



Growing Up, Gaining Independence: information for families of young people with a Learning Disability

At Great Ormond Street Hospital we encourage and support young people to become as independent with their healthcare as they can be. Some people might always need someone else to help them manage their healthcare and to make health-related decisions for them. How these decisions are made and who can make them changes as people get older.

This information sheet provides information for families about decision-making when their child is unable to make decisions for themselves once they are 16. While your child is under 18 years old you may hold Parental Responsibility for them. Anyone with Parental Responsibility can manage decisions on their child's behalf, although certain aspects of this change when your child reaches 16 years old.

What changes do I need to be aware of?

When your child reaches 16 years of age they will fall under the Mental Capacity Act. This means that they must be assumed to be able to make decisions for themselves, including health-related decisions such as giving consent for examinations, treatments and tests.

If your child is aged between 16 and 18 you will only be able to make these decisions for them if they lack the mental capacity to do so and you have Parental Responsibility for them. You may not be able to make all health-related decisions on their behalf.

What is mental capacity?

Having mental capacity means being able to use and understand information necessary to make a decision and to communicate that decision. Someone who is able to do this is said to have capacity and someone who is not able to do this is said to lack capacity.

When is capacity assessed?

Capacity is decision-specific and each decision must be considered separately. This means your child's capacity must be assessed every time a decision has to be made. Capacity can vary according to how complicated the decision to be made is. For example your child might have capacity to decide what to wear or eat, but lack capacity to make complex health-related decisions. It is possible for someone to temporarily lack capacity due to ill-health, medication or stress.

How is capacity assessed?

The Mental Capacity Act says that someone must be able to do all of the following:

- Understand the decision that has to be made and all the information relevant to that decision
- Retain the information long enough to make the decision
- Balance the information (weigh up the pros and cons)
- Communicate their decision

If your child is unable to do any of the above they will be assessed as lacking capacity for that decision at that time.

Who assesses capacity?

When the decision involves a medical procedure or treatment the healthcare professional involved will usually assess your child's capacity and will do this by talking to you and your child.

Decision making for someone who is over 16 and lacks capacity

If it is clear that your child isn't able to make a particular decision then the decision must be taken on their behalf. The person making the decision may vary depending on the type, or complexity, of decision to be made. You might be able to make the decision or it might be made by a health professional or a social worker acting in your child's 'best interests'.

Who will decide what is in my child's best interest?

This will depend on the type of decision that has to be made. Usually the decision will be made by a group of people working together. The healthcare professional in charge of your child's care will work with you, your child, and other health professionals to make sure any decisions taken are in their best interest.

What happens if we do not agree on best interest?

It can sometimes be complicated deciding what is in someone's best interests and parents and health professionals may disagree, although this is rare. The Mental Capacity Act and the Court of Protection provide guidance on what must happen in this situation. If necessary, the Court of Protection can be asked to decide on the right course of action and will make the decision.

What happens after my child's 18th birthday?

After their 18th birthday, even if you had Parental Responsibility, you won't be able to make health-related decisions unless you have been appointed as a Deputy by the Court of Protection. Everyone loses Parental Responsibility when their child reaches 18 years old. Decisions about treatment will be made by two Consultants in your child's best interests. They must consult you and listen to your views before making a best interests decision.

Mencap have more information about best interests decisions. Their helpline number is 0808 808 1111.

Becoming a Deputy under the Court of Protection

Some parents apply to become a 'Deputy' under the Court of Protection. If their application is approved they can usually continue to consent to medical treatment and/or manage their child's affairs after their 18th birthday. There are two sorts of Deputy – one covering property and financial affairs and the other covering personal health and welfare issues. Sometimes there are restrictions on the decisions that a Deputy can make. If you want to become a Deputy you will need to apply to the Court of Protection for both of these. There will be a cost involved but you may be able to get help if you are on a low income. Further information on becoming a Deputy is available at www.gov.uk/becomedeputy/overview.

Are there other changes I should know about?

Benefits

You might be receiving a Disability Living Allowance (DLA) payment to help with any additional costs of caring for your child. When they are 16 they will need to be reassessed to see if they qualify for a different payment called a Personal Independence Payment (PIP). The Department for Work and Pensions (DWP) will contact you before their 16th birthday to explain how to claim for a PIP. More details are available at https://contact.org.uk/media/1163273/pip_guide.pdf or from your local Citizens Advice Bureau (CAB).

Local service changes

The age that children's health services finish and adult health services start varies depending where people live. In some areas, adult services start at 16 years and in others they start at 18 years. It is a good idea to find out what age this happens where you live. Once your child is 16, if they became unwell or had an accident and needed to go to hospital they might be admitted to a children's or an adult ward depending on where you live. Your local General Practice (GP) clinic would be able to help you find out about the changes occur in your area.