

Transitioning to adult healthcare with a learning disability

This leaflet is for young people with a learning disability and their parents or carers. It explains the process for moving from paediatric (children) to adult services, and how the services supporting you will change.

Introduction

Learning disabilities (LD) and difficulties are common and may occur with complex health conditions or without. They start in childhood and may need you to have a wide range of professionals involved to help keep you healthy. Your GP will usually be responsible for routine prescribing of medications and seeing you for typical childhood illnesses.

When you are between 16 and 18 years of age, your healthcare will transition (move on) to adult services.

Transition is the process in which your care moves from paediatric to adult services. Some things may change but many things still stay the same. We often start early – around 14 years – so that there is plenty of time to plan.

Often, we tell parents / carers a lot about their learning and development when a child may be too young to understand. When you are older and ready to become more independent, it is very important that you know as much as you can about your own health, and how to manage your condition.

There are some specific laws that may relate to the way that decisions are made, which you may need to know about.

Associated conditions

Young people with a learning disability may be otherwise healthy, but can often have other conditions, for example epilepsy, dyslexia or anxiety. Sometimes, they may have more complex conditions, for example, Cerebral Palsy.

If you have an associated condition, then your paediatrician (hospital doctor) should be planning for the ongoing care of those conditions:

- **Neurodisability (e.g. Cerebral Palsy, Duchenne Muscular Dystrophy, etc)** – there is a separate information sheet you can ask for, to help guide your transition to adult services.
- **Epilepsy** – there is a separate information sheet you can ask for, to help guide your transition to adult services.
- **Complex planning** – when you have a large number of people involved in your care, it can be helpful to have a table drawn up, to describe who is looking after you now and who will look after you in the future. This helps you and the team plan for how to get there. Your team can start planning this from around 14 years of age, if needed. Your paediatrician might not know all the answers when you start, but you can work together to fill it in.

What do I need to know about before I move to adult services?

Your Paediatric team will share the information you need to get ready for adult health services. This may include some or all of the following topics:

- Who will be looking after your health condition/s.
- A range of adult matters including contraception, drugs, alcohol.
- How to keep yourself safe as you become more independent.
- Whether you might be eligible for driving.

They will also offer you the questionnaires from the **Ready Steady Go Programme**. These help the team know what information you need, as you get older.

You may have an EHCP (Education Health Care Plan) in place – Education should be planning with you about where to go for training after you are 16 and what jobs you might have and what you might like to do with your time. This will usually start when you are 14 years old.

The **Mental Capacity Act** is a law that you need to know about for when you are over 18 years old (and some decisions between 16 and 18).

- This means that where you can make decisions, then people should allow you to do so.
- The law also tells people how to make a decision if it is too tricky for you to make.
- There is a separate **information sheet** you can ask your hospital doctor for.
- You can ask your social worker for more information about this too.

You might like to try to learn the **'Ask 3 questions'** – these help you to be able to get the information if you are feeling nervous and are useful for anyone. There are always people about to help you if it is a tricky decision. If someone suggests an investigation or treatment (for example a new medicine), you can ask him or her:

- What are my treatment choices?
- What are the good things (benefits) and the bad things (risks) about those choices?
- What will happen if I decide **not** to do those treatments?

What will happen in different services? – In the hospital

In the hospital, there are two **Learning Disability Liaison Nurses**, Catherine Bradley and Jane Wooldridge, who can help you once you become an adult.

- Sometimes, they come to the Epilepsy or Neurodisability Transition Clinic. If you think this would be helpful, please let the administration team or your doctor or nurse know.
- If you have to have investigations in the future and need some support with these, then the LD nurses can be involved.
- If you need to come into hospital to be looked after because you are poorly, then they will help your team to find out how to look after you. For example, they might help your team know how to make sure that decisions are made that are right for you.

If you need to come to hospital for a lot of appointments, or admissions (day or night time stays in hospital) then you might like to use a **Hospital Passport**, where you and your family can put information about things you find tricky and things that help you. This helps the doctors and nurses to know how to help you best. Ask your hospital doctor or the LD nurses if you would like to start a Hospital Passport now. It can be used at any hospital that you go to be seen.

What will happen in different services? – Social services

Many young people find it helpful to have a transition social worker from the Disability Team (social services) to help with their planning, especially if they need care and respite. This social worker will help with your planning too; for example, where you might want to live, who might care for you. This will usually start from 14 years old. Please let someone in your team know if you need help getting referred.

What will happen in different services? – Education

You may have an EHCP (Education Health Care Plan) in place – Education should be planning with you about where to go for training after you are 16 years old and what jobs you might have and what you might like to do with your time. Your school team will usually start planning from 14 years old.

What role does my GP play?

Your GP will also become an increasingly important person in your care, as they may be able to make changes to your medication. Try to book a review on a yearly basis with your GP to review how things are going.

If you have a learning disability, it is important that you and your carers let the GP surgery know that you need to be on their **LD register**. This will entitle you to an **Annual Health Review** with your GP. This is usually a 30-40 minute appointment, once a year, where someone in your GP's team will talk with you about the following:

- Are your medicines right for you?
- Is your health good? They might check your blood pressure and listen to your heart or breathing.
- Is it easy for you to get to the GP practice or do they need to make any modifications when you are unwell (these are called 'reasonable adjustments')?
- Are there any adult screening tests that need to be considered, for example the Cervical Screening Programme?
- Are there any immunisations (regular 'jabs') which you need to have (e.g. winter flu vaccine)?

Further information about transition to adult services

Please ask your medical team for more information as you or your parents/carers need it.

To find out more about our Trust visit www.royalberkshire.nhs.uk

Please ask if you need this information in another language or format.

Dr S Hughes, Revised May 2023

Next review due: May 2025