing a Will means
- how much money they have and what property they own
- how making or changing a Will might affect the people they know – those who are named in the Will, and those who are not

To make or amend a Will for a person with dementia you will need to apply to the Court of Protection. This can be difficult and time-consuming; you will have to fill in a set of forms and provide a

number of supporting documents, such as records of their finances and a family tree. You may be required to attend a court hearing. For more information, please see Sources of support on p11.

Who should make decisions for a person who lacks capacity?

Any decisions on behalf of a person with dementia who lacks capacity must be made in their best interests, through discussion with close family members and, where relevant, a 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 in the person's LPA.

Some decisions, such as selling the person's home or moving into residential care, can be very difficult 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.

Making a 'best interests decision'

When a person with dementia can no longer make informed decisions, other people may have to make a 'best interests decision' on their behalf. A best interests meeting should be arranged to decide what would be best for the person with dementia. This should include their family, health and social care professionals and anyone else who is actively involved with supporting them.

Every attempt should be made to involve the person with dementia, and to find out their wishes regarding the decision. Their culture and beliefs should be respected in the decision-making process. If the

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

Best interests decisions should always be the least restrictive option possible. For example, if the person wishes to go out regularly for walks but they are vulnerable and would be at risk, the least restrictive option would be for someone to accompany them, rather than deciding they cannot go out at all.

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 in hospital or a care home. Deprivation of Liberty Safeguards (DoLS) are an extension of the Mental Capacity Act and are designed to ensure that the restrictions in place to keep the person safe are appropriate and proportionate. DoLS assessments are managed by the local authority.

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. They and a best interests assessor (usually a social worker, nurse, psychologist or occupational therapist) will then discuss 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.

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 Helpline on **0800 888 6678** (Monday to Friday 9am-9pm, Saturday and Sunday 9am-5pm) or email [▶ helpline@dementiauk.org](mailto:helpline@dementiauk.org)

To book a phone or video call appointment with an Admiral Nurse, please visit [▶ dementiauk.org/book](https://dementiauk.org/book)

Dementia UK resources

Advance Care Planning

[▶ dementiauk.org/advance-care-planning](https://dementiauk.org/advance-care-planning)

Delirium (sudden confusion)

[▶ dementiauk.org/delirium](https://dementiauk.org/delirium)

Dementia UK free Will offers

[▶ dementiauk.org/write-or-update-your-will-for-free](https://dementiauk.org/write-or-update-your-will-for-free)

Lasting power of attorney

[▶ dementiauk.org/lasting-power-of-attorney](https://dementiauk.org/lasting-power-of-attorney)

Other resources

Advance decisions

➤ [nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment/](https://www.nhs.uk/conditions/end-of-life-care/planning-ahead/advance-decision-to-refuse-treatment/)

Deprivation of Liberty Safeguards (DoLS) at a glance

➤ scie.org.uk/mca/dols/at-a-glance

Deputies: make decisions for someone who lacks capacity

➤ [gov.uk/become-deputy/apply-personal-welfare-deputy](https://www.gov.uk/become-deputy/apply-personal-welfare-deputy)

Independent mental capacity advocates

➤ [gov.uk/government/publications/independent-mental-capacity-advocates](https://www.gov.uk/government/publications/independent-mental-capacity-advocates)

Making decisions: who decides when you can't?

➤ [gov.uk/government/publications/making-decisions-who-decides-when-you-cant](https://www.gov.uk/government/publications/making-decisions-who-decides-when-you-cant)

Making a statutory Will on behalf of someone else

➤ [gov.uk/apply-statutory-will](https://www.gov.uk/apply-statutory-will)

Mental Capacity Act Code of Practice

➤ legislation.gov.uk/ukpga/2005/9/pdfs/ukpgacop_20050009_en.pdf

NHS: the Mental Capacity Act

➤ [nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act](https://www.nhs.uk/conditions/social-care-and-support-guide/making-decisions-for-someone-else/mental-capacity-act)

**To speak to a dementia specialist Admiral Nurse
about any aspect of dementia:**

Contact our Helpline:
0800 888 6678 or [👉 helpline@dementiauk.org](mailto:helpline@dementiauk.org)

Book a virtual appointment:
[👉 dementiauk.org/book](https://dementiauk.org/book)

**Our charity relies entirely on donations to fund our
life-changing work. If you would like to donate to help us
support more families:**

- Call **0300 365 5500**
- Visit [👉 dementiauk.org/donate](https://dementiauk.org/donate)
- Scan the QR code

Thank you.



DementiaUK
Helping families face dementia



dementiauk.org • info@dementiauk.org

Publication date: March 2024. Review date: March 2026. © Dementia UK 2024

Dementia UK, 7th Floor, One Aldgate, London EC3N 1RE
Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC 047429).