

Epilepsy

Most people with it are able to lead normal lives

Epilepsy is a common condition that affects the brain and causes frequent seizures. Usually they won't be diagnosed with epilepsy unless they have had more than one seizure. Seizures are bursts of electrical activity in the brain that temporarily affect how it works. They can cause a wide range of symptoms.

Seizures can affect people in different ways, depending on which part of the brain is involved.

Symptoms of epilepsy

Possible symptoms include:

- Uncontrollable jerking and shaking . called a 'fit'.
- Losing awareness and staring blankly into space.
- Becoming stiff.
- Strange sensations - such as a 'rising' feeling in the tummy, unusual smells or tastes, and a tingling feeling in their arms or legs.
- Collapsing.

Sometimes they might pass out and not remember what happened.

Epilepsy is usually a lifelong condition, but most people with it are able to have normal lives if their seizures are well controlled.

It is good to find out as much as you can about what sort of epilepsy they have. Different sorts of epilepsy produce different fits, need different treatments and can effect their life in different ways. Some sorts of epilepsy you can grow out of. Other sorts of epilepsy require treatment even when they are an adult.

Why start treatment?

Seizures can frighten them or others, they can stop them doing things, can be embarrassing, whether they are at home or school or out with their friends. The aim of the treatment is to control their seizures without giving them any side-effects from the treatment. Their doctor will probably suggest they take medication to try and stop seizures from happening. These are called anti-epileptic drugs (AEDs).

It's really important to take AEDs exactly as the doctor says. If they even miss one dose of their AEDs they might

have a seizure.

It's also a good idea to keep a seizure diary. They can write in it:

- When they've had a seizure.
- What they were doing or how they were feeling before each seizure, to see if they can find any patterns or triggers.
- When they last increased the dose of their tablets.
- Any side-effects or their AEDs.
- Anything else they think might be important.

Then, when they see the doctor, they can see straight away what's been happening. And whether, for example, they might need to increase their AEDs.

Some things make seizures more likely for some people with epilepsy. These are often called 'triggers'. Here are some common triggers:

- Missing doses of their epilepsy medication.
- Drinking too much alcohol.
- Feeling stressed.
- Lack of sleep.
- Strobe lighting in clubs, cinema etc.

Looking after their general health can really help with seizure control. Sometimes they might feel anxious, stressed or depressed about their epilepsy and the effect it seems to be having on their life. Make sure they find someone they can talk to about how they're feeling. Being able to talk to someone about their epilepsy can be one of the best ways of helping themselves. That way it's less likely you'll keep it all inside and feel like no-one understands them.

Education

Making sure their school knows about their epilepsy it will give them the best chance of getting the learning, social and health support they need.

If they feel like they're struggling with their learning get them to talk to their teacher or head of year, or whichever adult in school they feel okay with. The school may talk with them and possibly you as parents. They may want to talk about additional support they might need. They may advise that they meet with the school nurse so she can help draw up a healthcare plan to support them in school. This could help the teachers understand their situation better.

Exams are often stressful which can make seizures more likely for some people. If they know that stress triggers their seizures, they need to learn how to minimise it. Preparing well in advance for an exam can help or they could try

learning a relaxation technique. If they need extra help, get them to talk to their teachers well before exam time. They might need extra time to finish, or an early exam might be difficult for them if they have seizures in the morning.

Feeling down

Having epilepsy can make them feel different, especially if they can't join in with things their mates are doing. They might feel under pressure to drink or take drugs and worry about the consequences. They may be fed up having to consider their epilepsy. People might make fun of their epilepsy or they might want to hide it. It's up to them how much they tell. Many young people find they can relax more if a trusted friend knows what to do if they have a seizure. If their situation gets them down it really helps to talk to someone who understands. This might be the school nurse, a person they trust, a local support group, a helpline or online in a forum.

Staying safe

The Bathroom - This is the place where they are more likely to come to harm. Showers are safer than baths but baths can be ok if they follow some simple advice. It is not a good idea to have a bath if there is no-one in the house at the time just in case they have a seizure.

Let someone know that they are going to have a bath, don't lock the bathroom door - they could always put something on the door that will tell their family they are having a bath.

Swimming - Swimming is not a good idea if their seizures are not controlled and are a problem. If seizures are usually controlled they may want to go with their friends or family. Public pools have a lifeguard on duty. The epilepsy nurse can give them an ID card to give to the lifeguard which tells them that they have epilepsy, and what their seizures are like. It is not a good idea to swim on their own.

Cycling - We always recommend that anyone who uses a bike wears a helmet, just in case they fall or get knocked off their bike, it helps to protect their head.

Other sports - Most sports and activities are fine for people with epilepsy. This includes almost everything they might want to do. For example: football, rugby cricket, hockey, netball, basketball, netball, rounders, baseball, athletics, cross country, judo and other martial arts, dancing (all types), golf, gymnastics, circuit training, gym workouts and so on.

More difficult areas are swimming, sailing and canoeing -

although these can be ok. For more information they should ask their epilepsy nurse or doctor.

Holidays and travelling

Lots of common seizure triggers can crop up on holiday:

- Hot weather.
- Alcohol.
- Dehydration.
- Skipping meals.
- Upset stomachs.

So get organised to make sure the holiday goes without a hitch. Before they go make sure they've got enough medication and adequate travel insurance. They can't get an NHS prescription for more than 3 months so if their trip is for longer, they must speak to their doctor. Remember that they still need to take their medication at the same (UK) time. If they're flying keep their medication with them in case their luggage goes missing. Carry snacks with them, drink plenty of water and take time out to get over any jet lag. Sickness and diarrhoea can stop their antiepileptic medication from working properly. Being sick can also cause dehydration, low blood sugar and poor sleep and these can all make a seizure more likely.

Medical ID

Medical ID jewellery and ID cards let people know that they have epilepsy in case they have a seizure when they are out on their own. The card explains what to do and who to contact if they have a seizure. Ambulance staff and police will usually look for medical ID jewellery if they are found unconscious. It lets them know important facts about their condition. There are lots of styles and they don't need to look obvious. For more information visit www.epilepsysociety.org.uk/medical-id-cards-and-jewellery

Conatcts

www.epilepsysociety.org.uk
www.nhs.uk/conditions/epilepsy/
www.youngpilepsy.org.uk/for-young-people/
Young epilepsy helpline 01342 831342
www.healthtalk.org

School Nurse 020 8770 5409