

Transitioning to adult healthcare with a neurodisabling condition

This leaflet is for young people with a neurodisability 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

Many conditions that affect the neurology (nerve) or muscular systems, such as Cerebral Palsy and Duchenne Muscular Dystrophy, start in childhood or adolescence. During this time your care is supported by paediatricians (hospital doctors specialising in care of children) and a wide range of professionals, such as physiotherapists. Your GP will usually be responsible for prescribing routine medications and treating you for typical childhood illnesses.

When you are between 16 and 18 years of age, your healthcare will transition (move on) to adult services. Adult neurodisability care is provided by a combination of neurologists, neuro-rehabilitation consultants, epilepsy specialist nurses and a range of professionals, depending upon the care that you need.

Transition is the process in which your care moves from paediatric to adult services. Often, we tell parents/carers a lot about conditions 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.

Associated conditions

If you have an associated condition, then your paediatrician should be planning for the ongoing care of those conditions.

- **Epilepsy** – there is a separate information sheet you can ask for, about a young person's epilepsy transition to adult services.
- **Learning disabilities/difficulties** –there is a separate information sheet you can ask for to help you and your parent/carer with transition and about the Mental Capacity Act.
- **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. Please ask if this would be helpful for you.

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 services. This may include some or all of the following topics:

- Who will be helping you to look after your condition.
- 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.
- How your health might change as you get older.

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 other doctors and professionals looking after other parts of your health and they will need to give you information about the plans for transitioning those aspects of your care as you get older.

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 person will help with your planning too; for example, where you might want to live, who might care for you. This will usually start when you are 14 years old.

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.

What will happen in the Neurodisability Transition Clinic?

When you are between 16 and 18, depending upon your needs, you may be offered an appointment in the Neurodisability Transition Clinic.

This clinic usually has the following people in it:

- Paediatrician with special interest in Neurodisability (Dr Hughes, Dr Lomp or Dr Babu),
- Neurorehabilitation Consultant (Dr Feroz and team).

The following people may join your appointment, depending upon your needs:

- Adult Learning Disability Liaison Nurses (Catherine Bradley or Jane Wooldridge)
- Adult Respiratory Consultant (Dr Grace Robinson) and Physiotherapist (Frankie Knight)
- Epilepsy Transition Nurse (Hannah Gerrard)

They will:

- Review a summary of your medical history, before you arrive.
- Ask you how your condition currently is.
- You may have questions about what will happen with your condition as an adult.
- We can talk about how to keep yourself safe, and whether there are any things you are eligible for.
- A plan will be made for your follow-up and contact details shared.

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.

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, May 2023

Next review due: May 2025