Epilepsy

Transition 3 (Learning Disability)

Welcome

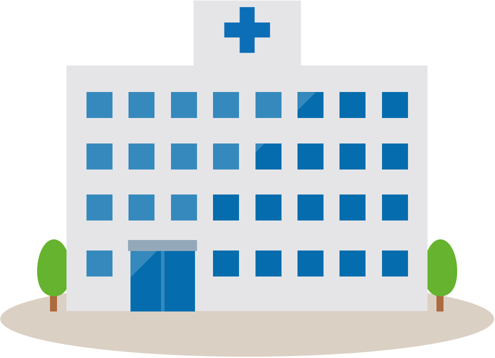
Children's epilepsy care moves to the adult services at the age 18 years.

If your child is at special school or receiving a high level of support in mainstream education, we will usually do this around their 18th birthday. This change of care to adult services is called 'Transition'. This is the third of 3 leaflets we have written to help you and your child be ready for the move to adult epilepsy care.

Contents

1. Transition clinics
2. Learning disability liaison nurse, the flag system and hospital passports
3. Working on being independant
4. Stress and anxiety
5. Alcohol and drugs
6. Bone health

1 Transition clinics



As discussed in leaflet 1, when your child moves to adult services, the adult consultant will see them first to decide if they or the GP will manage your child's epilepsy care. There may be a specialist epilepsy service for young people with a learning disability in your local area or at your local hospital. It would be common practice to see the adult consultant before children's services completely cuts ties. If adult services have an adult epilepsy nurse, you may see them after seeing the adult consultant. The adult epilepsy team might discharge back to your GP if your child's epilepsy is settled, but you can ask your GP for a referral back if you need to.

A clinic appointment with you, your child, the children's epilepsy nurse and adult epilepsy nurse, will usually take place just before transition is complete. This gives you and your child the chance to meet someone from the team and for your care to be handed over to the nurses.

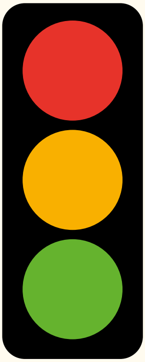
Many epilepsy services will try and offer you a joint appointment with both the child and adult epilepsy teams and your care will normally remain with the childrens team until your first appointment.

2

Learning disability liaison nurse, hospital Passports and Red flags

A lot of hospitals either have a learning disability liaison nurse or a frailty team that may be able to support making extra reasonable adjustments to enable care to take place. If you're unsure, the Patient Advice and Liaison Service is a common facility that could direct you.

A red flag that can be attached to your child's hospital record. If admitted, it may let the ward know in advance that your child has extra needs and will also alert the adult learning disability liaison nurse that a person with a learning disability has been admitted to a ward. This flag can be personalised to your child's specific needs. The red flag is not added automatically. We try and do this before your child leaves our service or you can ask for it to be added later on. It's not always possible to stay with your child on an adult ward.



A hospital/health passport can be completed and added to hospital records. This helps hospital staff understand your child and their learning needs better. If your child has a learning disability or autism, and they needs certain things in place for them to access health services, this is called "Reasonable Adjustments" and is a legal requirement. The traffic light symbol is often used to show that someone has a hospital/health passport and needs Reasonable Adjustments.

3 Working on being independent

If your child can be more independent they may need plenty of time to practice with you there to support them. Hopefully they will then be confident to be involved in making choices on how to manage their health when they get older.

In the first leaflet we talked about transition to adult health care and your child growing into an adult. We asked what your child knew about epilepsy, their seizures and medication.

Questions your child might be working towards	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?	○	○	○
Can your child spend the first few minutes of the clinic appointments on their own?	○	○	○
Can your child ask questions or tell me something about their health at appointments?	○	○	○
Can they remember to take their medication?	○	○	○
Do they help keep a seizure diary?	○	○	○

We also talked about being on the GP learning disability register and having yearly GP learning disability health checks.

Is your child registered at the GP as having a learning disability?

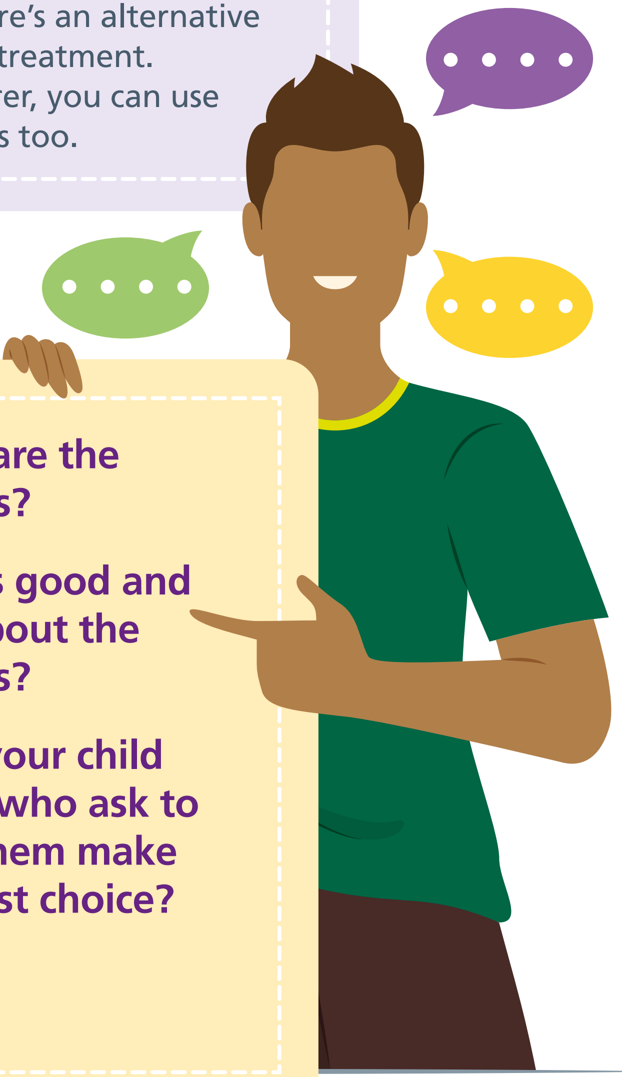
Are they getting a yearly GP learning disability health check?

And, we mentioned social workers. Transition social workers can help you and your child with the move to adult council services, extra support and independence. Schools usually do the referral.

Does your child have a transition social worker?

Look up on your local offer.

If able to, you could encourage your child to be even more involved in their epilepsy care. They can ‘Ask 3 Questions’. This may be for a new treatment choice or to see if there’s an alternative to the current treatment.
As a parent/carer, you can use these questions too.



1. **What are the choices?**
2. **What’s good and bad about the choices?**
3. **Does your child know who ask to help them make the best choice?**

4

Stress and anxiety

Both epilepsy and epilepsy medication can affect mental health. Low mood and stress are very common in the general population, more common in people with epilepsy, and even more common in people with learning disabilities.

Stress and anxiety can make people feel sad, anxious, worried, tired, frustrated, or angry.

This might be a side effect of the epilepsy medication – talk to your nurse or doctor if you think it could be a side effect.

What does your child do when they're stressed or anxious?

....

....

What make them stressed?

....

....

Do you know how to get extra support if you need it when they're sad, upset or angry?

....

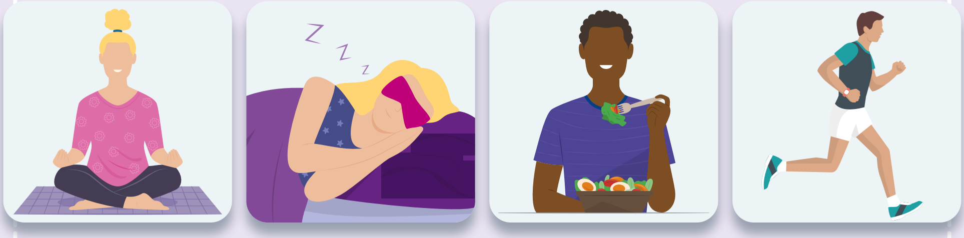
....

It’s also important to look after your own mental health

- Making small changes in life can sometimes help to improve your mood. Usually it lifts within a few days or a week. If it carries on for longer, it might be worth discussing with your GP to try and get some help.
- Apps like Headspace and Calm have useful information and advice to help.

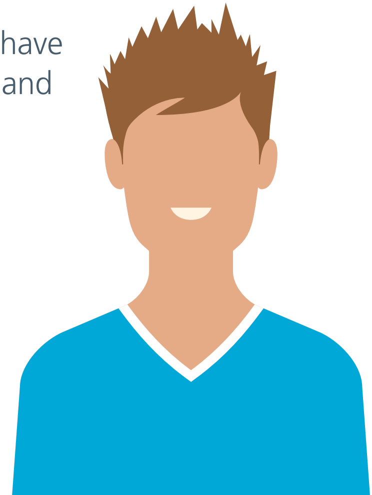
Tips to reduce stress and anxiety for you and your child

- Relaxation techniques like meditation, deep breathing techniques and grounding (eg, 5,4,3,2,1 grounding, square breathing, tracing the outline of an object with your eyes).
- Do something little you enjoy every day.
- Sleeping well.
- Eat a well-balanced diet. Lack of vitamins and minerals can make you feel unwell and tired.
- Exercise – it releases natural happy hormones and makes you more relaxed. Even if it’s just going for a walk somewhere that’s peaceful and green.



Children with autism, or features of autism, often have difficulties with managing sensory input like noise and touch. This can affect their behaviour.

For useful information, visit:
www.sensoryprocessinghub.humber.nhs.uk



5

Alcohol and recreational drugs

Alcohol in small amounts may not trigger seizures, but most people are at risk of seizures if they drink a lot. The risk is still there for up to 48 hours after you stop drinking alcohol.

Drinking alcohol can cause poor sleep. Lack of sleep can trigger seizures.

Taking drugs like cannabis, ecstasy and cocaine can make seizures worse.

Do you drink alcohol or take recreational drugs?

It’s not clear if normal use of E-cigs/vaping or cigarettes make seizures worse, but very high doses of nicotine have been known to trigger seizures.

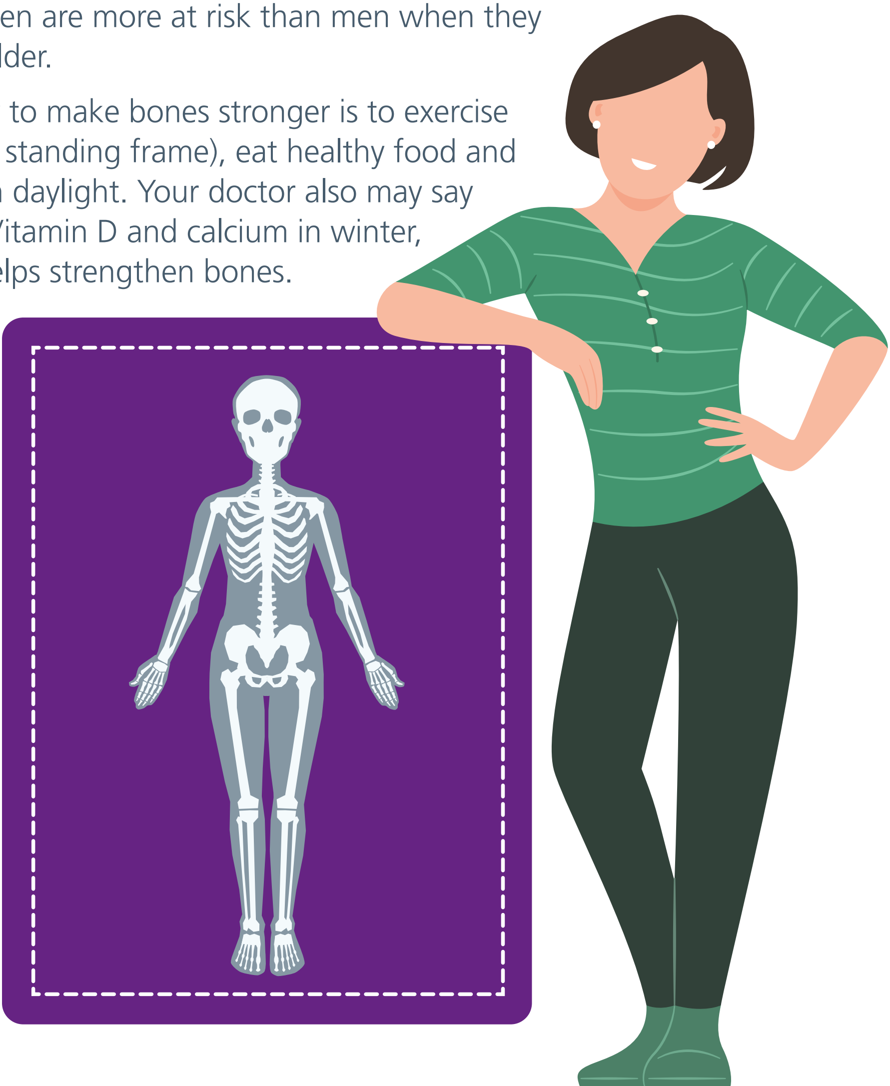
6

Bone health

Epilepsy medication can cause bones to become weaker and more likely to break. This is even more likely to happen if:

- your child is taking more than one anti-seizure medication
- has difficulty doing physical activities
- has a poor diet
- Your child doesn’t spend much time outside.
- Women are more at risk than men when they get older.

One way to make bones stronger is to exercise (or use a standing frame), eat healthy food and go out in daylight. Your doctor also may say to take Vitamin D and calcium in winter, which helps strengthen bones.



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**
  (currently working on resources for transition) charity for families with disabled children. Bringing families together.
- **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.
- **"The Local Offer":** This is set up by all English (not sure about UK) councils and list all SEND for 0-25 facilities in the local area. For example: Hull Local Offer, Scunthorpe Local Offer.

Young
Epilepsy

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

Developed by Children's Epilepsy Nursing Team,
Hull University Teaching Hospitals NHS Trust, with support from Young Epilepsy.

NHS
Hull University
Teaching Hospitals
NHS Trust

Young
Epilepsy

CS57661 NHS Creative 2025