



**Ambitious
about Autism**

Making decisions for your autistic young person

Resource



Making decisions for your autistic young person

What does mental capacity mean?

Every person from the age of 16 and above has the right to make their own decisions if they have the capacity to do so. Capacity means a person's ability to understand information and make decisions about their life.

This resource covers the key principles of mental capacity. It will help you understand whether someone can make their own decisions and provides information on how to determine if they cannot.

The Mental Capacity Act

The **Mental Capacity Act 2005** (MCA) provides a legal framework around capacity which is explained in more detail in the **Mental Capacity Code of Practice**. The Code of Practice was created to help families, carers and professionals understand how to interpret the law and apply it to their situations.

The legal framework aims to protect people who lack capacity in decision-making, but also to support their ability to participate in decision-making, as far as they are able. The MCA and Code of Practice are intended to be enabling and supportive of people who lack capacity, not restricting or controlling their lives.

There are five key principles in understanding mental capacity which we will explain in this resource.



Principle one

A person must be assumed to have capacity unless it is established that they lack capacity

A person does not have to prove they can make their own decisions, it is for the person who thinks they cannot to establish that fact. Capacity is not a state of being, it is about a specific decision at a specific point in time.

The MCA describes when a person lacks capacity: **“A person lacks capacity if, at the time they are making the decision, they are unable to make that decision because of an impairment/disturbance in the functioning of the mind or the brain.”** (Section 2, MCA)



Scenario

Saul, a man with a physical disability, has some problems with his mobility and stutters when he speaks.

When he trips in the street near his home, bystanders are concerned that he is injured and call for an ambulance even though Saul seems to indicate he is fine and wants to go home. The medical staff arrive at the scene and importantly do not make assumptions about Saul based on his appearance or

How do I decide if my young person has mental capacity?

From this description, you will see there are two steps to deciding on capacity:

Step one

Does the person have an impairment of or a disturbance in the functioning of their mind or brain? An impairment or disturbance could be because of a disability, condition, or injury.

Step two

Does the impairment or disturbance mean that the person cannot make a specific decision when they need to?

It is important when applying these two steps that the right things are considered. For example, it would be wrong to decide that a person lacked capacity in all areas of their life or to decide about capacity based only on their appearance.

communication style. They speak with him and quickly establish that he can make healthcare decisions for himself. Saul is then able to make his way home.

Had the medical staff insisted on taking Saul to the hospital against his wishes, Saul would have been justified in making a complaint.



To understand when a person can make their own decision you must decide whether the person can:

- understand the information relevant to the decision
- retain that information long enough to make the decision
- use or weigh that information as part of the process of making the decision
- communicate their decision (whether by talking, using sign language or by any other means such as muscle movements, blinking an eye or squeezing a hand).

In cases where the decision is complex or where it is difficult to decide if a person can do any of the things above, you may need to get advice from a professional or ask a professional to carry out a mental capacity assessment.

Learn more about [who decides capacity](#) below.



Principle two

All practical steps are taken to help someone make their own decision

People have different ways of understanding information and if a person has an 'impairment or disturbance' of the mind they may understand information or communicate information differently. The MCA requires that a person has support to allow them to make their own decision.

Some examples of supporting a person to make a decision are:

- providing all the options and relevant information in a way the person will understand
- considering whether there are times of day when the person's understanding is better
- using a different form of communication, for example, non-verbal communication or sign language
- providing information in a more accessible form, for example, using photographs or drawings
- can anyone else help or support the person to make choices or express a view?

There are multiple ways to provide practical steps to support someone make a decision, it will just need some thought as to what those steps are.

Scenario

Toni is an autistic young person with an additional learning difficulty, and he must make a health decision.

He is very daunted by the prospect and immediately asks his mother what she thinks. His mother recognises that with information and support, Toni is likely to be able to make his own decision. She finds some leaflets for Toni and goes through these several times. She checks Toni understands the medical procedure on offer by discussing it with him over weeks. In their discussions, Toni indicates he understands the procedure. When Toni and his mother

feel they have all the information they need, and Toni has had time to process it and ask questions, they are asked by the health professional what their view is on having the medical procedure.

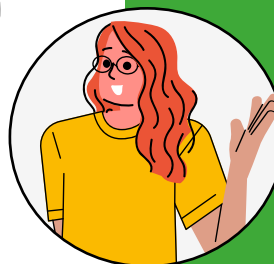
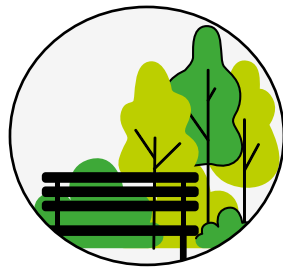
Toni can show that he understands what has been offered and that he has weighed up the benefits and drawbacks of the procedure. Toni then makes an informed decision.



Principle three

Just because a person makes an unwise decision does not mean they lack the capacity to make it

People make decisions all the time for all sorts of reasons and sometimes these could be viewed as unwise. Just because the decision is not one you agree with, or you think is unwise, it does not mean the person lacks capacity. The steps above must be followed to conclude their capacity. However, there could be a red flag to consider if a person with an 'impairment or disturbance of the mind' regularly makes unwise decisions that put them at significant risk of harm or exploitation, or if they make an unwise decision that is out of character. In this scenario, you could think about whether the person has had enough practical support to weigh up the decision they are making.



Principle four

Best interests

Where a person cannot make their own decision, any decisions made on a person's behalf must be made in their best interests and not in the best interests of the decision maker. Best interests will often mean considering things from a range of perspectives. It is crucial to understand that just because a person lacks capacity it does not mean their views, wishes and feelings are ignored.

Scenario

Pam is moving into a new care home. There is a choice of two homes. One is close to a park. Pam loves spending time outdoors and enjoys being in environments with plants and trees. The other does not have any open space nearby and staff would have to drive Pam for 20 minutes to get to the nearest park. Pam does not like being in the car.

The second home is nearer to Pam's sister, and she would like her to be nearby, so it is not such a journey for her to visit. Pam's care staff have observed that Pam enjoys seeing her sister, however, they have also seen that she equally enjoys spending time outdoors.

On balance, they believe it is in Pam's interests to be in the care home nearer to the park so Pam can access it on a day-to-day basis. Pam's sister concedes that the decision on the suitability of the care home must be based on Pam's best interests as they are understood, and not her own.

Principle five

Least restrictive

Best interest decisions must be made because of a 'reasonable belief' and should be least restrictive of the person's basic rights and freedoms. Basic rights and freedoms are things like being able to go out when you want or being able to see or spend time with your family. When deciding on whether a decision is 'least restrictive' it will be important to consider the views, wishes and feelings of the person, where you can.

Scenario

Sophia is a young person with learning disabilities. Sophia also has epilepsy which can result in her collapsing and injuring her head.

One of the options being explored to protect her from injury is to provide constant one-to-one supervision. The second option is for Sophia to wear a protective helmet. After assessment by Sophia's carers, it is decided that she lacks capacity and therefore any decisions about protecting her must be made in her best interests and must be least restrictive. Through her actions and behaviour, Sophia makes it clear she does not like to be too closely observed or supervised.

Her carers concluded that close supervision is a restriction on Sophia's liberty, and this can be avoided if she wears the helmet. Of the two actions, the helmet is therefore seen as being in her best interests and the least restrictive.

Who decides on capacity?

It will be those involved in the care of the person, for example, a parent/carer, care worker or support staff who will usually decide on capacity. This is because it is the family or carers who have day-to-day contact with the person, knows them best and may even be present when the specific decision needs to be made.

For significant and/or complex decisions where there is doubt about capacity or where capacity is challenged, then advice should be sought from a professional such as a doctor, psychologist or social worker to advise on whether the person has the capacity or not. Remember, even if they don't have capacity, any views, wishes and feelings should be considered.

Any person deciding on capacity must have a 'reasonable belief' that the person lacks capacity, and they must have taken reasonable steps to satisfy themselves about the lack of capacity. In case of any questions or challenges as to the decision made, the person or people who made the decision should be prepared to explain the steps they have taken to decide on capacity and what decision was made in the person's best interests and that is least restrictive.



Challenging a decision

Disagreements about the outcome of a mental capacity assessment, a best-interest decision, or how it has been implemented could be challenged by any of the following people:

- the person whose mental capacity has been assessed
- the representative of a person who lacks capacity
- family members or friends concerned with the welfare of the person
- carers
- health professionals
- social care professionals
- a legal representative of the person
- the Court of Protection.

Disagreements can be dealt with informally through conversations or emails. The Code of Practice says that any disagreements should be resolved as quickly as possible.

If you wish to make a formal complaint or cannot reach an agreement informally, you can make a formal complaint through the Local Authority or health body complaints processes. Where you are not satisfied with the outcome of the formal complaint, you can also complain to the **Local Government and Social Care Ombudsman** or the Health Ombudsman.

Another avenue to challenge a decision is in the **Court of Protection**. The court has the responsibility for deciding on issues relating to mental capacity including appointing Welfare or Financial Deputies. An application to the Court of Protection may be considered by a health or social care body, family or carer where there is disagreement about a person's mental capacity, or a specific decision made on a person's behalf. There is a cost to making an application.

Applying to be a welfare or financial deputy

There are two different types of deputyships: health and welfare or property and finance. Being a deputy is different to having a lasting power of attorney (LPA). A power of attorney is a legal document that you can sign to appoint another person to decide on things on your behalf in case you lose your ability to make decisions in the future. To sign the LPA documentation, you would need the capacity to understand the decision you are making. It is not an arrangement that you can put in place if you cannot make that decision.

A deputy is appointed by application to the Court of Protection when someone cannot make decisions on their own behalf. The court will consider the evidence and decide whether to appoint a deputy. There is no guarantee you will be granted the deputyship when you apply. If you are appointed as a deputy, you will be required to follow the key principles above and comply with the annual reporting requirements.

Learn more about [acting as a deputy](#).




Learn more about making decisions for your young person

Hosted by **Jo Salsbury**

Sign up to Talk about Autism, the online community for parents and carers, to watch a webinar on understanding mental capacity. The webinar is hosted by Jo Salsbury who is Head of Family Services at Ambitious about Autism and an experienced solicitor in the SEND sector. She is also a parent to an autistic young person.

[Sign up now.](#)

TalkTalk
For Everyone

We are Ambitious about Autism

Ambitious about Autism is the national charity standing with autistic children and young people.

We believe every autistic child and young person has the right to be themselves and realise their ambitions.

We started as one school and have become a movement for change. We champion rights, campaign for change and create opportunities.

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