



# Children's Community Nursing

## Transitioning to Adult Services Growing Up, Gaining Independence

### Information for families of young people with a Learning Disability

If you would like this information in another language or format, please contact the **Community Children's Nursing Team** on **0203 316 1950**.

- At Whittington Health 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.
- This information leaflet provides information to families about decision-making when their young person is unable to make decisions for themselves, once they are 16 years old.

### How are these decisions made and who gets to make these decisions as young people get older?

- When your young person is under 18 years old you may hold Parental Responsibility for them.
- Anyone with Parental Responsibility can make decisions on their young person's behalf, although certain aspects of this change when they reach 16 years old.

### What changes do I need to be aware of?

- When your young person reaches 16 years of age, they are covered by the Mental Capacity Act.
- This means that they are considered capable of making decisions for themselves, including health-related decisions, such as giving consent for examinations, treatments, and tests.
- If your young person 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 so that you can make choices and talk about those choices.
- When someone can do this, we say they have **capacity**. But if someone is unable to do these things, we say they **lack capacity**.

## When is capacity assessed?

- Capacity means being able to make decisions, but it's not the same for every decision.
- Each time your young person needs to decide something, we look at their ability to make that choice.
- We take it one decision at a time to see if they can do it.
- Just because they can decide one thing does not mean they can decide everything the same way. Each decision is unique.
- For example, your young person might have capacity to decide what to wear or eat but lack capacity to make complex health-related decisions.
- It is also possible for someone to temporarily lack capacity due to ill-health, medication, or stress.

## How is capacity assessed?

The Mental Capacity Acts says that a person must be able to do the following:

- Understand the decision that has been 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 young person 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 young person's capacity and they will do this by talking to them and you.



### Decision making for a young person over 16 and who lacks capacity

- If your young person is unable to make a particular decision, then the decision must be made on their behalf.
- The person making the decision may vary, depending on the type, or complexity of the decision being 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 young person's **best interests**'.

### Who decides what is in my young person's best interests?

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

### What happens if we do not agree on best interests?

- 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 young person's 18<sup>th</sup> birthday?

- After their 18th birthday, even if you had Parental Responsibility, you will not be able to make health-related decisions for them, unless you have been appointed as a **Deputy** by the Court of Protection.
- A "deputy" in parental responsibility, is appointed by the court to help make decisions for a young person who is unable to make decisions for themselves.
- Everyone loses Parental Responsibility when their young person reaches 18 years old.
- Decisions about treatment will be made by two Consultants in your young person's best interest.
- They must talk to you and listen to your views before making a **best interest** decision.



- Mencap have more information about best interest 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 young person's affairs, after their 18th birthday.
- There are two sorts of Deputy – one covers property and financial affairs and the other, covers 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.
- There is a cost involved, but you might 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](http://www.gov.uk/becomedeputy/overview)

## Are there other changes that 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 young person.
- When they reach 16 years old, 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](https://contact.org.uk/media/1163273/pip_guide.pdf) or from your local Citizens Advice Bureau (CAB).

### Local service changes

- The age when children's health services end, and adult health services start, can vary.
- This can depend upon where people live.
- In some areas, adult services start at 16 years old and in others, they start at 18 years old.
- It is a good idea to find out what age this happens where you live.
- Once your young person is 16, if they become unwell or have an accident and need to go to hospital, they might be admitted to a children's ward or an adult ward, depending on where you live.
- Your local General Practice (GP) clinic can help you to find out about these service changes in your local area.



### Patient advice and liaison service (PALS)

If you have a compliment, complaint or concern please contact our PALS team on 020 7288 5551 or [whh-tr.PALS@nhs.net](mailto:whh-tr.PALS@nhs.net)

If you need a large print, audio or translated copy of this leaflet please email [whh-tr.patient-information@nhs.net](mailto:whh-tr.patient-information@nhs.net). We will try our best to meet your needs.

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