

# Transitioning to adult healthcare with epilepsy

**This leaflet is for young people with epilepsy 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

Epilepsy often starts in childhood or adolescence and is managed by paediatricians, paediatric epilepsy nurses and paediatric neurologists. 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 (including epilepsy care) will transition (move on) to adult services. Adult epilepsy care is provided by a combination of neurologists, epilepsy specialist nurses and your GP.

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

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

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

- **Learning disabilities/difficulties** – there is a separate information sheet you can ask for to help you and your parent with transition and about the Mental Capacity Act.
- **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.

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

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

- Who will be looking after your epilepsy.
- 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.

## Roald Dahl Epilepsy Transition Nurse

When you are over 14, we will aim to introduce you to our Transition Epilepsy Nurse, sponsored by the Roald Dahl Charity, in one of your clinics. She can see you if you are between 14 and 25 with a diagnosis of Epilepsy. We hope that this will make it easier for you to move across to adult care safely. You can ask to meet with Hannah Gerrard by yourself or with your parents if you need help getting ready to manage your epilepsy, or have questions about how to keep yourself safe. You can contact her through [rbb-tr.cat7@nhs.net](mailto:rbb-tr.cat7@nhs.net) or 07721599778.

## What will happen in the Epilepsy Transition Clinic?

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

This clinic usually has the following people in it:

- Paediatrician with special interest in epilepsy (Dr Hughes or Dr Aldouri),
- Neurologist leading for epilepsy (Dr Armstrong)
- Transition Epilepsy Nurse (Hannah Gerrard) and/or Adult Epilepsy Specialist Nurse (Jackie Scott).
- You may also have one of the hospital Learning Disability Liaison Nurses (Catherine Bradley or Jane Wooldridge) in the clinic if you struggle with your learning.

The team will:

- Review a summary of your epilepsy history, before you arrive,
- Ask you how your epilepsy currently is.
- It can be a good time to review the type of epilepsy you have
- You may have questions about what will happen with your epilepsy 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.

Please contact the paediatric epilepsy specialist nurses if you would like more information about transition – they can be contacted by:

- Emailing [rbb-tr.cat7@nhs.net](mailto:rbb-tr.cat7@nhs.net)
- Calling 07721 599 778
- Booking an appointment on 0118 322 7531 (option 1)

To find out more about our Trust visit [www.royalberkshire.nhs.uk](http://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