

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?

If you have epilepsy, it means you have had more than one epileptic seizure and could have more in the future.

Electrical activity is happening in our brain all the time. A seizure happens when there is a sudden burst of intense electrical activity. This is often referred to as epileptic 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. (Epilepsy Action, 2018).

Providing an Accurate Witness Description

- Time the event.
- Try to video.
- Describe what brought your attention to the seizure.
- Try to describe the movement witnessed in order of events.
- Think about what your child was doing prior to the seizure.
- Describe what they are like after the seizure has finished.

What does this mean to my child?

The most important thing to remember is that your child should continue to lead a normal healthy active lifestyle with a few safety precautions. It is also important for your child to get enough sleep and relaxation.

How is it diagnosed?

The diagnosis of epilepsy is always made from the information that you can 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.

Will my child have any tests?

The doctor may request that your child has an EEG (or brain wave test). 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.

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.

What is the treatment?

It may be necessary for your child to take medication every day which will be in the form of tablets or medicine. Please check with your epilepsy team prior to changing brands of medication.

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. **YOU MUST NOT STOP THE MEDICATION UNLESS INSTRUCTED BY THE DOCTOR.** The doctor will discuss plans for treatment in the outpatient clinic.

Where can I get further advice?

Any worries or concerns may be discussed with the Children's Epilepsy Specialist Nurse on Monday - Friday, telephone: - 01633 - 234128 there is an answer-phone available when the nurses are out of the office, for non-emergencies. Please note your call may not be returned on the same day.

In the event of an emergency, or out of office hours please ring Children's Assessment Unit at The Royal Gwent Hospital on:-01633 - 656020 or Children's Ward at Nevill Hall Hospital on:-01873 - 732474.

First Aid Advice for Generalised Tonic Clonic Seizures

- Protect the child from injury.
- Call an ambulance if this is your child's first seizure.
- Cushion head.
- Aid breathing by gently placing in the recovery position once the seizure has finished.
- Stay with them until recovery is complete.
- Be calmly reassuring.
- Time the seizure.
- Video if possible.
- If the seizure continues beyond 5 minutes, or if having repeated seizures without gaining full awareness please call 999.

First Aid for other types of Seizures

- Guide the child away from danger.
- Stay with child until recovery is complete.
- Be calmly reassuring.
- Explain anything that they may have missed.

Safety

- Encourage showers rather than baths
- All baths must be supervised
- For other safety advice please refer to Epilepsy Action's Website

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Some common questions and answers

It is my fault?

Many parents feel guilty and sometimes wonder whether it was something that they did or failed to do that might have contributed. This is highly unlikely.

Is epilepsy common?

Yes. Approximately one in two hundred children have epilepsy - it can start at any age.

Is there anything that can trigger off a seizure?

Yes. There are a number of factors, which can contribute to a seizure including:-

- lack of sleep or relaxation
- being generally unwell
- anxiety and stress
- forgetting or omitting medication
- alcohol and drugs

Does my child suffer discomfort or pain during a seizure?

No. The child is usually unconscious and unaware of what is happening. The seizure is much more disturbing to you than the child. Your child may have a headache following the seizure.

Websites to obtain further information:-

Epilepsy Society <u>www.epilepsysociety.org.uk</u>

Epilepsy Action <u>www.epilepsy.org</u>

"This document is available in Welsh / Mae'r ddogfen hon ar gael yn Gymraeg".