Epilepsy

Transition 2 (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 around their 18th birthday. This change of care to adult services is called transition.

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

Contents

1 Practising being independant

In the first leaflet, we talked about transition to adult health care and your child growing into an adult. If able to, we asked what your child knew about epilepsy, their seizures and their medication and talked about being more independent in the clinic.

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 talk about their health at appointments?	○	○	○

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?

2

Reducing your child's risk of SUDEP

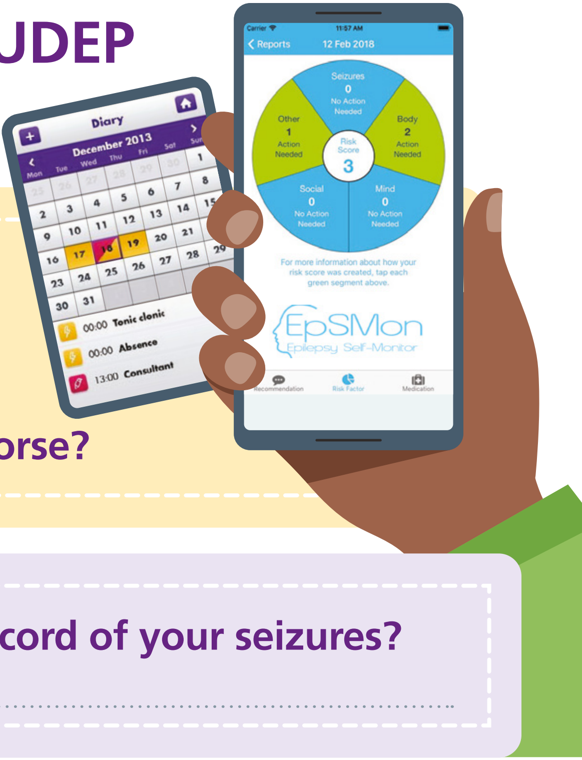
SUDEP stands for Sudden Unexpected Death in Epilepsy (**www.sudep.org**)

SUDEP Action
SUDEP.ORG

The risk is rare in children – approximately 1 in every 4,500 – but the risk increases when they get older. This is partly because of lifestyle choices, worsening health or because your child is more independent, so won't have as many people around them to notice if seizures are getting worse. It is therefore important. that your child gets more involved in their health care.

Ways to reduce SUDEP

Keep a seizure diary



Do you or your child keep a diary of your seizures and tell your nurse or doctor if seizures are getting worse?

How do you keep a record of your seizures?

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Is your child able to help keep a record of seizures?

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Looking after your child's health

Like other health conditions, it helps to keep healthy. By keeping fit, eating and sleep well, the risk of seizures decreases.

How does your child stay healthy?

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Is there anything that makes it difficult for your child to stay healthy?

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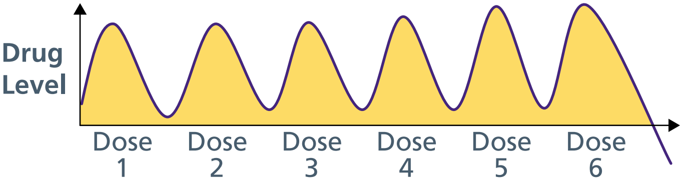
Read the drug leaflet

All medication comes with a drug leaflet. This will tell you things like what to do if you forget a dose or take too much, what other drugs might affect epilepsy medication and side effects.

Taking medicine at the right time

Medication levels in the body rise when it’s taken and lowers in between doses. If a dose is missed, the medication level can get too low and cause your child to have a seizure.



Remembering to take medication every day is an important part of epilepsy care.

Is your child able to take their medication on their own?

Can you encourage your child to remember to take their medication?

What to do if you run out of medication

It's important that you don't miss a dose as this can make seizures worse.

If you do run out, call your GP surgery, or your epilepsy team to ask for an emergency supply. If you can't do this, go to your usual pharmacy and ask if they can give you an emergency supply.

If you can't go to the pharmacy, ring **111** to see if they can get you an emergency supply.

Triggers

Sometimes certain things can make it more likely you child will have a seizure. This might be things like over-excitement, boredom, having a period, flashing lights, illness or tiredness.

Do you know of anything that triggers seizures?

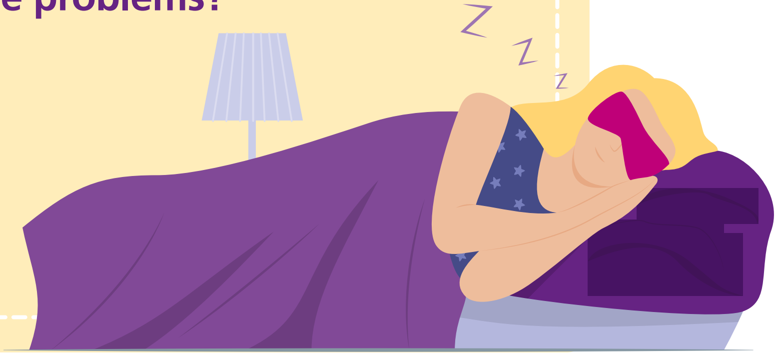
Does your child and those around them know what triggers their seizures?

Sleep

Poor sleep is a common trigger for seizures.

Does your child have trouble sleeping?

Does it cause problems?



Seizure monitors

If your child has seizures in sleep, there is an increased risk of SUDEP. Having a night time seizure monitor can help you treat seizures that you might not be aware of.

You will need to choose the right sort of monitor carefully to pick up the type of seizures your child has. You may need to speak to a member of the sales team to make sure you get the right monitor.

Do you have a night time seizure monitor?

3

Education and learning

Epilepsy can sometimes affect what higher education courses your child can do. For example, if their seizures are happening a lot in the day time, they might not be able cook with hot ovens as there maybe a high risk of them being burnt.

What does your child want do when they leave school?

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....

Other people looking after your child

It's important that whoever is looking after your child knows what epilepsy is, how to spot seizures and what to do to help your child when they have a seizure. When your child is with children's services, we offer epilepsy training to schools and write epilepsy plans for them. When they go into the adult services, the adult nurses still offer epilepsy training but are less likely to write epilepsy plans. Adult education placements may need you to help write an epilepsy management plan.

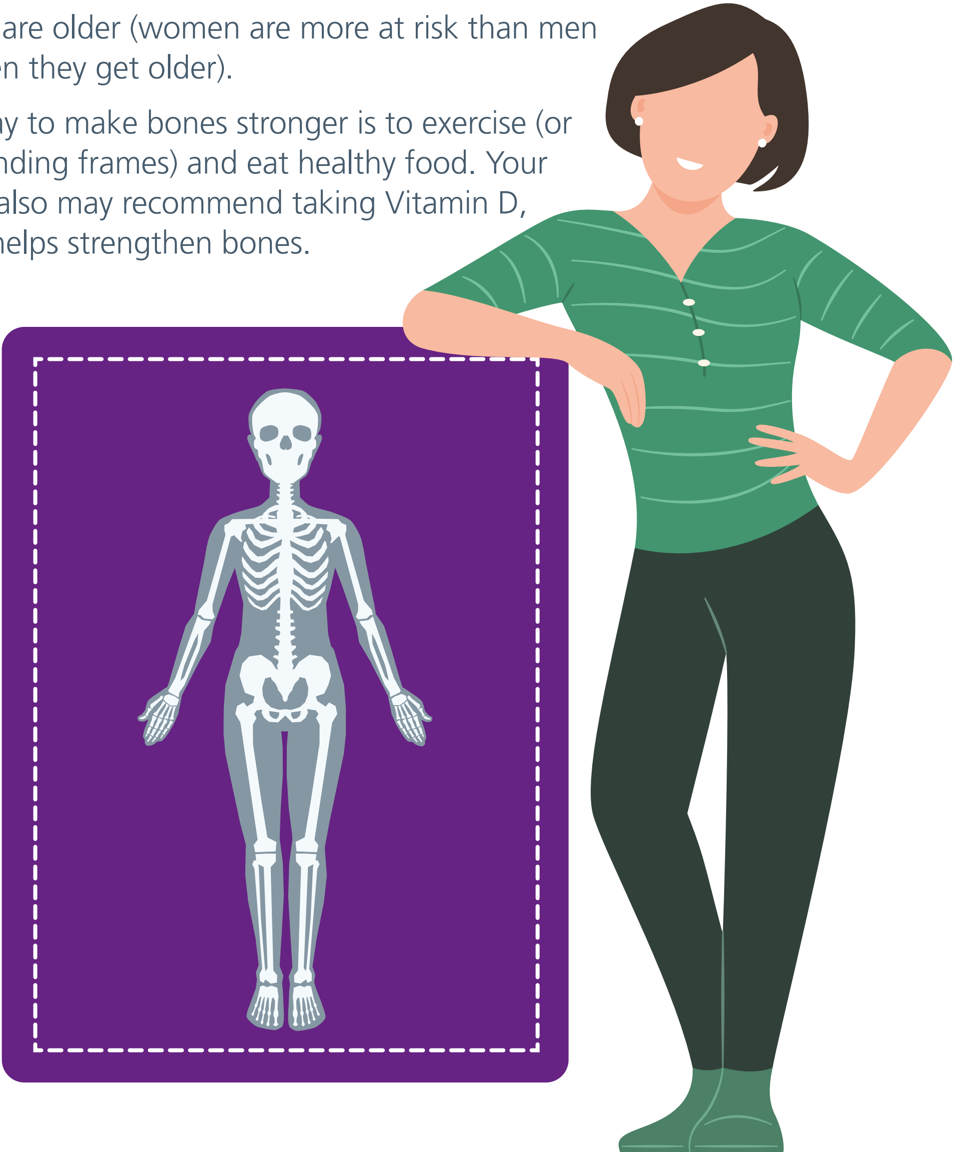
4

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
- you are older (women are more at risk than men when they get older).

One way to make bones stronger is to exercise (or use standing frames) and eat healthy food. Your doctor also may recommend taking Vitamin D, which helps strengthen bones.



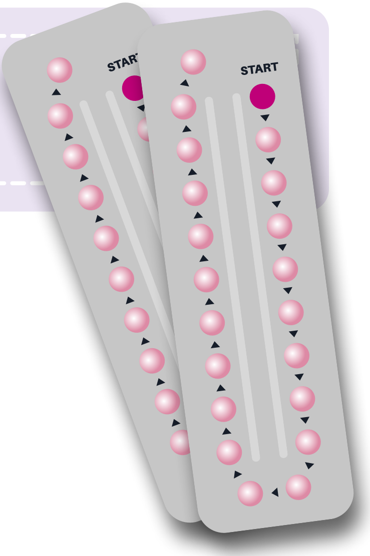
5 Periods, contraception and sexual health

Some girls and women find that their seizures can be worse when they have periods. You might want to keep a diary of seizures and periods to see if they're linked. Your epilepsy nurse or doctor can make a referral to the gynaecology (gynae) team for help if you feel that seizures are worse at certain times of the month.

Do periods affect your child's seizures?

Epilepsy medication can affect how well some types of contraception pills work.

Does your child take a contraception pill?



If your child is thinking of starting a family or may be pregnant, you need to let your GP or epilepsy team know. Their epilepsy medication may need altering and they may need extra health checks.

6 Register with a dentist

People with a learning disability often have poorer oral health and have more difficulty going to the dentist that other people. Poor teeth and mouth pain can affect your child's health and behaviour and can cause seizures to become worse.

If your local dentist knows your child has a learning disability, they can make it easier for your child to go by getting to know them first and giving them longer appointments.

They can also refer you to a specialist dentist that works with people with learning disabilities.

It is just as important to visit a dentist regularly if your child doesn't eat orally.

Is your child registered with a dentist?

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 offering advice and support improve the lives of everyone affected by epilepsy.
- **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

Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy Charitable Trust. Registered Charity number 311877 (England and Wales)

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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