

# Epilepsy and hemiplegia

## Information resources

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### About this information

This information sheet aims to answer your questions about epilepsy: what it is, why it is associated with hemiplegia and how it might be treated. This was written with children in mind, but it is equally relevant to adults.

### About epilepsy

Epilepsy is the tendency to have repeated epileptic seizures. Epileptic seizures happen when the way the brain normally works is temporarily disrupted (when the messages the brain sends to communicate with the rest of the body become disorganised). This disrupted activity can last from a couple of seconds to a few minutes, and can make the person's body do things they wouldn't usually do. Many people (about 1 in 30) will have an epileptic seizure some time in their lives. But having one seizure does not mean you have epilepsy. Epilepsy is the tendency to have repeated seizures and so is usually only diagnosed after two or more seizures. Nevertheless it is a common condition, affecting 1 in every 131 people.

An epileptic seizure is an event that causes a change in a person's awareness of where they are or what they are doing, their behaviour or their feelings. What happens during a seizure depends on where in the brain the disrupted activity is, and how much of their brain is affected.

There are many types of seizures but we can divide them into two groups – generalised and focal (or partial) seizures.

### Generalised seizures

In generalised seizures the whole of the brain is affected by the seizure. The person becomes unconscious and will not remember the seizure. Examples of these seizures include:

- **Absences:** in which the person briefly looks blank and loses awareness.
- **Tonic clonic seizures:** in which the person's body suddenly stiffens, they fall down and then their body shakes or convulses.



## Focal seizures

In focal seizures the seizure affects just part of the brain and the person may not lose consciousness, although they might become quite confused. What happens depends on where in the brain the seizure happens, and what this part of the brain normally does. For example, the person may get a strange taste in their mouth or a sudden feeling of fear; they may get pins and needles in part of their body; they may become very confused, or make strange movements with their arms or legs; or they may make strange noises or lip-smacking or chewing movements with their mouth. The behaviour depends on which part of the brain is affected.

*“When I thought of epilepsy, I imagined people losing consciousness, falling to the ground and shaking uncontrollably. Our experience was very different.”*

## Hemiplegia and epilepsy

Both hemiplegia and epilepsy are neurological conditions. There are many causes of epilepsy but when someone with hemiplegia has epilepsy it is usually because a specific area of the brain has been injured and this injury causes the epilepsy. In most cases, but not all, this will cause focal seizures that start and affect only that part of the brain. If the epileptic activity spreads to other parts of the brain a generalised seizure happens.

About one in five (or 20%) of children with hemiplegia also have epilepsy. In most cases the epilepsy starts before the age of five.

The chances of a child developing a new case of epilepsy seem to decrease as they get older, particularly after the age of ten.

*“The emotional impact of seeing [our child] having seizures never stopped being distressing. It makes you feel so helpless.”*

## What to do if your child has a seizure

It can be very frightening when your child has a seizure but there are a few points to try and bear in mind.

### Do:

- note the time – so you know how long the seizure lasts
- move objects that may cause injury or guide them from danger during a focal seizure
- put something soft under their head if you can
- turn them onto their side as soon as possible
- stay with them
- explain things they might have missed after a focal seizure

### Don't:

- panic
- move the child unless they are in danger
- restrict their movements or restrain them
- place anything in their mouth
- give anything by mouth until they are fully recovered
- make any abrupt movements or shout during a focal seizure

### Call 999 if:

- you are frightened or need help in any way
- it's the first seizure
- if one seizure follows another
- the seizure continues for more than five minutes
- if the child is injured or you're worried about their breathing
- you believe they need medical attention

If you don't call an ambulance because the seizure doesn't last long you will still need to tell your GP that it's happened.

### Recording a seizure

A seizure is a very stressful event to witness and it can be very hard to remember details of what has happened. Recording a seizure on your smart phone or camera can be extremely helpful to doctors while diagnosing epilepsy. Although it may feel

like a difficult thing to do it is very worthwhile if you can manage it. Having a proper record of what has happened will also help you feel more confident when explaining to doctors what a seizure looks like.

### Here are some tips:

- Make sure you know how to use your recording equipment before a seizure.
- Keep your child safe during the seizure (see What to do).
- Turn on as many lights as you can.
- Remove any blankets.
- Video the child's whole body including all limbs.
- Record their body for about 10 seconds and then focus on their face for another 10 seconds.

### If it is difficult to get a recording, the following questions may be useful:

- Did anything set off the seizure?
- Was there any warning that the seizure was going to happen?
- Were there any changes in mood, like becoming quieter or excited?
- Was there any unusual behaviour just before, like fiddling with clothes or making strange movements?
- Was there any loss of consciousness?
- Was there any confusion?
- Did the seizure cause stiffness, jerkiness or floppiness?
- After the seizure did your child sleep more or less?
- How long did it take to get back to normal?





This list is not exhaustive, the more detail you can provide the better. Depending on your child's age they can also explain how they feel before and after; their account will also be important in getting a diagnosis.

## Diagnosis

Getting a diagnosis is not always easy as there is no single test that can diagnose epilepsy. If it is possible that your child might have epilepsy, NICE (the National Institute for Health and Care Excellence) recommends that you are referred to a specialist paediatrician (with training in diagnosing and treating children) within two weeks.

Doctors will base their diagnosis on medical history, symptoms and, most importantly, eye witness accounts of what happens before, during and after the seizures. This is why the video can be important.

## Diagnostic tests

If necessary, your doctor may do some more tests to get extra information or to rule out other causes. These may include:

- Blood test to check general health and check that seizures aren't caused by something else like low blood sugar or diabetes.
- An ECG (Electrocardiogram) to check that there aren't any problems with the heart that could be causing seizures. Electrodes, like round plasters, are stuck to the chest, arms and legs to read the electrical signals from the heart. It's totally painless.
- An MRI scan – a detailed scan of the brain made of pictures created by magnetic waves. This can take up to 30

minutes. A general anaesthetic might be used for young children or for children who will find it hard to keep still.

- A CT scan is another kind of x-ray that isn't as detailed as an MRI but can be used if an MRI isn't suitable for some reason.

## Treatment

In 70% of cases epilepsy is treated by anti-epileptic drugs (AEDs). These drugs cannot cure epilepsy, but they work on the brain to try and stop seizures from happening. Which particular AED is used depends on the type of seizures your child has because some AEDs work better for certain seizures. It's also important to get the dosage right, and this can be a long process.



*“I was put on medication to try and reduce the frequency of my seizures. Over the past few years I have had my medication increased over time and I now seem to have reached the right amount of medication to considerably reduce my seizures.”*

If your child’s epilepsy doesn’t respond to AEDs and they continue to have seizures, there are other treatment options:

- **Ketogenic diet:** a high-fat, low-carbohydrate, controlled protein diet that should only be followed with the support of an epilepsy specialist and a dietician.
- **Vagus Nerve Stimulation:** a therapy which uses a pulse generator to send mild electrical stimulations to a nerve that carries information to and from the brain. It aims to reduce the number, length and severity of seizures.

- **Brain surgery:** this aims to separate or remove the part of the brain causing seizures. Strict eligibility criteria need to be met before surgery will be considered. Any child for whom this treatment is being considered would be entered into an epilepsy surgery programme at a Children’s Epilepsy Surgery Service centre (in NHS England) for a series of intensive investigations and discussions before surgery would be considered. Although it sounds frightening, a lot of support should be made available to you if this option is recommended.

The Epilepsy Society has more detailed information on the various treatments available: [www.epilepsysociety.org.uk/treatment](http://www.epilepsysociety.org.uk/treatment)

## Living with epilepsy

Both hemiplegia and epilepsy affect people in different ways and to different degrees. Your healthcare team will be able to answer any questions you have and should provide you with all the information you need about diagnosis, tests and treatment. There are a number of organisations who can provide epilepsy specific information, including advice about safety, first aid, education, memory problems and travel.

Epilepsy Action  
0808 800 5050  
[www.epilepsy.org.uk](http://www.epilepsy.org.uk)

Epilepsy Society  
01494 601400 (helpline)  
[www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)

Epilepsy Scotland  
0808 800 2200  
[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)



## How can HemiHelp help you?

HemiHelp:

- has a helpline staffed by trained volunteers who all have personal experience of hemiplegia (**0345 123 2372**) – [helpline@hemihelp.org.uk](mailto:helpline@hemihelp.org.uk)
- runs a UK-wide home visiting service
- has an extensive website with news and free information downloads [www.hemihelp.org.uk](http://www.hemihelp.org.uk)
- has a Facebook group and Twitter feed ([@hemihelp](https://www.facebook.com/hemihelp))
- puts members in touch with others who have faced similar problems (available upon written request) and is developing a network of local groups
- has over 30 information sheets on various aspects of living with hemiplegia
- provides a resource booklet of useful names and addresses for members
- produces a quarterly magazine where members can share information and experiences
- runs regular conferences and workshops around the UK for parents and professionals
- organises sports and activity days for children in different regions
- has a transition support service for young adults including employment workshops, 1:1 support, and work placements
- membership is from £10 a year and benefits include HemiHelp's quarterly magazine, access to our services and schemes, and priority booking at HemiHelp events

We can provide references on the source material we used to write this information product. Please contact us at [info@hemihelp.org.uk](mailto:info@hemihelp.org.uk)

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