

Moving to adult services – making decisions and giving consent

As children and young people develop and mature, most become increasingly able to make informed decisions about their own health care. This is an important part of getting ready to be an adult. Watching a young person taking on more responsibility for their own health can stir up all sorts of emotions for parents and carers – pride, relief, a sense of loss, pleasure, and anxiety (and sometimes all at the same time!).

The Law assumes that young people can make their own decisions from the age of 16 years onwards. Although sometimes they may be able to decide for themselves earlier than this.

Some young people and adults may never be able to do this or need extra help to make an informed choice around a particular health related decision. The Mental Capacity Act 2005 sets out what should happen in these circumstances.

For a detailed guide to all the issues relating to the Mental Capacity Act:



Mental-Capacity-Act-
Resource-Pack.pdf

What is the Mental Capacity Act?

The Mental Capacity Act 2005 is a law that applies to people in England and Wales. The purpose of the law is to support and empower people who are unable to make some or all decisions for themselves.

It applies to people who are 16 years and over. These decisions can be big or small decisions. In healthcare, these can range from whether to take a multi-vitamin through to whether to have a major operation.

What is meant by mental capacity?

Mental Capacity is when a person has the ability to:

- Understand information given to them in relation to a decision.
- Retain the information long enough to make a decision.
- Weigh up the information (this could include pros and cons or risks).
- Communicate their decision in any way which can be understood.

If someone can't make a decision for themselves on one occasion, it could be that they will be able to do this on another occasion. Their mental capacity should be considered in relation to each decision that comes up, to make sure that they have as much choice and control as possible over their own life.

What happens if a young person or adult struggles with decision-making?

Some young people and adults will always find it difficult, or impossible, to make decisions for themselves. Every day, the people around them who care for them and support them, make routine decisions on their behalf in their best interests.

As parents or carers, you know what sorts of decisions your young person can and can't make for themselves and act accordingly. For example, them choosing what to have for dinner may be fine – but not whether to take their medication (because they don't understand the risks of not taking it).

You will be exercising your judgement on these sorts of issues day in day out and be so used to doing it that you probably won't even give it a second thought.

From 14 to 16 years of age, these day-to-day situations won't change – but the practitioners working with your young person will increasingly want to make sure that your young person is provided with the information they need, in the right way, to be able to make their views known – and make decisions for themselves about healthcare when they can. Once a young person is 16 yrs, if the practitioner feels that the young person may lack capacity, they will carry out a mental capacity assessment. If the young person doesn't have capacity, then the practitioner will make a 'best interests' decision on their behalf. This might be so they can provide some new treatment or medication.

It can seem strange, or even be upsetting, to find that you can't make the decision on your young person's behalf any more but it's important to remember that this isn't because your views don't count, it just reflects the law. Your views will continue to be heard.

What is involved in a mental capacity assessment?

This will be carried out by the practitioner who is supporting the young person or adult with the particular issue. For example, if a decision needs to be made about a new medication, it would be the doctor who would be the "decision maker" as the doctor is responsible for prescribing the medication.

To give people the best possible chance of making decisions for themselves, the law expects that "practicable steps" will be taken to support the young person to make a decision. This might include:

- All the relevant information: including information about different options.
- Have opportunities to get support from other people who know them well.
- Get the information in a way that helps them understand e.g. it could be given in a different way, such as pictures or easy read guides.
- A suitable time of day to be considered: for example, if a young person is more likely to engage in an afternoon rather than a morning.
- Time – Can the decision wait? If the decision can wait the practitioner must consider additional time to be given.
- Information can be recapped and repeated if considered necessary and appropriate.
- This is not an exhaustive list, and other steps may be taken that are considered important to your young person. However, these are some examples.

- Give time for the young person to think about the decision and repeat information if necessary.

What is a 'best interests' decision?

The Law says anything you do or any decision you make for a person who lacks capacity must be in their "best interests" and "less restrictive". Practitioners making a "best interests" decision should:

- talk to people who know them to find out about their life (likely to be parents or carers when it is a young person)
- factor in anything that the young person has communicated (directly or indirectly) about what they want, how they feel and what they believe
- include the person in making the decision.
- put the person's needs at the centre – not those of anyone else.
- not make any assumptions about them, for example, because of their age or behaviour
- make sure the decision minimises any impact on their rights and freedoms.

If delaying the decision might mean the person can make it for themselves (for example, waiting for them to recover from an illness) then the law states that the decision should wait, unless it's urgent.

Can a parent get legal authority to make decisions about their young person's health and welfare?

Yes. This is possible in certain circumstances.

If a young person lacks capacity to make their own decisions about their health or welfare, then the Court of Protection can appoint somebody to be their 'deputy'. The 'deputy' would have legal authority to make particular decisions for the young person. This can be put in place from 16 years onwards. An application to the Court of Protection is required to become someone's deputy and the forms are accessible on the internet. There is a cost attached (however help for people on lower incomes can be supported).

For more information please see: [Deputies: make decisions for someone who lacks capacity: Overview - GOV.UK \(www.gov.uk\)](https://www.gov.uk/guidance/deputies-make-decisions-for-someone-who-lacks-capacity)

If the young person can make their own decisions currently – but may not be able to in the future. The young person may choose to nominate someone to support them. This is known as a 'Lasting Power of Attorney'. This can be applied for when the person turns 18 years old.



Mencap - Appointees
deputies and power of attorney

For more information about both:

Whatever arrangements are in place, ultimately decisions about healthcare will always be made in the person's best interests. Taking on board other people's views including parents, carers and guardians.

What decisions can under 16 year olds make?

If they have sufficient maturity and understanding, health practitioners may enable some children to make decisions about their own care before they get to 16 years, this is known as "Gillick Competence". They will normally be encouraged to talk it over with their families too. For example, they may be able to decide whether they want to:

- Go ahead with a brace for their teeth
- Get a vaccination
- Attend physiotherapy appointments
- Having an operation.

This does not apply to all children, just those who can demonstrate the level of understanding and maturity required to make an informed decision.

What changes when the young person gets to 18 years?

In terms of healthcare, not much changes when the young person gets to 18 years because 'Gillick Competence' and the legal changes on consent that happen at 16 years.

What happens if a young person is 16 or older but they don't want to engage with practitioners?

Sometimes young people may not want to take on more responsibility for making their own decisions. They might feel quite content to let their parent or carer continue to organise their healthcare and maybe quite satisfied for their parents or carers to have conversations with health practitioners on their behalf.

This can put both the parent/carer and health practitioners in a difficult situation when a decision needs to be made. Health practitioners have a legal duty to communicate with the young person about their options and establish whether they have the capacity to make the decision themselves. Parents and carers can feel stuck in the middle if their young person doesn't want to engage.

It can really help if a young person understands well ahead of their 16th birthday that things are going to change. Supporting them to think about how they can make their voice heard can really reap rewards further down the line.

What is advocacy?

Everyone has the right to have their voice heard, especially when it's about their health, care, and wellbeing.

Not everyone can do this easily - so that's where an advocate comes in. They give people a voice when they find it difficult to express their views, but more than that - they make sure that decisions about them are not made without them.

Some young people may benefit from having an advocate. Carers can also access the advocacy service. In Rotherham, Cloverleaf is commissioned to offer this support. For more information visit :[Cloverleaf Advocacy \(cloverleaf-advocacy.co.uk\)](http://Cloverleaf Advocacy (cloverleaf-advocacy.co.uk))

In a nutshell.....

This is a summary of the main changes to consent that happen as young people approach adulthood

Young people who are not able to make informed healthcare decisions, even with support

Ages	What the law says about consent
Before 16 years	Those with parental responsibility can give consent. Unless the child is considered to be "Gillick Competent".
16 years onwards	When decisions need to be made about health interventions, the practitioner will need to establish whether the young person has mental capacity to consent to the decision being made. If the person lacks capacity to consent, a 'best interests' decision will be made. This will take account of parents' and carers' views, as well as any other professionals involved in the decision required to be made. Parents / carers can apply to the Court of Protection to become a 'deputy' and make certain decisions for their young person.

Young people who may be able to make some or all of their own healthcare decisions if they get the right support

Ages	What the law says about consent
Before 16 years	If the young person demonstrates that they have the understanding and maturity to take a particular decision for themselves, then this is possible. They will be encouraged to discuss decisions with their parents/carers – but they can still make a decision that their parents think is unwise.

If they can't demonstrate that they have the understanding and maturity, parents / carers will take the decision, but taking into account their young person's feelings on the matter.

16 years onwards In healthcare, practitioners' starting point will be that young people are assumed to make their own decisions.

If there is a concern that the young person does not understand, or cannot retain, weigh, or communicate information in relation to the particular decision practitioners will assess their mental capacity.

Every effort will be made to give them the right information, at the right time in the right way to help them make the decision for themselves. This is known as "Practicable Steps". Practitioners will ensure all practicable steps have been taken that are relevant for the young person to engage with the assessment.

Parents and carers usually play a really important role in supporting the young person and helping them to understand what's being asked.

If it's still not possible for the young person to make their own decision, the practitioner will make a decision that's in their 'best interests'. This considers lots of different factors, including the views of the people who know the young person best (including parents and carers).

If the young person has capacity and wishes to make a Lasting Power of Attorney when they turn 18 years old. They can do this by applying to the Office of Public Guardian. If they lack capacity, to make health and welfare related decisions, you as the carer and / or parent can apply to the Court of Protection to become the person's deputy for health and welfare related decisions. You will need to follow the advice on the gov.uk websites for more information.