Epilepsy

Transition 1 (Learning Disability)

Welcome

Children's epilepsy care moves to the adult services between the ages of 16-18.

If your child is at special school or receiving a high level of support in mainstream education, we will usually do this move around their 18th birthday. This change of care to adult services is called 'transition'.

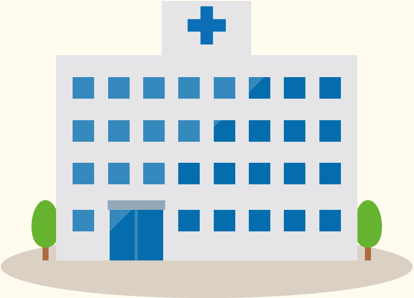
This is the first of 3 leaflets we have written to help you and your child be ready for the move to adult epilepsy care.

Contents

1 Transition

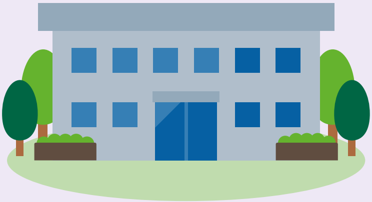
If your child has a learning disability, they will usually move to adult epilepsy services around their 18th birthday.

There are 2 different epilepsy nurse teams in Hull. The same group of consultants work in both teams but they have different epilepsy nurses and work a bit differently. The adult consultants decide which team will manage your child's care.



If your child doesn't have a very severe learning disability, they will probably go to the Hull Royal clinics. You can still attend all the appointments with your child. Adult health care, including epilepsy, is usually managed by your GP. If you have a particular problem, that is when your GP might refer you to see an epilepsy specialist at hospital.

At the first adult epilepsy appointment, the consultant will decide if they or the GP will manage their epilepsy care. The adult epilepsy team might discharge back to the GP once your child's epilepsy is settled.



If your child has epilepsy and has a very severe learning disability, they will probably go to the community epilepsy clinics. This specialist epilepsy team is part of a much larger team and together they form the adult Community Team for people with a Learning Disability (CTLD). Other members of the team in include specialists such as physios, Occupational Therapists (OTs), behavioural support nurses and complex disability nurses. If your child has a learning disability, they may still be able to use some of these other adult services.

2 Asking questions and making decisions

If you are able to, it's important that your child gets the chance to learn about their health and learn how to make decisions. It might take them a long time to get used to doing this so they'll need practice.

To help get your child involved and have choices, encourage your child to ask questions at health appointments or to tell the doctor or nurse something about their health (for example, the last time that they had a seizure or what medication they take).

Is your child able to ask a question or tell the nurse/doctor something?

Can they think about coming into part of the appointment on their own?

3 Epilepsy knowledge

In adult services, you usually deal more with your GP about your child's health needs than a hospital specialist, so it's more important that you and your child know a lot about their epilepsy and you have a good relationship with your GP.

Will your child be able to answer the following questions?	No	Working on it	Yes
What is epilepsy?	○	○	○
What do their seizures look like?	○	○	○
How do those around them manage their seizures?	○	○	○
What medication do they take?	○	○	○
How much medication do they take?	○	○	○
Do they know what is meant by 'side effects'?	○	○	○
Do they know if anything triggers their seizures?	○	○	○

4 The learning disability register and GP health checks

If your child has a learning disability, they should be on your GP's learning disability register. This means that your GP should make reasonable adjustments to make sure your child doesn't miss out on having their health needs assessed and met. For example, they might give you longer appointments. It's important that the GP knows if your child has a learning disability so they don't miss out on health care, especially when they get older.

Has your GP registered your child as having a learning disability?

Being on the register also means that your child may get an annual health check. Most GPs will offer people with a learning disability a yearly health check from the age of 14. It's not always easy to identify health problems early in this group of people, so it's important to have regular health checks. Your GP should check your child's physical and mental health. It's also a good idea to go to your GP when your child is well so they can get to know GP and see what happens there.

Most GPs offer these health checks, but not all. You might need to change GP if you want this service.

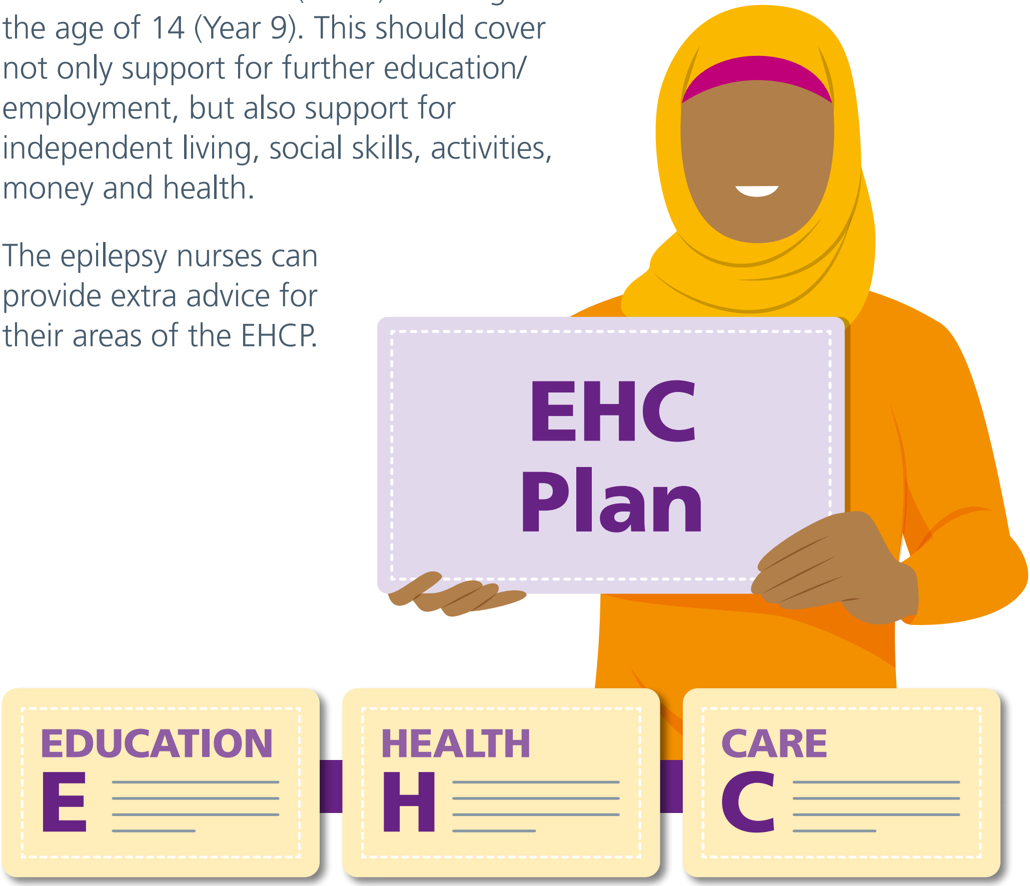
There is also a move to ensure that everyone having a GP health check has a health passport made with the GP that can be use at the GPs or in hospital. This passport tells people a little more about your child, what they like, don’t like, how to communicate with them, what scares them, etc.

5

Education and Health Care Plans

Your child's school will start to talk about transition into adulthood in the Education and Health Care Plan (EHCP) meetings from the age of 14 (Year 9). This should cover not only support for further education/employment, but also support for independent living, social skills, activities, money and health.

The epilepsy nurses can provide extra advice for their areas of the EHCP.



School can refer you to a transition social worker to help with the move to adult services. They cover extra care support that your child might need when they are 18.

Parents can also request a 'Carers Assessment' for a social worker which takes into account your own personal needs, for example, if you work or have your own health needs.

Resources

- **Scope: scope.org.uk** (then search 'Transition')
  General learning disability support around transition, hospitals and doctors, making decisions, banks, benefits and social care.
- **Epilepsy Action: epilepsy.org.uk**
  Charity to improve the lives of everyone affected by epilepsy. Advice and support.
- **Contact: contact.org.uk**
  Charity for families with disabled children.
- **Together for short lives:**
  Charity helping families caring for a serious ill child.
- **Mencap:**
  Charity adding value and support to people with a learning disability, their families and carers. Advice on transition, education and employment, relationships/sex, housing, health.
- **My adult, still my child: www.myadultstillmychild.co.uk**
  Outlines the legal changes that happen to consent when your child is an adult.
- **Preparing for Adulthood: preparingforadulthood.org.uk**
  Aimed at professionals but has some good links to resources and national guidelines.

We are Young Epilepsy

Epilepsy can be frightening, and it can feel lonely. Sometimes people just don't understand what you are dealing with.

Young people living with epilepsy have told us how important it is for them to understand their condition, and how making connections with other young people, and hearing their experiences, really helps.

From trusted information and real stories about living life with epilepsy, to support services and opportunities to have your say and influence the world around you, we're here for you.

youngepilepsy.org.uk

GO PURPLE

GET TALKING ABOUT EPILEPSY

For more information about epilepsy, what it is, and how it is managed can be found on these websites:

www.epilepsy.org.uk

www.youngepilepsy.org.uk

www.youngminds.org.uk

www.howareyoufeeling.org.uk (Hull)

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