



Mersey Region
Epilepsy Association

Guide for Newly Diagnosed



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Epilepsy - a definition

A medical definition of epilepsy is “repeated seizures of primary cerebral origin”. This means that you have a tendency to have seizures, which originate in the brain. It follows that, since the word ‘repeated’ is an integral part of the definition an isolated seizure does not constitute epilepsy.

Also, some people, for instance, have seizures as a result of an imbalance of sugar levels in the body (diabetes) but this is clearly not epilepsy since the seizures are not linked to brain disorder.

What causes epilepsy?

For many people, there is no known cause for their epilepsy - this is referred to as cryptogenic epilepsy. For some people the cause is thought to be genetic (also referred to as idiopathic), while in others the condition develops as a result of damage to the brain, for example, from injury, birth trauma, or stroke - this is known as symptomatic epilepsy.

All our brains have the capacity to produce a seizure in certain circumstances. Most brains won't do this unless encouraged, and so are said to have a ‘high seizure threshold’.

Recognising epilepsy

There are many different types of seizures, and only some involve losing consciousness. Some seizures, known as generalised seizures, affect the whole brain, while others, called partial (or focal) seizures, affect only part of the brain. Apart from the seizure types featured here, there are other, more rare, types of seizures, including atonic, when someone suddenly goes limp and falls to the ground, but recovers soon afterwards; and myoclonic, a very brief seizure, which involves a muscle jerk such as a nodding of the head or a jerk of the arm.



Generalised Seizures

Absence seizures

These usually start in childhood. An absence seizure usually shows itself in a blank stare, sometimes accompanied by slight twitching or blinking, which lasts only a few seconds. These seizures can occur many times a day. How best to help: There is no action required during the seizure. Be patient, understanding and reassuring, repeating what has been missed, if necessary.

Tonic-clonic seizures

During a tonic-clonic seizure (formerly called 'Grand Mal') the people fall down, their bodies stiffen and start to convulse (to shake). Their faces may turn blue, they may bite their tongue, they may be incontinent. Tonic-clonic seizures usually last from between one to three minutes and, afterwards, people generally feel headachy and tired.

The seizures are 'self-limiting' - they run their own course.

Partial seizures

The most common form of partial seizure, in which only part of the brain is affected, is called a complex partial seizure. People experiencing complex partial seizures lose awareness and may act in an automatic way, making lip smacking or chewing movements, talking to themselves, pulling and picking at their clothes, or walking around in circles.

The behaviour, during which time there may be some impairment of consciousness, usually lasts a few minutes. Sometimes, complex partial seizures can turn into tonic-clonic seizures.

Dispelling Some Myths and Prejudices

People are more than a medical condition – the seizures are epileptic, not the person.

- Epilepsy is not selective. It can affect anyone at any time.
- Epilepsy is not contagious. It never has been and it never will be.
- Some people with epilepsy are extremely clever, others are of average ability and there are some with learning difficulties.
- Epilepsy is not a mental illness. Seizures are merely symptoms of a physical problem in the brain.
- Epilepsy is not necessarily an inherited condition. It can be genetically inherited but more commonly there is no family history of epilepsy.
- Epilepsy is not always a lifelong condition. Many people who have been seizure free for three or four years have their medication very carefully withdrawn under close medical supervision and remain seizure free for the rest of their lives. Surgery can sometimes be successful in eliminating certain types of seizure.
- Epilepsy does not have to be a barrier to success. Many people with epilepsy enjoy highly successful lives.
- Seizures do not necessarily injure the brain. A prolonged seizure, lasting over 30 minutes (also known as Status Epilepticus), might, however, injure the brain.





Triggers

Seizure frequency can be provoked by:

Lack of medication

The withdrawal or variation of medication must not be done without medical supervision.

Feverish illness

A rapid rise in body temperature due to some illness can provoke seizures in children.

Emotional stress

Areas of concern can include such things as a breakdown in personal relationships, financial problems or difficulties in the workplace.

Tiredness

It is important to avoid long periods of sleeplessness and to maintain a regular sleep pattern.

Alcohol

Excessive drinking can reduce the effectiveness of antiepileptic drugs. There is no evidence to suggest that the occasional social drink is in any way harmful.

Photosensitivity

In a minority of people seizures can be provoked by flickering light. Many people with epilepsy assume that they are photosensitive when they are not.

Menstrual periods

Seizures associated with the monthly cycle are called peri menstrual seizures or catamenial seizures.

First Aid for Convulsive Seizures

Move objects out of the way, which could hurt the person having the seizure.

If possible, place something under the person's head so that the head doesn't bang against the floor causing injury.

Let the seizure run its course. When it is over, if possible, move the person to a comfortable place.

Let the person have a sleep or at least a good rest once the seizure is over.

Above all

- **Keep calm**
- **Never force anything in the mouth during the seizure.**
- **If one seizure follows another without the person regaining consciousness, or if a seizure lasts longer than 5 minutes, get medical help immediately**

Medical Treatment

The control of seizures is usually managed by using antiepileptic medicines either with a single drug or in combination with others.

The preferred option is to gain control using a single drug (monotherapy) but sometimes it is necessary to add a second or rarely even a third drug to acquire control (polytherapy).

The drugs are known both by their generic (chemical) names and brand names.

Generic Name	Brand Name	Generic Name	Brand Name
Acetazolamide	Diamox®	Phenytoin	Epanutin®
Carbamazepine	Tegretol® Tegretol Retard®	Pregabalin	Lyrica®
Clobazam	Frisium®	Primidone	Mysoline®
Clonazepam	Rivotril®	Retigabine	Trobalt®
Ethosuximide	Zarontin® Emeside®	Runifimide	Inovelon®
Gabapentin	Neurontin®	Sodium Valproate	Epilim® Epilim Chrono®
Lacosomide	Vimpat®	Tiagabine	Gabitril®
Lamotrigine	Lamictal®	Topinamate	Topamax®
Levetacetam	Keppra®	Vigabatrin	Sabril®
Oxcarbazepine	Trilapel®	Zonisimide	Zonogran®
Phenobarbital	No trade name		



Surgical Treatment

Where epilepsy is difficult to control, surgery may be considered as a possible way forward.

It has to be stressed, however, that not everybody with uncontrolled seizures is a suitable candidate for surgery.

Those who are deemed suitable undergo a series of tests before the final decision is made as to whether the operation could or should go ahead.

The final decision is in the hands of the patient.

When making the final decision it is vital to bear in mind that no guarantee about the outcome can be given and that all the risks of major surgery apply.

That having been said, the decision will be guided by medical and surgical experts and they will spell out very clearly the possible outcomes and so patients are not left to their own devices to arrive at a possible life changing choice.

Prescription Charges

Those with epilepsy are exempt from paying for prescribed medication whilst the treatment lasts.

If you have been prescribed continuous antiepileptic medicine ask for an exemption application form from your doctor's surgery.

You need to fill it in and your doctor (or an authorised member of the practice staff) will sign to confirm the information you've given is correct. You will then be sent a Medical Exemption Certificate.

If you have a Medical Exemption Certificate all your prescriptions are free, whatever the medication is for.



Driving

For an ordinary entitlement the person who has epilepsy may qualify for a driving licence if he or she has been free from any epileptic attack for one year. (An epileptic attack is interpreted as any seizure involving episodes such as limbs jerking, auras or absences and need not necessarily involve loss of consciousness.)

A person who cannot meet these conditions may qualify for an ordinary driving licence provided that he or she has established over a period of at least three years (beginning on the date of an asleep attack), a history or pattern of attacks which occur only when asleep.

In either case, the applicant or licence holder suffering from epilepsy must not be regarded as a likely source of danger to the public as a driver.

If while holding a driving licence a driver suffers from an epileptic attack, driving must cease immediately (unless the sleep regulations can be met) and Driver and Vehicle Licensing Agency (DVLA) be notified.

For a Vocational Entitlement demanding either a Large Goods Vehicle (LGV) licence or a Passenger Carrying Vehicle (PCV) licence, drivers must satisfy all the following conditions:

- Hold a full ordinary driving licence.
- Be free of an epileptic attack for at least the last ten years.
- Have not taken antiepileptic medication during this ten year period.
- Have no continuing liability to epileptic seizures.

Women and Epilepsy

Women of childbearing age who have epilepsy should ask for specific medical advice on the following aspects of having the condition:

- Fertility
- Contraception
- Pregnancy and childbirth
- Effect of drugs on developing foetus
- Breast feeding
- Childcare
- Menopause



