Bwrdd Iechyd Prifysgol
Aneurin Bevan
University Health Board

Information for Parents & Carers about Epilepsy

Child & Family Division

Your child has had a seizure, often described as a fit or convulsion.
We know it was a very frightening experience for you. We have produced this leaflet to provide you with information about epilepsy.

What is Epilepsy?

Epilepsy can happen to anyone at any age and there are many different types. Some types last for a limited time and some can be lifelong.
Electrical activity is happening in our brain all the time. A seizure happens when there is a sudden burst of intense electrical activity.
This intense electrical activity causes a temporary disruption to the way the brain normally works, meaning that the brain's messages become mixed up. The result is an epileptic seizure.
The brain is responsible for all the functions of your body. What you experience during a seizure will depend on where in your brain the epileptic activity begins and how widely and rapidly it spreads.
For this reason, there are many different types of seizure and each person will experience epilepsy in a way that is unique to them.

Seizure types

There are two main seizure types, these are known as focal seizures and generalised seizures.

Generalised seizures are when the sudden burst of electrical activity causing a seizure occurs in both sides of the brain, individuals will be unresponsive during these events. A generalised tonic clonic seizure, this means activity all over the brain causing tonic (stiffness) and clonic (jerking) presentations.

Focal seizures start in one section of one half of the brain. With these seizures an individual has impaired awareness. During a focal seizure individuals may have slurred speech, be unable to speak but will respond to voice using their eyes and some individuals will still be able to walk around during a focal event. It is important to have awareness that a focal seizure can sometimes progress a bilateral tonic clonic generalised seizure.

When managing a Focal seizure try to assist the child/young person to:	When managing a Generalised seizure ensure:
• Sit to the floor • Time the event • Be calm and reassuring and maintain a safe environment. Call 999 if a focal seizure with impaired awareness continues at 10 minutes. (Focal seizures can progress too generalised)	• Safe environment – if safe to do so move objects out of the way rather than moving the child • Cushion the head • Be calm and reassuring • Time the event • Place into recovery position on recovery. If an unresponsive generalised seizure continues for 5 minutes or 2 seizures within 24 hours – call 999.

How is epilepsy diagnosed?

The diagnosis of epilepsy is often made from the information that you give to the doctor. You will be asked many questions and the diagnosis can be made solely on this information even if the other tests prove to be normal.

To help support a diagnosis:

- Keep a diary – always note the duration of the event. Include what was happening before, during and after the seizure. When documenting a seizure presentation try and note which part of the body has been affected including arms, legs, eyes, mouth and noises heard. It is important to try and identify your child's level of response during all events witnessed.
- Filming seizures - This may not feel like a natural thing to do but having video clips of a seizure to show a doctor can be a very helpful way of getting the right diagnosis. When capturing an event try to include the full body including the face.

Will my child have any tests?

The doctor may request that your child has a test called an EEG (electroencephalogram). An EEG detects electrical activity in the brain by using little wires which are placed on the scalp. It is a painless test and usually takes about half an hour. Many people with epilepsy only have unusual electrical activity in their brain when they are having a seizure. Often, we cannot fully rely on results of an EEG. If a result doesn't show any unusual activity, it may only mean that there is no epileptic activity happening in the brain at the time the test was being performed. This does not prove that an individual doesn't have unusual activity in their brain at other times, history taking is the most important form of supporting a diagnosis of epilepsy.

Another type of test which may be required is a brain scan, which allows detailed pictures of the brain. This may either be a CT scan or an MRI scan which may take up to one hour.

Genetic testing can also be done to look at whether there are changes in your genes that might cause epilepsy. The test is usually done using a sample of your blood or saliva. This sample is then sent to a laboratory where it is tested.

The above investigations will be discussed and advised if required by your named consultant.

What is the treatment?

The main treatment for epilepsy is taking epilepsy medicines. It may be necessary for your child to take medication every day, there will be a discussion as to which formulation of medicine is best for your child (tablets/granules/liquid). Check with your epilepsy team prior to changing brands of medication. Certain epilepsy medications have implications with contraception, please discuss this with your specialist nurse, consultant or GP.

Compliance

Ensure that no medication doses are missed, this is a preventative medication and missed doses can increase the risk of seizure activity and poor control.

- **What to do if dose is missed?** If you remember up to 4 hours after you should have given dose, administer dose. If you remember after that time, do not give dose, give next dose as usual.

- **What to do if multiple doses missed**? Contact the CENS duty desk number (01633 234128), GP or CEAU at the Grange University Hospital for advice.

- **What do I do if my child vomits?** If within 30 minutes of administered dose repeat, if over 30 minutes do not repeat the dose.

How long is treatment for?

Some patients may be able to discontinue treatment after a few years, but this depends on the type of seizure your child is having. Your consultant will discuss plans for treatment in the outpatient clinic appointments. **Never stop taking a prescribed medication unless instructed by a doctor**.

Safety netting

You should always encourage your child to continue to lead a normal healthy, active lifestyle while following some safety precautions:

- **Water** – your child should never be in or around water unsupervised. Showering is a safer option and all baths should be fully supervised.
- **Heat** - Be cautious when cooking, always supervise and avoid using open flames. Place beds away from radiators for safety.
- **Height** - no unsupported climbing higher than bench height. Supported rock climbing is suitable with safety equipment in place

- **Road** – We recommend walking with someone, wear helmets if riding bikes and avoid busy roads where possible.

Seizure triggers

Seizure triggers are things that make seizures more likely in people with epilepsy. Most people with epilepsy can identify at least one or two things that trigger their seizures. But not everyone can. And the things that trigger one person's seizures might not affect someone else in the same way. Keeping a diary can help to identify if your child has a certain trigger that affects their seizures. See common triggers below:

- **Sleep deprivation** – Try to maintain a regular bedtime routine, no electronic devices 30 minutes before bed and ensure adequate sleep time.

- **Illness** – If your child becomes unwell promote adequate fluid, paracetamol/ibuprofen if needed and seek further assessment with your GP/A&E if required.

- **Stress** - For some people, feeling stressed can lead to other changes. This might include feeling anxious or depressed, or changes to your sleeping patterns or eating habits. All of these can also increase your risk of having a seizure.

- **Overexcitement** – Sometimes around occasions such as birthdays/religious festivals or exciting events. It is important that children enjoy exciting events but for families to have an awareness of this as a possible trigger cause.

Sudden and unexpected death in epilepsy (SUDEP)

Currently rates of SUDEP in children is 1.2 deaths for every 1,000 children with epilepsy each year.

What causes SUDEP?

It is not known for sure, but it's unlikely that there's a single cause to explain all SUDEP deaths. Possible reasons it happens include:

- Heart rhythm changes
- Brain function – seizures may suppress or interfere with the function of vital parts of the brain
- Breathing changes – a seizure may cause someone to have pauses in breathing. If these last too long, oxygen in the blood may reduce to dangerous levels
- Other causes – either from a combination of the above or as a result of factors not yet known.

What are the main risk factors of SUDEP?

- Generalised tonic-clonic seizures. Risk increases with the number of convulsive seizures experienced.

- Seizures when sleeping or shortly after waking (sometimes known as nocturnal seizures).
- Not taking anti-seizure medication as prescribed.
- Seizures not controlled by medication (also known as treatment-resistant epilepsy).
- Changing lifestyle factors can increase risk and impact on routines and stress, for example, moving home, going to university or pregnancy.
- Other health conditions.
- Gender – SUDEP is more common in men, but women can still be at risk.

(SUDEP Action, 2025).

Ways to support reducing SUDEP risks:

- Attend planned appointments with clinicians and discuss any changes noted to seizures.
- Take all medication as prescribed on time and no missed doses.
- Keep a seizure diary to help spot patterns and changes.
- Always carry key information about your epilepsy with you.
- Have an alarm/monitor in your child's bedroom to alert of possible night time seizures.

Where can I get further advice?

For urgent advice please attend your local A&E.

Once a diagnosis of epilepsy has been made, parents/carers can contact the children's epilepsy nurse specialist duty desk (01633 234128). **This is a non-emergency contact line** for information sharing, medication queries/concerns, support and advice, this will include things like:

- Increased seizure activity.
- Discharges from inpatient hospital admissions.
- Medication queries and concerns.
- Support and advice.
- Information on care plans.
- Education and training.

This service operates via an answerphone service. A response call will be made for a nursing assessment which will be triaged by a trained children's epilepsy specialist nurse within 3 working days of message receipt (excluding bank holidays and weekends).

For epilepsy evidence-based information:

- **Epilepsy Action** website – www.epilepsy.org.uk
- **Young epilepsy** - www.youngepilepsy.org.uk
- **National society for Epilepsy** – www.epilepsysociety.org.uk

Some common questions and answers

Is epilepsy common?

According to Epilepsy Action (2025) One in every 220 children under 18 will have a diagnosis of epilepsy. That is an average of two children with epilepsy in every primary school and nine in every secondary school.

What do I need to do to ensure my child is supported in school?

When your child has epilepsy, it’s natural to worry about them having seizures at school. But with the right communication and school support, having epilepsy should not stop your child getting the most out of their education. All children with a diagnosis of epilepsy should have an Individual Healthcare Plan (IHP). This is to be completed between parents and education and reviewed annually. Furthermore, free online training “basic epilepsy for schools” is advised to support education with epilepsy knowledge. A template and online training can be found on the Epilepsy Action website.

Am I able to learn to drive with epilepsy?

You must tell the driving agency about your seizures. If you have seizures that affect your consciousness, you must be seizure free for at least 12 months before you are able to apply for a driving license.

What can I do if my wellbeing if affected by my epilepsy?

People with epilepsy are at a higher risk of mental health problems like stress, anxiety or depression. Having low self-esteem due to epilepsy can also have a big impact on mental wellbeing. Stress is a common seizure trigger for many people so it is important to look after your mental health. If your child is struggling with their diagnosis your children’s epilepsy nurse specialist can make a referral to psychology for support. Furthermore, having a balanced diet, good sleep routine, exercise and having good awareness to manage your individual seizure triggers can support with better overall wellbeing. See Epilepsy Action online “epilepsy and wellbeing” for lots of useful support.

**“This document is available in Welsh /
Mae’r ddogfen hon ar gael yn Gymraeg”.**