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Training



# Epilepsy Awareness Handbook



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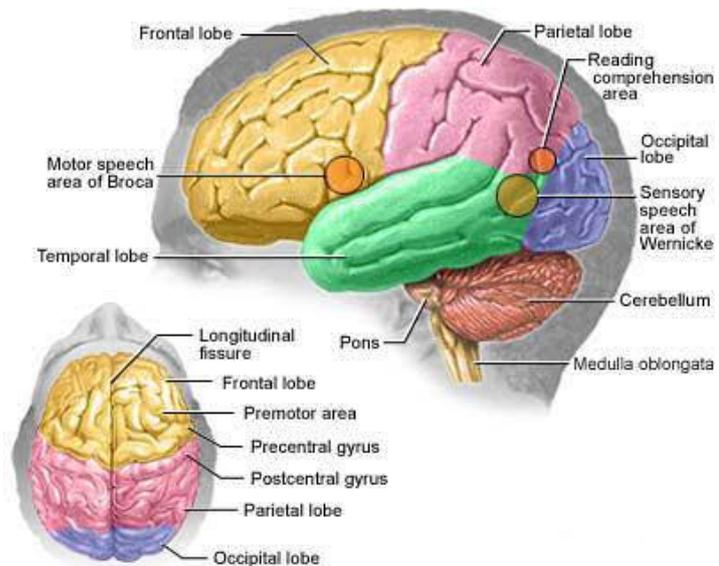
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# EPILEPSY

## WHAT IS EPILEPSY?

The brain is a highly complex structure of millions of nerve cells (neurons). Their activity is usually well organized, and they possess mechanisms for self-regulation. The neurons in the brain are responsible for a wide range of functions including:

Consciousness  
Awareness  
Movement  
Bodily Posture



A sudden temporary disruption in some or all of these functions may be termed a “seizure” or “fit”.

Such an event may be caused by some disturbance arising within the brain itself (an intrinsic cause) or, more rarely by a lack of oxygen or glucose. Many people have a single seizure at some time in their lives, but this does not constitute epilepsy. If an individual has a tendency to experience repeated seizures, due to an intrinsic disturbance of neuronal function within the brain, then the term “epilepsy” may properly be used.

It should be noted, however, that epilepsy is not just one condition. Also, it is not always easy to give an explanation in each individual case of why seizures begin, or why they continue. The epilepsies, therefore, affect different people in different ways. When offering explanations, it is important to remember that there are still many misconceptions about this condition. People may need reassurance that it is not an illness or a disease.

## WHAT IS A SEIZURE?

A seizure (often called a fit, an attack, a turn or a blackout) happens when ordinary highly complex brain activity is suddenly disrupted.

Seizures can take many forms, since the brain is responsible for a wide range of functions. Intelligence, personality, mood, memory, sensations, movement and consciousness are controlled within the brain; any of these functions may be temporarily disturbed during the course of an epileptic seizure.

Other factors may also determine the type of seizure, such as, whether the person is asleep or awake, what they are doing at the time, the type of epilepsy they have and whether all or part of the brain is affected.

## WHAT CAUSES EPILEPSY?

Any person's brain has the capacity to produce a seizure, if the circumstances are appropriate. Most brains are not likely to do this spontaneously, and can, therefore, be said to have a high "seizure threshold" or high resistance to seizures. Individuals vary as to their threshold and it is probably one part of the genetic characteristics. Someone with a low threshold might develop epilepsy spontaneously, without other factors being involved. Sometimes, a predisposition to seizures can be seen in some families, where several members are affected.

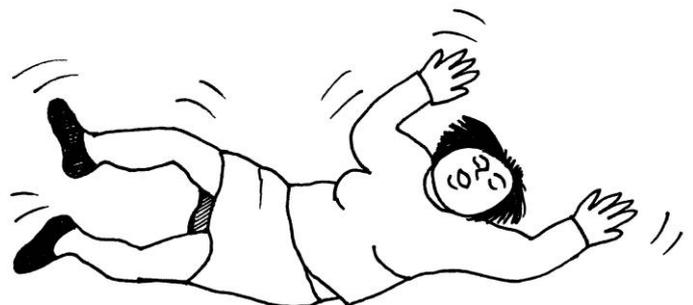
The genetics of epilepsy, however, are not straightforward. In some individuals, the existing seizure threshold may be lowered if the brain is subject to unusual stimulation, such as, certain frequencies of flickering light and some drugs, or is injured. If the injury is severe e.g. due to a road traffic accident, infection, birth trauma, stroke or tumour, then epilepsy may develop as a consequence.

Many individuals attribute the onset of their seizures to some relatively minor event, such as a blow on the head or an emotional upset. Although, these cannot be completely discounted, in such cases, it is likely that family predisposition to seizures plays a more important role.

## HOW MANY PEOPLE HAVE EPILEPSY?

Epilepsy is the most common serious neurological disorder, affecting people of all ages. Official figures suggest that there are at least 456,000 people with epilepsy in the UK.

Anyone can develop epilepsy; it occurs in all ages, races and social classes. Seizures tend to start in infancy or by late adolescence, but the incident rises again after 65 years of age.



## Diagnosing Epilepsy

To make a diagnosis of epilepsy, it is necessary to establish a tendency to recurrent, spontaneous epileptic seizures. Many people have a single, isolated epileptic seizure at some point in their lives, but if a person has more than one, then a diagnosis of epilepsy may well be considered.

Epileptic seizures are due to intermittent and temporary disturbance in the brain, which produces some or all of the following symptoms:

Disturbance of consciousness or awareness

Alterations of bodily movement, sensation or posture

More often than not, the person concerned will have no recollection of what has actually happened. For this reason, it is very important for someone else i.e. a parent or spouse, to report the seizure to the person's doctor who may be their GP, a Hospital Doctor or Consultant Neurologist.

Seeing an epileptic seizure for the first time is a frightening experience. Nevertheless, it is very important to remember and relate, accurately, all the events surrounding the seizure and the details of the seizure itself. The Doctor is heavily dependent on an accurate eye-witness account which may be the only information on which the diagnosis rests:

*He fell to the ground and began to shake and twitch uncontrollably - seemed to have trouble breathing and became pale and clammy. After about 2 minutes, the shaking ceased and he came around, but was a bit confused. Before the seizure he was acting quite normally - but suddenly he cried out and the seizure began.*

Once the doctor has this information, a number of questions are asked:

Has the person really had a seizure, or is there some other explanation for the events that occurred?

Was the seizure due to disturbance within the brain, or was it due to some other cause?

Has the person only had one seizure, or have other seizures occurred in the past?

If the doctor is satisfied that the events were epileptic seizures (there are many other conditions that can be confused with epilepsy), then the question is asked:

Is there some identifiable cause, within the brain itself, such as a tumour, which itself is treatable?

To help answer this, the doctor may arrange for the patient to have a number of

tests. These are designed to help confirm diagnosis, and also to determine any identifiable cause of the epilepsy.

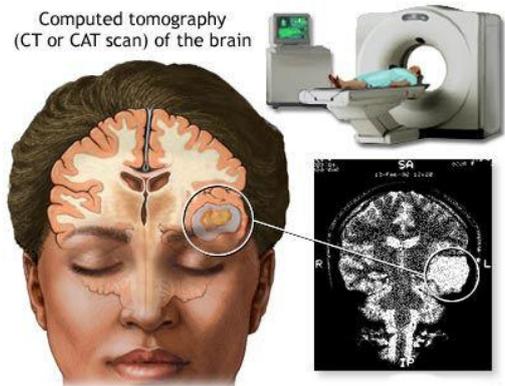
The tests do not always make a diagnosis of epilepsy; this usually remains a clinical decision based on what happened to the person. It's perfectly possible to have normal or clear tests results and still be diagnosed with epilepsy.

## BLOOD TESTS

These check the general health of the person and help to exclude the presence of abnormal amounts of various substances in the body as a cause for the seizures.

## BRAIN SCANS

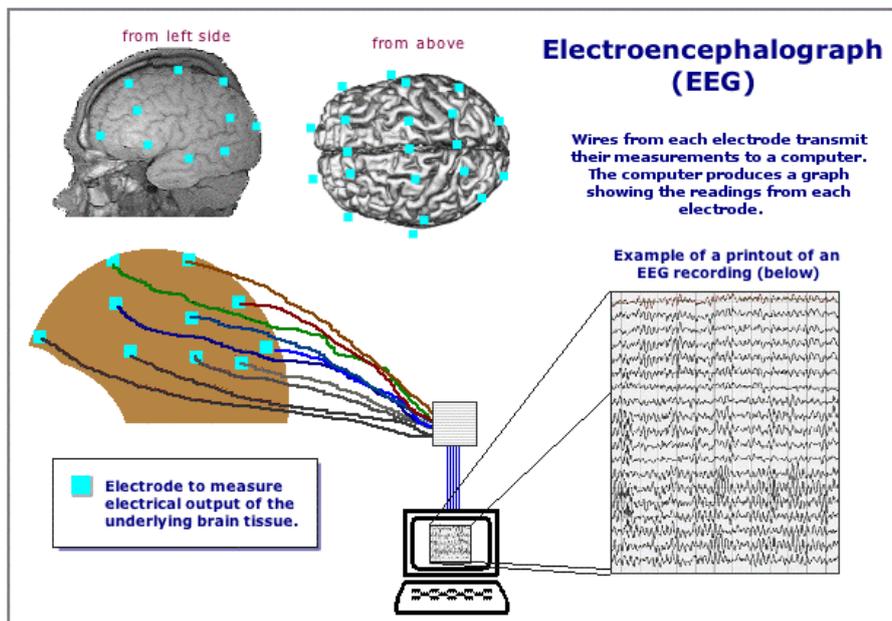
These help to exclude a structural cause for the seizures. CT or MRI scans of the brain may be requested. In many people, such tests will be normal.



## EEG – ELECTROENCEPHALOGRAM

This test measures the electrical activity of the surface of the brain. Electrodes are placed on the brain. Electrodes are placed on the scalp and the signals picked up are amplified and recorded onto paper. It is a painless procedure lasting about 30 minutes.

It should be remembered that the EEG can only give information about the electrical activity of the brain during the period of the recording. Only if patterns characteristic of epilepsy are seen during the routine recording, is the EEG of value in the diagnosis. A normal EEG does not exclude the possibility of epilepsy.



Sometimes longer-term EEG (ambulatory EEG) may be necessary. The person wears a small pack containing an audio cassette tape around their waist, with wires underneath their clothing, going up to their head. EEG monitoring can then take place over a number of days and the person can carry on with their normal activities.

## Children and Epilepsy

Absence seizures - when the child appears to be daydreaming or 'switched off' but is in fact momentarily unconscious - often go unrecognised despite occurring many times a day.

In a busy classroom, the teacher may mistake such episodes as straightforward lapses of concentration or inattention.

Unrecognised seizures at night can also affect school performance during the day. Once a child has been properly diagnosed as having epilepsy, it's possible to get the right medical and educational help.

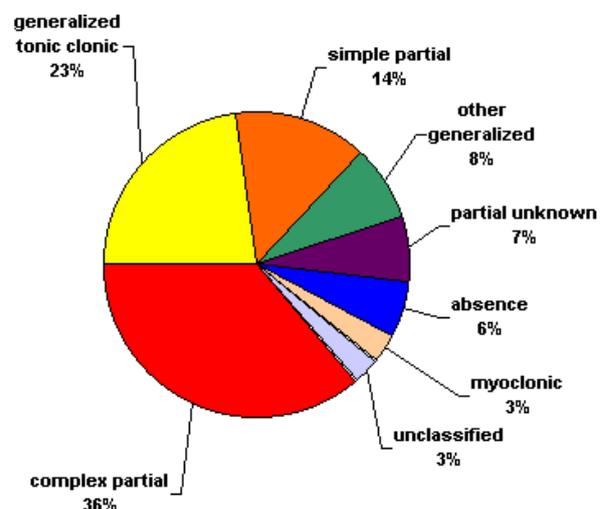
## Help at school

The majority of children with epilepsy attend mainstream schools. Only a minority who have epilepsy and learning difficulties, or severe epilepsy, need to attend special schools.

Many children with epilepsy under-achieve at school. Epilepsy and anti-epileptic drugs can impair a child's ability to learn. Recent treatments cause fewer problems with memory, and completely control seizures in most children.

Low expectation, poor school attendance and low self-esteem can all contribute to poor school performance. Good communication between school, parents, child and doctor is essential.

If it's likely that a child will have a seizure at school, it's often worthwhile educating the other children in the class about seizures and epilepsy. Education packages for schools are available from a number of charitable organisations (see extra information). Children with epilepsy should be encouraged to join in school activities and shouldn't feel restricted by their epilepsy.



## Medical Treatments

### Medication

Once epilepsy has been diagnosed and the doctor has discussed this with the patients, an anti-epileptic drug (AED) will be prescribed to prevent further seizures.

Sometimes patients can experience side effects, especially with higher doses of drugs. The most common are drowsiness, unsteadiness and dizziness. There may also be longer term side effects such as weight gain and acne.

If there are side effects or the seizures don't stop, the doctor will try another drug. In most cases it's possible to stop the seizures with minimal or no side effects.

Suddenly stopping AED's can cause prolonged, severe seizures. Withdrawal of drug therapy must, therefore, take place gradually.

Many AED's interact with other drugs, so care has to be taken when starting other medication (for example, antibiotics or painkillers). Many also make the contraceptive pill less effective, so if you're on the pill you must discuss this with your doctor.

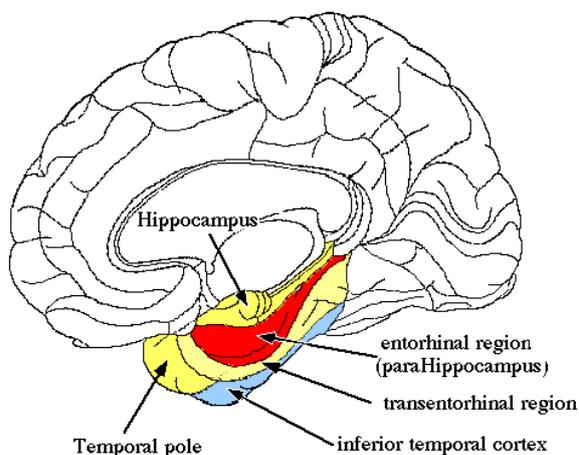
### Surgical treatment

For those whose epilepsy doesn't respond to AEDs, surgical treatment is sometimes appropriate.

The assessment for surgery is complex and involves:

- Identifying a local brain abnormality that can be removed.
- Confirmation that the seizures are indeed originating from the abnormality.
- Confirmation that removal of the abnormality won't cause unacceptable side effects (for example, stroke, memory and speech problems).

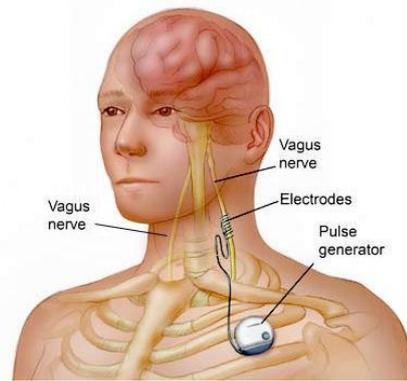
The most usual curative surgery is the removal of a scarred hippocampus, as this is a common cause of epilepsy that's resistant to drugs. (The hippocampus is a part of the brain involved in memory and is very susceptible to damage.)



Sometimes neurosurgery is used not to cure the epilepsy but simply to reduce the severity or frequency of the seizures by making it more difficult for the seizures to spread.



**Vagal nerve stimulation** is a form of surgical treatment that doesn't involve an operation on the brain. Instead, a stimulator (pacemaker) is placed under the skin and stimulates the vagus nerve in the neck. This is a major nerve that runs from the abdomen to the brain and controls many functions. This form of treatment doesn't usually cure the epilepsy but can reduce seizure frequency and severity.



## Diet

### **Ketogenic diet (developed early 1900's)**

The ketogenic diet is a high fat, adequate protein, very low carbohydrate diet which is carefully and individually calculated for each child.

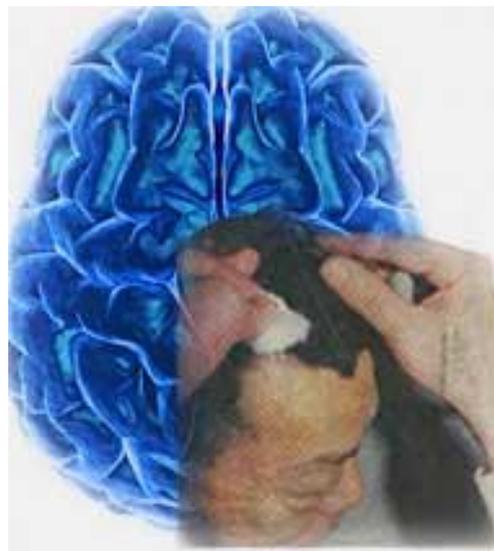
The diet must be supplemented with vitamins and calcium.

**No attempt should be made to change a child's diet without medical supervision**

### **Complementary treatments**

There are a number of proposed alternative and complementary treatments for epilepsy. These should not be used as alternatives to conventional treatments, but in addition to them. None has been shown conclusively to work.

- **Relaxation therapies** - epilepsy can worsen at times of stress so there's some evidence to suggest that yoga and aromatherapy can help.
- **Herbal remedies** - these should be used with caution, as some can interact with anti-epileptic drugs.
- **Acupuncture and homeopathy** - although there's no definite evidence these treatments work, some patients do benefit from them.



## **First Aid:**

### **Safeguard the person having the seizure**

Only call the emergency services if:

- It is the person's first seizure
- They have injured themselves badly
- They have trouble breathing after the seizure has stopped
- One seizure immediately follows another with no recovery in between
- The seizure lasts two minutes longer than is usual for them, or
- The seizure lasts for more than five minutes and you do not know how long their seizures usually last.

**After the seizure put the person in the recovery position for their safety.**



### **Extra information can be obtained from:**

- <http://www.epilepsy.org.uk>
- <http://www.epilepsy.ie>
- 0808 800 5050
- <http://www.epilepsynse.org.uk>
- <http://www.bbc.co.uk/health/conditions/epilepsy>
- <http://www.nhsdirect.nhs.uk>
- <http://www.netdoctor.co.uk>

## How to administer Epistatus

**Epistatus** is used to stop **prolonged, acute, convulsive seizures** in adults, adolescents, children and infants aged 3 months and above. It must only be given by parents or caregivers of patients diagnosed with epilepsy.

Use this medicine exactly as directed by your doctor or epilepsy nurse and in line with the person with epilepsy's care plan.



As soon as the person's seizure starts, make a note of the time.



Place something soft under the head for protection and support. Locate the person's Epistatus and continue timing the seizure. If it goes on for 5 minutes or more, Epistatus should be administered.



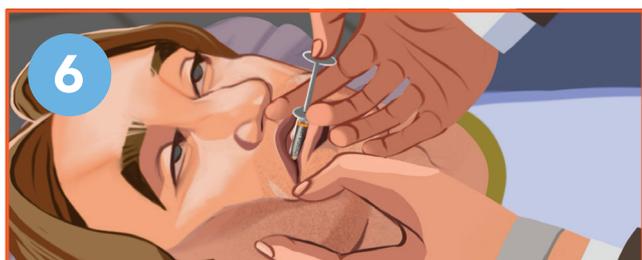
Check the medication for the expiry date, and do not use if the solution is not clear (e.g. cloudy or white particles present).



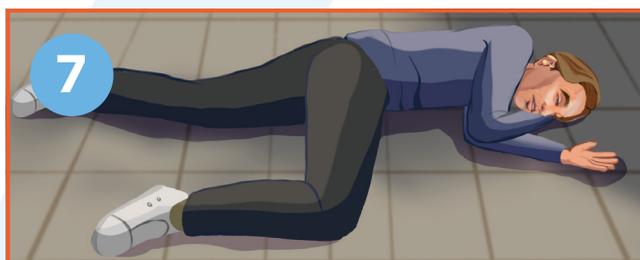
Unscrew the amber cap/sheath.



Pull back the cheek and insert into the space between the cheek and teeth (buccal cavity). Do not put in between teeth.



Administer medicine slowly, 2-3 seconds in each cheek, or just into one over 4-5 seconds if difficulty in accessing one buccal cavity.



Put the person into the recovery position once the seizure has finished.



Note the time. If the person's seizure does not stop within the time noted in their care plan to wait after giving Epistatus, call an ambulance.



Record what happened in the person's care plan.

## Call an ambulance if:

- the seizure does not stop within the time noted in the person's care plan to wait after giving Epistatus
- the person has another seizure
- the person has breathing difficulties or stops breathing
- the person has chest pain, loses consciousness or has no pulse
- they get a sudden lumpy rash
- they get swelling of the face, lips, tongue or throat
- they take too much Epistatus (for example if they become weak, drowsy or feel faint)
- they become unconscious

**DO NOT** give more than the amount of medicine prescribed by a doctor for the person with epilepsy. Only one syringe should be used unless prior medical advice has been received. If in doubt, call for immediate medical help.

## Further information

For further information on Epistatus, please speak to your doctor, nurse or pharmacist. You can find additional support resources at [www.epistatus.co.uk](http://www.epistatus.co.uk)

## Reporting of side effects

If you get any side effects, talk to your doctor, pharmacist or nurse. This includes any possible side effects not listed in the package leaflet. You can also report side effects directly via the Yellow Card Scheme at <https://yellowcard.mhra.gov.uk/> or search for MHRA Yellow card in the Google Play or Apple app store.

By reporting side effects you can help provide more information on the safety of this medicine. Side effects should also be reported to SERB Pharmaceuticals at the address below.

## SERB Pharmaceuticals

SERB S.A.,  
Avenue Louise 480,  
1050 Brussels,  
Belgium  
email: [medinfo.uk1@serb.eu](mailto:medinfo.uk1@serb.eu)  
[serb.com](http://serb.com)



Scan the QR code to visit [www.epistatus.co.uk](http://www.epistatus.co.uk) and find additional support resources

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**Food Hygiene Plus**

**Intermediate Food Hygiene**

**Advanced Food Hygiene**

**Emergency First Aid at Work**

**First Aid at Work**

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**Manual Handling**

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