

Making everyday, financial, health and welfare decisions post 16

What the law says in England and Wales

What does the law say?

It is important for families to understand the legal framework around decision making for young people once they turn 16. It can come as a surprise to some parents to discover that they do not have the automatic right to make decisions for their older teenagers and adult children with Down's syndrome. This page gives a brief summary of the Mental Capacity Act and some specific information on financial and health and welfare decisions.

When a person turns 16, under the Mental Capacity Act (2005), the starting point is to assume they have capacity to make decisions for themselves. The law says a person must be given relevant information in an appropriate format and time to understand it before a decision on their capacity is made. This may mean that over a period of time pictures, symbols, diagrams, videos, sound clips, verbal conversation or other formats that the person normally uses to communicate are used to help the person to understand the options open to them. This is known as **supported decision making**. Depending on the decision to be made, this support may be required under the Mental Capacity Act (2005) to be provided by parents, carers or a professional such as a doctor or social worker.

For a person over 16, to be found to lack capacity to make a particular decision for themselves, the following criteria must have been met:

- The person has been given ample opportunity and appropriate support to understand the options they have
- The person has an 'impairment of, or disturbance in the functioning of, the mind or brain' (Mental Capacity Act, 2005)
- The person is unable to retain and weigh up information and communicate their decision

Only if a person's individual situation meets all three of the above, at the time the decision needs to be made, may a decision be made on their behalf.

The Mental Capacity Act (2005) states '*a person's capacity (or lack of capacity) refers specifically to their capacity to make a particular decision at the time it needs to be made*'. This means capacity must be assessed in relation to every decision that needs to be made, at the time it needs to be made. Therefore it is not possible to assess overall capacity and make blanket decisions on a person's behalf based on the fact that at a particular time they were found not to have capacity. For every decision to be made, work must be done, and time given, to support the person to understand the relevant information before it can be determined who the decision maker will be. If the person themselves is able to retain and weigh up information and communicate their decision, they are deemed to have the capacity to make the decision for themselves. It is important to be aware that under the Mental Capacity Act

(2005) a person is entitled to make, what others may deem is an unwise decision, provided they are able to retain and weigh up the information and communicate their decision.

Small day-to-day decisions

If a person lacks capacity, depending on the decision to be made, the decision maker may be parents, carers, or a professional such as a doctor or social worker. Any decision made on a person's behalf, where it has been established they lack capacity to make the decision for themselves, must be made in the 'best interests' of the person to whom the decision being made relates. It must also impose the least restrictive option in relation to the 'person's rights and freedom of action' (Mental Capacity Act, 2005).

For small day-to-day decisions such as what clothes a person should wear, assuming they lack the capacity to make this decision themselves, the decision may be made by one person alone, such as a parent or carer who is supporting the person at the time. In this circumstance capacity can be assessed informally at the time by the person supporting the individual.

Big or complex decisions - 'best interests' process

For any big or complex decisions where it has been established a person lacks capacity, a formal best interests approach must be taken. A best interests approach must involve anyone who knows the person to whom the decision relates to well. It should therefore involve discussion and consultation with the person's family and/or advocate and any other person's who are involved in the care of the individual and the relevant professional(s) (sometimes a doctor, dentist or a social worker depending on the decision being made).

The people involved in a best interests process should provide information about what they feel would be in the best interests of the person based on what they know of them and/or based on their professional expertise. The wishes of the person to whom the decision being made relates must also be considered, regardless of the fact they lack capacity to make the decision themselves. The views of all concerned should be formally recorded, as this evidence will be scrutinised in the event that there is a dispute over what is in the person's best interests.

In the event a decision needs to be made about a medical procedure, and there is no Health and Welfare Power of Attorney (see section below titled 'Health and welfare decisions where a person has capacity') the decision maker would be the medical practitioner who is expert in the particular medical procedure being considered. Where there is a Health and Welfare Power of Attorney, the person holding this would be the decision maker. Regardless of who is the decision maker, they must take into account all the information gathered to ensure the final decision is in the best interests of the person to whom the decision relates. The decision maker must also ensure the course of action is the least restrictive option in relation to the person's rights and freedoms.

There is more information about the Mental Capacity Act (2005) and best interest decisions in the DSA [Mental Capacity Act \(2005\) and Code of Practice factsheet](#). It also contains information about the options available in the event there are disagreements about best interest decisions of the person to whom the decision relates.

There is also a [Code of Practice that must be followed by everyone which can be viewed here](#).

Can I make decisions on behalf of someone else?

In certain circumstances it is possible to have formal authority to make decisions on behalf of someone else. Under the law, decision making is split into two categories. These are health and welfare decisions and financial decisions. There are however differences in process

depending on whether the person themselves has the capacity to understand what it means to award someone decision making powers regarding their affairs and on whether this is in relation to health and welfare or financial decisions.

There are also particular circumstances under the Children and Families Act (2014) when parents are able to make decisions on behalf of young people (who lack capacity) in education between the ages of 16-25. You may also want to download our Education Rights factsheet, [Young People over 16 with additional needs](#).

Financial decisions when a person has capacity

In the event a person is over 18 and has the capacity to understand what it means to award someone decision making powers regarding their property and financial affairs they are able to use a Lasting Power of Attorney to give these powers to someone.

Under a Property and Financial Affairs Lasting Power of Attorney the donor (person giving powers to someone) is able to stipulate exactly which financial decisions they are happy for the attorney (person receiving power to make financial decisions on their behalf) to make. In order to grant a Lasting Power of Attorney regarding financial affairs a person need not have an in depth knowledge about the legal process. It is enough that they understand they are giving the power to another person to manage their money and what this might entail.

[You'll find more information about how to apply for a Lasting Power of Attorney here.](#)

Financial decisions when a person lacks capacity

In the event someone lacks the capacity to understand what it means to award someone decision making powers regarding their financial affairs there are two options that may be considered:

- Become an appointee to manage benefits on the person's behalf. [You can find information on how to apply to the Department of Work and Pensions to become an appointee here.](#)
- Apply to the Court of Protection to become a Property and Financial Affairs Deputy to manage a person's financial affairs.

As a Deputy you will receive a court order detailing what you can and can not do. There is a charge to set this up and an annual fee. As a deputy you will need to keep your own property and money separate from the other person's and you will need to keep records of the finances you manage on their behalf. [You'll find more information on this here.](#)

Health and welfare decisions when a person has capacity

In the event a person is over 18 and has the capacity to understand what it means to award someone decision making powers regarding their health and welfare, they are able to use a Health and Welfare Lasting Power of Attorney to give these powers to someone.

However unlike decisions made under a Property and Financial Affairs Lasting Power of Attorney, under a Health and Welfare Lasting Power of Attorney the attorney (person receiving power to make health and welfare decisions on the person's behalf) is only able to make decisions in the event the person lacks the capacity to make decisions themselves. This means the steps explained above regarding assessment of capacity under the Mental Capacity Act (2005) must still be followed before any decisions about a person's health or welfare can be made by another person even if they hold a Health and Welfare Lasting Power of Attorney.

Only in the event the person themselves are deemed to lack the capacity to make a specific decision themselves would a person holding a Health and Welfare Lasting Power of Attorney be

able to make the decision on their behalf. In this instance the attorney must act in the best interests of the person to whom the health or welfare decision relates and must ensure the course of action is the least restrictive option in relation to the person's rights and freedoms.

Where a person has the capacity to award a Lasting Power of Attorney to another person, they are able to apply to the office of the public guardian to do this. In order to grant a Lasting Power of Attorney regarding health and welfare a person need not have an in depth knowledge about the legal process. It is enough that they understand they are giving the power to another person to make decisions about their health and welfare in the event they are, in future, unable to make these decisions for themselves. There is a one off cost of making a Lasting Power of Attorney. [Go to Gov.uk for more details](#).

From age 18 an adult may have a needs assessment and a care and support plan undertaken by the local authority. The Care Act (2014, section 9, (5), c and 25 (3), c) says the local authority must involve: *'any person whom the adult asks the authority to involve or, where the adult lacks capacity to ask the authority to do that, any person who appears to the authority to be interested in the adult's welfare'*.

Therefore, when an adult who is being assessed has capacity, local authorities must involve those who the adult asks them to involve. People who are keen to have a particular person or people involved in their assessment, care and support planning, may wish to ask the local authority to consult the person(s) they want involved and can use the quote from the Care Act above to do so. They may also wish to ask the local authority to write to them confirming they have placed a note on their file that identifies the people they wish to have involved with assessment, care and support planning to ensure they are consulted.

Health and welfare decisions when a person lacks capacity

In the event someone lacks the capacity to understand what it means to award someone decision making powers regarding their health and welfare it is unlikely that the Court of Protection will appoint a Deputy to make health and welfare decisions on their behalf.

Only in very rare and complex cases will the Court of Protection consider appointing a Deputy to make personal health or welfare decisions. In these cases the powers given to the Deputy will be limited in scope and duration. The Court of Protection prefers that the best interests approach is followed in most cases. In the event the Court of Protection is involved because there is a dispute between the parties involved in a best interests process, the court generally prefers to make an order on that specific issue rather than to appoint a Deputy.

In the event a needs assessment or a care and support plan is being undertaken by the local authority, the Care Act (2014, section 9, (5), c and 25 (3), c) says the local authority must involve: *'any person whom the adult asks the authority to involve or, where the adult lacks capacity to ask the authority to do that, any person who appears to the authority to be interested in the adult's welfare'*.

Therefore, local authorities must involve those who are interested in the welfare of a person who lacks capacity in relation to assessment and care and support planning.

Further help and information

From the DSA

The Information Team at the DSA would be happy to provide further information and answer any questions you may have..

Please call the helpline on 0333 1212 300 or email info@downs-syndrome.org.uk

[The Mental Capacity Act: frequently asked questions](#)

Government

[Statutory guidance relating to children of compulsory school age](#)

[Post 16 travel: Statutory guidance for young people of sixth form age](#)

[16-19 bursary fund](#)

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