

Epilepsy

Information for young adults, families and carers

We have given you this information factsheet because you have been diagnosed with epilepsy. We hope it will help to answer some of the questions you may have and give you some practical safety information. Please ask any of our staff if you have further queries or need help while you are with us.

What is epilepsy?

Epilepsy is one of the most common medical conditions affecting the brain and it can affect people of all ages. People with epilepsy have recurring seizures, so having one seizure doesn't necessarily mean you have epilepsy. For more advice and information on epilepsy, please visit www.epilepsy.org.uk

What is a seizure?

A seizure is a brief disruption of the brain's normal electrical activity, which leads to a variety of symptoms. The symptoms experienced by the person with epilepsy during a seizure depend on where in the brain the abnormal electrical activity occurs.

During a seizure the brain unexpectedly has a surge of electrical activity, which causes you to lose control of your body. This might cause you to randomly shake, jerk, drool, lose focus, be sick or lose control of your bladder. You may get no warning before a seizure, but some people have a funny feeling or an upset stomach right before. Afterwards, you may feel really tired or confused.

Most people with epilepsy can lead full and active lives. It is estimated that around three quarters of children with epilepsy will either be able to control their condition with medication or grow out of it. The chances of this happening will depend on the type of epilepsy you have. Most people, including those who never outgrow epilepsy, don't have any other medical problems. They can go to mainstream schools and participate in most sports.

What can trigger a seizure?

For many people with epilepsy, seizures seem to happen randomly. However, some people find that particular things make it more likely that they'll have a seizure. These things are known as triggers. Triggers aren't the actual cause of the epilepsy. Even if a person only ever has a seizure in response to a particular trigger, it is the disruption in the brain that makes it send off the clusters of messages that result in a seizure.

Triggers can include:

- not taking, stopping or regularly missing doses of your prescribed medication that would otherwise control seizures
- lack of sleep
- high temperature, illness or vomiting (medicine may not be taken as well, if at all)
- stress or excitement (good or bad), such as school, exams, recent arguments, birthdays, holidays or big events
- missing meals and/or being hungry
- alcohol and recreational drugs

General safety advice

Water safety

- If possible, take showers instead of baths to reduce the risk of going underwater if you have a seizure.
- Bathroom doors should remain unlocked and you should tell someone else when you have a shower.
- When you are swimming, tell the lifeguard that you have epilepsy. If you are in open water, try not to go out of your depth and make sure you're in arm's length of a confident swimmer.

Road safety

- If you are walking alone, try to stay on well-lit roads.
- Cross at designated crossing points.
- If you are using a bike or scooter, wear a well-fitting cycle helmet.

Night-time safety

We recommend that you don't sleep in the top of a bunk bed or on a high sleeper. This is to make sure that people can reach you if a seizure occurs and also to prevent falls from a height during a seizure.

Make sure the bed area is clear of clutter or anything you could become tangled in or injure yourself on during a seizure. For example, move away any headphones, fairy lights and blind cords. Although we are not able to recommend or endorse any external products, many people use night-time safety devices, such as video monitors and anti-suffocation pillows. More information on night-time safety equipment can be found online at www.youngpilepsy.org.uk

Epilepsy identification

You may choose to carry or wear some form of epilepsy identification, especially if you're out on your own. This could be an ID card or medical identity jewellery. These can be purchased from www.medicalert.org.uk/products

Emergency contact and medical details should be entered into your phone. Medical ID apps are also available for smartphones.

Medication

- You can find the details of your current medication at the top of your most recent clinic letter.
- Know the main side effects of your seizure medicines. Information on epilepsy medication can be found at www.medicinesforchildren.org.uk
- Some side effects occur from interactions between your seizure medicines and other ones you take (even over-the-counter and herbal supplements). Some foods, such as grapefruit juice, can affect medicine absorption and lead to higher levels of the medicine in the blood.

Epilepsy as a young adult

Driving

- The regulations around driving with epilepsy may change and it is best to consult the DVLA website www.gov.uk/epilepsy-and-driving for the most up-to-date advice. Currently to apply for a driving license you have to be seizure-free for 12 months (either on or off medication). This is for your safety and the safety of others on the road. Although this can be very frustrating, it's a good motivation to follow your doctor's advice and take your medication correctly.

- You may be eligible for an off-peak travel bus pass to help you get around. For more information visit www.southampton.gov.uk and select 'SmartCities card/bus pass' under 'Roads and Parking'.

School and work

- Supporting you to achieve your best at school or work is an essential part of our role as the epilepsy team. At your clinic appointments we will discuss how you are progressing at school and whether there's anything we can help you with.
- It's possible that your epilepsy may interfere with school due to side effects from medication, repeated absences from school or the seizures themselves. You may also have trouble with remembering information and concentrating. If you're having any problems with school, it may be useful to talk about these with your parents or teachers. After that, the epilepsy team may be available for additional advice.
- When you have exams, it's important to find ways to reduce stress and avoid seizures. Eat regular meals and make sure you sleep well to reduce your seizure risk. You may be able to get extra help for exams, such as more time, private rooms and teaching assistant help. If you think any of these will be useful, contact your school well ahead of time to make sure you get the support you need.
- In the future, your epilepsy shouldn't prevent you from doing the job you choose. There are a few rare exceptions, such as working in the armed forces. Some commercial driving jobs may also require an extended seizure-free period. Most places of work should be accommodating to your condition. They may carry out a risk assessment to make sure you can stay safe in the workplace.

Alcohol and recreational drugs

- Alcohol is illegal for those under the age of 18. If you are 18 or over, having epilepsy doesn't mean you can't drink alcohol. However, excessive alcohol intake is a known trigger of seizures so be careful when drinking. Alcohol can also increase the side effects of some epilepsy medicines or make you forget to take your epilepsy medication. Some epilepsy medicines may make you feel drunk and out of control faster than your friends, even if you've had the same amount of alcohol. Take care of yourself, know your limits and don't feel pressured to drink more than you want to.
- As well as being illegal, the contents of recreational drugs can be completely unknown and your body may react in a number of different ways, increasing the risk of seizures. We do not recommend the taking of recreational drugs at any point.

The move to adult services

- If you have had epilepsy in childhood and your seizures continue, our children's service will begin to prepare you to move to adult services when you turn 18. We will usually start to prepare you for this from around the ages of 13 or 14 by giving you more control and independence in your epilepsy care. Our specialist epilepsy nurses will guide you and make sure you are ready for the change in structure.

Contact us

If you have any questions or concerns, you can contact us using the details below.

Your consultant is: _____

Paediatric epilepsy nurses

Telephone: **023 8120 3760**

Email: **uhs.schpens@nhs.net**

Consultants and secretaries

Telephone: **023 8120 4315**

Telephone: **023 8120 4310**

Non-emergency telephone: **023 8120 3760** (Monday to Thursday, 7am to 5pm)

When leaving a message, please leave **your name, date of birth, hospital number** and a **contact number to call back**. We will try to respond to you within two to three days.

Emergency telephone: **999**

If you need a translation of this document, an interpreter or a version in large print, Braille or on audiotape, please telephone **023 8120 4688** for help.

www.uhs.nhs.uk/childrenshospital

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