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Mental Capacity Act 2005

This section of the Family Carer Advocacy Pack covers what you need to know about the Mental Capacity Act 2005 (MCA) if you are a family carer and your relative is approaching the age of 16 years old and you have been making decisions on their behalf.

What is the Mental Capacity Act?

The Mental Capacity Act is a law that says that anybody aged 16 years old and over regardless of whether they have a learning disability, autism or both, has the right to make their own decisions wherever possible. It covers day-to-day decisions like what to wear or what to eat for lunch and serious life-changing decisions like whether to have surgery. If your relative



is assessed as not having the capacity to make a specific decision at a specific time, then a best interests process must be followed.

Are there any decisions not covered by the Mental Capacity Act?

There are certain decisions that cannot be made for another person under Mental Capacity Act law. This is because the decision is either so personal to the individual concerned, or because it is governed by other legislation. Decisions that cannot be made under the Mental Capacity Act law include:

- Consenting to marriage or a civil partnership
- Consenting to sex
- Consenting to a child being placed for adoption
- Voting at an election

There is a Mental Capacity Act Code of Practice which explains the Mental Capacity Act 2005 in detail. There is a duty under the Act for all organisations and individuals (e.g. doctor, nurses, social workers and paid support staff) to consider the code at all times if they have a responsibility for making decisions when a person had been assessed as lacking the mental capacity to do so themselves.

[Click here to read the Mental Capacity Act Code of Practice](#)



The MCA sets out 5 core principles:

5 rules for supporting me

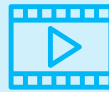
- 1 Start by thinking I **can** make a decision
- 2 Do **all** you can to **help** me make a decision
- 3 You must **not** say I lack capacity just because my decision seems unwise
- 4 Use a **best interest checklist** for me if I can't make a decision
- 5 Check the decision made **does not** stop my freedom more than needed

1. Presumption of mental capacity (the ability to make a decision and understand the consequences of that decision).

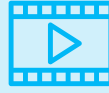
We should never assume that just because a person has a learning disability, autism or both that they lack capacity to make decisions. A lack of capacity cannot be determined solely by a person's age or appearance, diagnosis or an aspect of their behaviour, which might lead others to make unjustified assumptions about the person's capacity. Capacity changes over time for all of us. For example if a person has been unwell recently their ability to make decisions may be impacted. Where possible, major decisions should be postponed until the person's circumstances and ability to take part in the decision-making process improves

2. People must be supported to make decisions.

Information should be given in a way that makes sense to the person. A person may also require support from a family carer, other family member, friend or support worker to help them.



[Click here to watch the video from Infodeo on the Mental Capacity Act](#)



[Click here to watch the video from the Social Care Institute for Excellence on the Mental Capacity Act](#)

Helping people make their own decisions

Before deciding a person lacks capacity, it is important to take steps to enable them to try and make the decision themselves.

For example:

- Does the person have all the relevant information they need?
- Have they been given information on any alternatives?
- Could information be explained or presented in a way that is easier for them to understand?
- Have different methods of communication been explored, such as non-verbal communication, e.g. sign, talking mats, social story?
- Could anyone else help with communication, such as a family carer, other family member, friend, support staff or independent professional advocate?
- Are there particular times of day when the person's understanding is better?
- Are there particular locations where the person may feel more at ease?
- If the person is usually able to make decisions independently but their current circumstances (e.g. illness) are preventing this, can the decision be delayed until they are back to their usual self?

[Watch this video from SCIE](#) showing how a young man was supported in a person-centred way to be involved in a decision about moving house



3. Unwise decisions do not necessarily mean a lack of capacity. A person has the right to make an unwise decision. The purpose of a capacity assessment is to determine a person's ability to make a decision, not to make a value judgement on their decision.

4. Decisions must be taken in a person's best interests. This is a difficult concept. It means putting yourself in the person's shoes. Past decisions and knowledge of what is important to the person are important considerations during this process. Everyone involved should imagine what the person would choose if they did have capacity.

5. Consider how a decision can be made in a way that is the least restrictive.

Consider this example of good practice:

Eddie's mobility has recently deteriorated, and he is struggling to get up and down the stairs. An assessment found that even with support he lacks the capacity to understand his changing health needs and ability to manage stairs. However he was able to indicate that he did not want to move house.

A best interests process was followed, and the options discussed were:

- The least restrictive option would be to adapt the home by fitting a stair lift or moving Eddie downstairs
- The most restrictive option would be to decide that Eddie should move home.

The least restrictive option should always be chosen, where possible

These 5 core principles must be considered and followed in every instance when working with someone who has been assessed as lacking capacity to make a decision for themselves.

How is mental capacity assessed?

There is a two-stage test to decide if someone lacks mental capacity.

Stage one: Does the person have an impairment of, or a disturbance in the functioning of, their mind or brain? This could include people with a learning disability, autism or both.

Stage two: Does the impairment mean the person is unable to make a specific decision when they need to? People can lack capacity to make some decisions but have capacity to make others. Mental capacity can also fluctuate with time.

Someone may lack capacity at one point in time but may be able to make the same decision at a later point in time. This is why a capacity assessment should only ever relate to a specific decision at a specific time.

What does the Mental Capacity Act mean for family carers?

If your relative cannot make all their own decisions after they turn 16 years old, you can continue to make some decisions for them in their best interests. However, you cannot automatically do this for them in all aspects of their life. Other people may need to be involved in the decision-making process, e.g. if it is a medical decision, this will be a doctor. Anyone making a best interest decision on behalf of a person who has been assessed as lacking capacity **must consult with the person's family carer, other family members and friends and take their views into account.**

[Watch this video from Hft about involving family carers](#)



The same 2 stage test applies for every assessment of mental capacity. However the nature of the information and steps will vary depending on:

- The person's needs
- The nature of the decision to be made
- The urgency with which the decision needs to be made
- The impairment or disturbance does not have to be diagnosed but a judgement must not be made solely based on:
 - the person's age
 - the person's outward appearance
 - any physical disability or sensory impairment
 - the person's behaviour (including making an unwise decision)

What is the point of doing a mental capacity assessment?

The purpose of any capacity assessment is not to judge the decision a person makes but to determine whether a person is able to make the decision. Section 3 of the Mental Capacity Act says that a person is able to make their own decision if they can do all of the following 4 things:

1. Understand the information relevant to the decision
2. Retain that information long enough to be able to make the decision (if only for a short amount of time)
3. Use or weigh up that information as part of making the decision
4. Communicate the decision (whether verbally, using sign language or any other means of communication, e.g. talking mats)

Who assesses mental capacity?

For day-to-day decisions, e.g. what to wear, whoever (e.g. family carer, paid support staff) is involved with the decision because they are providing care and support/and or treatment is the one who would assess mental capacity. If the decision is a complex one e.g. whether to have surgery, move house, then a professional opinion might be necessary, for example the opinion of a hospital consultant, psychologist, social worker. For complex decisions there is a process which should be followed, including:

- A formal record of the assessment should be recorded as soon as possible after it has been carried out
- The record must demonstrate that the statutory principles of the Mental Capacity Act have been applied and each element of the functional test assessed
- The record should contain all of the following:
 - the evidence that has been used to confirm the presence of an impairment or disturbance of the mind or brain
 - the decision to be made
 - the relevant information that has been provided to the person
 - the steps that have been taken to support the person to make their own decision
 - the outcome of each element of the functional test of capacity
 - the reason that the person has been deemed to lack capacity, that consideration has been given to delaying the decision, if they are likely to regain capacity

Notifying Others

The following people should be notified of the outcome of the assessment:

- The person who lacks capacity
- Any representative of the person e.g. family carer, other family member or friend
- Any Lasting Power of Attorney or Court Appointed Deputy
- Anyone that the person has asked to be notified
- Anyone else that it is deemed relevant to notify either with the person's consent or in their best interests if they have been assessed as lacking the capacity to consent

What can I do if I disagree with a mental capacity assessment decision?

If you disagree with a mental capacity assessment decision, for example if your relative is assessed as lacking mental capacity when you think they have mental capacity, there are various ways you can try and resolve this.

- You can raise the matter with the person who carried out the assessment and ask them to give the reasons why they believe your relative lacks the mental capacity to make the decision and ask them to provide objective evidence to support that belief
- You can try and get a second opinion from an independent professional
- If you cannot resolve the disagreement then you may be able to apply to the Court of Protection, who can make a decision as to whether a person has mental capacity



Best Interests Decisions

When somebody is assessed as lacking mental capacity, then any decision made on their behalf should be done in their best interests. This is the case whether the person making the decision is a family carer, another family member, a friend, paid support staff, a lasting Power of Attorney, a Court Appointed Deputy, or a professional independent advocate.

Who makes the best interests decision will depend on the decision and whether there is anyone with the legal right to make the decision. If the decision is an everyday decision, for example if somebody needs support to identify appropriate clothing then the person most directly involved should be the decision maker e.g. a family carer or paid support staff. These types of decisions are not usually formally recorded. For more complex best interest decisions the nominated decision maker e.g. GP, psychiatrist, social worker should consult with:

- Any Lasting Power of Attorney or Court Appointed Deputy. If the Power of Attorney or Court Appointed Deputy does not have the relevant authority to be the decision maker themselves i.e. a Power of Attorney for property and financial affairs should still be consulted about a decision relating to health and welfare
- Family carers, other family members and friends
- Paid support staff
- And anyone else who is interested in the welfare of the person

and there should be a formal record kept of the process and the outcome. The Mental Capacity Act says that when deciding what is in a person's best interests this checklist should be used:

- Encourage participation – do whatever is reasonably possible to permit or encourage the person who lacks capacity to take part or to improve their ability to take part in making the decision
- Identify all relevant circumstances – try to identify all the things the individual assessed as lacking capacity would consider if they were making the decision themselves
- Find out the person's views – including:
 - their past wishes and feelings about the matter to be decided
 - their present wishes and feelings about the matter to be decided
 - any beliefs or values that would be likely to influence the decision in question, e.g. religious
 - any other factors that the person would be likely to consider if they were making the decision or acting for themselves
- Avoid discrimination – do not make assumptions based on age, appearance, condition or behaviour
- Assess whether the person might regain capacity – if this is a possibility, could the decision be postponed

Best Interests Decision Meeting – Good Practice

Keep the person at the centre of the meeting. This is the responsibility of the Chair. Ways to do this include:

- A photo of the person on the agenda
- Having an empty chair in the meeting to represent the person (if it is not appropriate for them to attend)
- A profile of the person which includes their personal history, description of their personality, values, wishes, beliefs, attitudes to health, life goals, religion and spirituality, and the quality of life that is acceptable to them
- During the meeting, regularly asking people to consider what the person would say, for example:
 - Mum/Dad/Friend: what do you feel is most important here? What do you think Yusuf would say?
 - If Melanie was here and for five minutes could fully appreciate all these issues, what would she say about this decision now?

After the meeting consider the best way to communicate the outcome to the person to maximise their understanding of the decision, for example:

- Meeting one-to-one after the meeting
- Asking them to join the meeting at the end
- Using their preferred method of communication which may include a social story, signing, AAC

[The British Psychological Society provides information and resources about best interests decision making](#)



Advance Statements and Decisions

An advance statement is a written document that sets out a person's preferences (likes/dislikes), wishes, feelings, values and beliefs about their future care. Although not legally binding, the aim is to provide a guide for anyone who might have to make decisions in a person's best interests if that person has lost the capacity to make decisions or communicate their decision. An advance statement can cover any aspect of a person's future health or social care. This could include:

- Where they would like to live
- How they would like to be supported
- How they like to do things for example, if they prefer a shower instead of a bath, or like to sleep with the light on

Using the principles of an advance statement can ensure that care and support and/or treatment is provided in a person-centred way. For example, if your relative is admitted to an acute or mental health hospital, it is a way of ensuring that staff know what they were like before they became unwell. This can help judge whether the care and support and/or treatment they are receiving is resulting in good outcomes.

The following documents can be used to record this information:

- Communication passport
- Hospital passport
- Health action plan
- Positive behaviour support plan
- Activity schedule
- Person-centred plan
- Support plans for activities

Family Carer Advocate

If your relative is assessed as lacking capacity then you can continue to act on their behalf (e.g. apply for their entitled benefits, contribute to their Care Act assessment) and make some decisions even when they turn 16 years old.

More complex decisions may involve professionals such as a social worker if there is a decision about where your relative lives or a doctor if your relative requires surgery, but they must include you (and your relative).

If you do not wish to represent your relative or there is disagreement, for example between your views and that of a social worker/health care professional, then an independent mental capacity act advocate may become involved



[Read this information from the Challenging Behaviour Foundation](#) about being involved in making decisions with or on behalf of your relative



[Read more on](#) consenting to healthcare treatment



If you feel that your right to be involved as a family carer is not being upheld [use this template letter](#):

Independent Mental Capacity Act (IMCA) Advocate

If your relative has been assessed as lacking capacity to make a specific decision at a specific time (e.g. about serious medical treatment, or where they live) and does not have a family carer, other family member or friend to represent their best interests they have a statutory (legal) entitlement to an IMCA. An IMCA's role will include:

- Supporting your relative to make/be included in the best interests decision
- Explaining to your relative what is good and bad about the proposed decision
- Trying to identify all of the things that your relative would think about if they were making the decision, e.g. their past and present wishes, feelings, values and beliefs
- Gathering the views of people who know your relative well and are interested in their quality of life
- Using any documents to provide information to those involved in the best interests decision to help work out what is in your relative's best interests

- Represent your relative to those involved in the decision making so that their best interests are known
- Asking questions or challenging decisions that do not appear to be in your relative's best interests



[Read more](#) about the role of an Independent Mental Capacity Act Advocate



[Read Carol's story](#)



[Read this factsheet](#) from Cloverleaf Advocacy

Further information



The Challenging Behaviour Foundation's factsheet 'How do my family member's rights change as they become an adult' includes information about decision making with or on behalf of your relative once they reach the age of 16 years old:

<https://www.challengingbehaviour.org.uk/wp-content/uploads/2021/03/7-How-do-my-family-members-rights-change-as-they-become-an-adult.pdf>

Read Mencap's Mental Capacity Act Resource Pack:

https://www.mencap.org.uk/sites/default/files/2016-06/mental%20capacity%20act%20resource%20pack_1.pdf

Read these scenarios from Coventry City Council about the use of the Mental Capacity Act/Best Interest Decisions:

<https://www.umccoventry.co.uk/case-scenarios-mental-capacity-best-interest-decisions/>

Read the Mental Capacity Act - Decision Making Pathway:

https://www.derbyshirehealthcareft.nhs.uk/application/files/3315/7547/2222/appendix_4a- decision_making_pathway.pdf

Read the Care Quality Commission guidance for health and social care services to check whether they are following the Mental Capacity Act. Within the guidance there is information about the use of restraint and the Mental Capacity Act and the role of Independent Mental Capacity Act advocates.

https://www.cqc.org.uk/sites/default/files/documents/rp_poc1b2b_100563_20111223_v4_00_guidance_for_providers_mca_for_external_publication.pdf



We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@thecbf.org.uk, or visit our website: www.challengingbehaviour.org.uk

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