



**Down's Syndrome
Association**

A Registered Charity No. 1061474

Making everyday decisions post 16



The Mental Capacity Act: *Frequently asked questions*

A Down's Syndrome Association publication

Our resources and Information Team are here to help

Please see our website for up-to-date information: www.downs-syndrome.org.uk

If you would like to talk about the activities or where to start, then please get in touch with our helpline by calling 0333 1212 300 or by emailing us on info@downs-syndrome.org.uk.

Helpline Monday - Friday 10am-4pm | Telephone: 0333 1212 300

The Mental Capacity Act (MCA) Code of Practice

In the past, people with learning disabilities often had decisions made for them. This led to a lack of control in their lives and enabled things like financial abuse and forcible treatment to occur. The MCA attempts to address this situation by providing a common sense approach to supporting people in making their own decisions when they are able and to protecting their interests if they can't make specific decisions for themselves.

The MCA Code of Practice provides guidance for decisions made under the Act. It gives guidance to people who:

- work with people who can't make decisions for themselves
- care for people who can't make decisions for themselves

It says what you must do when you act or make decisions on behalf of people who can't act or make those decisions for themselves.

It can be downloaded here: gov.uk/government/publications/mental-capacity-act-code-of-practice

If in doubt, the Code of Practice is a good place to start. It is important for families to understand the legal framework around decision making for young people in England and Wales once they turn 16. It can come as a surprise to parents to discover that they do not have an automatic right to make decisions for their older teenagers and adult sons and daughters who have Down's syndrome.

Key information about the Act

- It empowers people to make decisions for themselves wherever possible.
- It protects people whose capacity is questioned.
- It ensures people are included as much as possible in any decisions made on their behalf.
- It provides a common sense approach.

The Act is based on five key ideas/principles. They are:

- Assume a person has capacity unless it is proved otherwise.
- Take all practicable steps to enable someone to make their own decisions (see supported decision making, below).
- Do not assume incapacity simply because someone makes an unwise decision; in other words, if a person can make a decision themselves, you should not stop them just because you think it's a bad decision.
- Always act, or decide, for a person without capacity in their best interests. There is a formal process for this. The bigger and more important the decision, the more formal the best interests decision making process should be.
- Carefully consider actions to ensure the least restrictive option is taken. If you are making a decision/taking an action for another person that is in their best interests you must try and ensure the act/decision provides the person with as much freedom as possible whilst maintaining their rights.

What does mental capacity mean?

Mental capacity is the ability to make decisions. If someone lacks mental capacity, they are assessed as unable to make a particular decision for themselves. These decisions can range from choosing what clothes to wear to major life choices, such as deciding where to live.

"My brother can't make decisions."

We know that people can have capacity for some day-to-day decisions, for example, but may lack capacity for some bigger and more complex decisions.

According to the MCA, there must be no 'blanket decision' made about an individual person's capacity. A person's mental capacity is always assessed on a decision by decision basis. The starting point should always be that the person has the capacity to make the decision in question.

Key principle of the MCA – Every adult has the right to make their own decisions if they have the capacity to do so. Family carers and healthcare and social care staff must always assume that a person has capacity to make a decision unless it can be established they do not.

What is supported decision making?

'Can my son have support to make a decision?'

A person is not to be treated as unable to make a decision unless all practicable steps to help them to do so have been taken without success. This is generally referred to as supported decision making.

Key principle of the MCA – People must have support to help them make their own decisions. Types of support could include using alternative forms of communication, providing information in different formats (e.g. photographs, drawings, tapes), having a structured programme to improve a person's capacity to make particular decisions (e.g. a healthy eating programme) and having extra time to process relevant information.

This principle is to stop people being automatically labelled as lacking capacity just because they have a learning disability.

When should capacity be assessed?

Capacity assessments should only be carried out if people are having difficulty understanding or making decisions. The assessment should be decision specific and the more serious or complex the decision, the more formal the process should be. Sometimes a professional may be called upon to carry out a capacity assessment. Someone may be assessed as lacking capacity to make a specific decision if they cannot do one or more of the following:

- Show some understanding of the information given to them.
- Retain the information long enough.
- Weigh up information and use it to make the decision.
- Communicate the decision.

What is best interests decision making?

If the person does not have capacity to make a decision for themselves, their decision maker (holder of a Lasting Power of Attorney (LPA) or their Deputy) would have to make a best interests decision in accordance with the requirements of the MCA.

If the person does not have a decision maker, others (including professionals from social services, NHS or the local authority) would have to decide what is in the person's 'best interests'.

Here are some examples of decisions that may have to be made in someone's best interests if they lack capacity either by their decision maker or the lead professional (e.g. social worker or GP):

- Contact with others.
- Where to live.
- Medical intervention/treatment.
- What care is received.

A best interests decision does not mean cutting out the person who has Down's syndrome. Everything should be done to include the person in the best interests process and to establish what their wishes/feelings (past and present) might be.

Their welfare should be looked at in the widest sense and relevant medical/social circumstances considered before a decision is made. The decision must be in their best interests and not in the interests of any other person or the state.

- Encourage participation/find out views: What are the person's wishes? What are their beliefs and values?
- Identify all relevant circumstances.
- Consult others: What do other people who know the person well think would be in their best interests? Family members with an interest in a person's welfare should be consulted by professionals (including social services, NHS and local authority).
- Avoid discrimination and restricting rights; what would be the least restrictive option?
- Weigh up the evidence.

There are informal and formal ways to challenge a best interests decision if you are unhappy with the decision.

As a parent, I feel I'm being cut out of decisions made by professionals about my daughter's care

You do not need to be appointed welfare deputy or LPA to be consulted. If your daughter lacks capacity to make a specific decision for herself, professionals have a duty to consult you as a family member. Decisions made on behalf of a person who lacks capacity (big and small decisions) have to be made in their best interests. As part of this process family members must be consulted before the decision is made. However, it is important to note they do not have to follow your views if they believe they are not in the person's best interests.

If your daughter has capacity to make a specific decision for herself, you do not have a right to be consulted by professionals. Your daughter can involve you in making the decision as much as she wants to and professionals must respect this.

If you feel that best interests decisions are going to be made without your input, you should raise your concerns with the relevant professional(s), explain your right to be consulted, and ask to be included in the decision making process. We would suggest you put this in writing; you will find links to some examples of template letters (from Irwin Mitchell) you can use for this purpose in the resource section at the end of this article.

What the Act is not intended to do

We have heard of cases where people have refused services, for example, and this has been accepted by local authorities because the person is expressing their view and they must be assumed to have capacity.

The Act should not be used by local authorities as an excuse to do nothing.

In reference to such cases the Law Society has commented on the principles of the Act being 'applied perversely' with local authorities using the assumption of capacity to avoid assessing capacity and thus avoiding having to provide support/services.

The Act should not be used to justify poor social or health care. Families have expressed concerns to us over the years about the simplistic manner in which choice is interpreted by support staff leading to concerns over their loved-one's welfare and health.

The Act should not be seen primarily as a framework for making decisions for, or on behalf of, a person. Rather it should be viewed as a framework for encouraging and maximising participation in decision making.

A few myths:

You must have a LPA (Lasting Power of Attorney) to receive direct payments.

This is not the case. Plenty of people who have Down's syndrome receive direct payments without family members holding an LPA. If you do not hold an LPA, you can act as a 'nominated person' or an 'authorised person' for the purposes of direct payments:

- A nominated person is a person whom an adult with capacity to request a direct payment nominates to receive the direct payment on their behalf.
- An authorised person is a person who can request as well as receive direct payments to spend on meeting the needs of an adult who does not have capacity to request direct payments.

For further information, see section 12 (Direct Payments) of Care and support statutory guidance – the link is in the resources list.

As the next of kin, I can automatically make decisions for my relative

One of the most common misconceptions we hear concerns the idea that being the 'next of kin' of an adult who has Down's syndrome comes with the automatic right to make decisions on that person's behalf whether they lack capacity or not. This is not the case and the term 'next of kin' has no basis in law.

This article is a brief look at some of the main issues and themes that families and supporters contact us about. For further information, take a look at the resource list below and/or call our Helpline (Tel: 0333 1212 300).

DSA Resources

Making every day financial, health and welfare decisions post 16

downs-syndrome.org.uk/for-families-and-carers/making-everyday-decisionspost-16/

Information about making choices

downs-syndrome.org.uk/for-families-and-carers/teenagers-and-young-adults/making-choices/

Why is being heard and included in decision making processes important?

downs-syndrome.org.uk/news/why-is-being-heardand-included-in-decision-makingprocesses-important/

Other Resources

If you are concerned that decisions have already been taken and you were not consulted, then you can use Irwin Mitchell's template letter to register your concern and request a "best interests meeting":

irwinmitchell.com/medialibrary/im%20com/home/activities/documents/template-letter-2.doc

If you are concerned that decisions may be taken by professionals without consulting you in the future, you can use Irwin Mitchell's template letter to explain your right to be consulted:

irwinmitchell.com/medialibrary/im%20com/home/activities/documents/template-letter-1.doc

You can also download both letters as part of a resource from the Challenging Behaviour Foundation:

challengingbehaviour.org.uk/learning-disability-files/MCAletter---FINAL.pdf

Care and support statutory guidance – Dept of Health and Social Care

gov.uk/government/publications/care-act-statutoryguidance/care-and-supportstatutory-guidance

The Down's Syndrome Association provides information and support on all aspects of living with Down's syndrome.

We also work to champion the rights of people with Down's syndrome, by campaigning for change and challenging discrimination.

A wide range of Down's Syndrome Association publications can be downloaded free of charge from our website.

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