Dementia UK
Helping families face dementia

Mental capacity and decision-making

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, finances and living arrangements. In this situation, family members, friends or professionals such as a doctor, social worker or solicitor may need to make decisions for them.

Assessing mental capacity

Under the Mental Capacity Act 2005, anyone involved in caring for a person with dementia can make an assessment of their capacity. In many cases, a family member can do this, especially for smaller, everyday decisions.

As a carer, you may naturally make decisions on behalf of the person with dementia many times a day – for example, when shopping for their groceries, planning daily activities or booking a doctor's appointment. When you are making routine decisions like these, you should follow the key principles of the Mental Capacity Act Code of Practice:

- The person must be assumed to have capacity unless it is established that they lack 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 act or decision made must be in the person's best interests
- The decision must be made in the least restrictive way, respecting the person's rights and freedom

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, so you should not make a decision on their behalf if it can wait until they can do it themselves.

Sometimes, a person with dementia may make decisions that you consider unwise or disagree 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 (such as whether to sell their home).

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

Mental capacity assessments

If more complex decisions need to be made – for example, about care options, property and finances or medical treatment – the Mental Capacity Code of Practice must be followed and clearly documented. For big decisions like these, it is usually best to ask a health or social care professional or legal representative (such as a solicitor) to carry out a formal mental capacity assessment (MCA) and document the outcome in writing.

Having a formal MCA is especially important if the person with dementia has not made a lasting power of attorney (known as power of attorney in Scotland, and enduring power of attorney in Northern Ireland) which legally nominates someone to make decisions on their behalf. In this situation, you should seek legal advice from a solicitor.

MCAs only cover the specific decision being made at that time – for instance, whether the person should receive a medical treatment. If further decisions need to be made, there should be a separate MCA for each.

The professional who carries out the MCA should keep a detailed written record of the assessment and outcome, for example in person’s medical notes.

Planning for the future

When a person is diagnosed with dementia, they should be encouraged to think about their future plans and wishes as soon as possible. This will make managing their care and finances less complicated and ensure their wishes are considered in any decisions made on their behalf if they lack capacity.

There are certain important documents and processes for putting plans in place for a time when the person with dementia lacks capacity, including:

- **advance care plan (ACP):** a document setting out the person's wishes for their future medical and personal care
- **lasting power of attorney:** where the person legally appoints a trusted person to make decisions on their behalf if they lack capacity
- **advance decision:** a legally binding document stating the person's wishes around medical treatments, including resuscitation

Please see Sources of support on p10 for information on advance care planning, power of attorney and advance decisions.

Making a 'best interests decision'

If a person with dementia cannot make informed decisions, other people may need to make a 'best interests decision' on their behalf. This means taking into account:

- what the person would have decided if they were able to make the decision
- their past and present values and wishes, including cultural, moral, political and religious views

Best interests decisions should always be the least restrictive option possible. For example, if the person wishes to go out 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.

In some cases, a 'best interests meeting' may be arranged to decide what would be best for the person with dementia. This might happen if a decision is complex and may not be fully understood by everyone involved (for example a decision about medical treatment), or if there are differing opinions about what is in the person's best interests.

A best interests meeting should include anyone who holds power of attorney for the person with dementia, family members, health and social care professionals, and anyone else who is actively involved with supporting them. Every attempt should be made to involve the person and find out their wishes regarding the decision. If they have made a power of attorney and/or advance care plan, these should be considered in any decisions made.

Independent Mental Capacity Advocates

If a person lacks capacity and does not have a power of attorney or a family member or friend who can be consulted on their behalf on matters such as medical treatment or a change of accommodation, they are entitled to an Independent Mental Capacity Advocate (IMCA) to represent their interests. This might happen if, for example, their family member lives a long way away, has not seen them for some time, does not want to be consulted or is ill or frail themselves.

An IMCA is instructed on the person’s behalf by a professional from the NHS or a local authority, such as a doctor, care manager or social worker. It is a free service. For more information, please see Sources of support on p11.

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 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 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

If you are living with dementia or caring for someone with the condition, register for our free online sessions, 'Dementia: what next?' at **dementiauk.org/dementia-what-next**

To speak to a dementia specialist Admiral Nurse, call our free Helpline on **0800 888 6678** (Monday-Friday 9am-9pm, Saturday and Sunday 9am-5pm, every day except 25th December) or email **helpline@dementiauk.org**

If you prefer, you can book a phone or video call with an Admiral Nurse at a time to suit you: please visit **dementiauk.org/book**

Dementia UK resources

Advance care planning (including template)

dementiauk.org/advance-care-planning

Delirium (sudden confusion)

dementiauk.org/delirium

Lasting power of attorney

dementiauk.org/lasting-power-of-attorney

Other resources

Advance decisions

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

Independent Mental Capacity Advocates

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

Mental Capacity Act Code of Practice

gov.uk/government/publications/mental-capacity-act-code-of-practice

NHS: the Mental Capacity Act

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**

Book a virtual appointment:
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**
- Scan **the QR code**

Thank you.

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Publication date: April 2026 Review date: April 2029.

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Dementia UK is a registered charity in England and Wales (1039404) and Scotland (SC 047429).