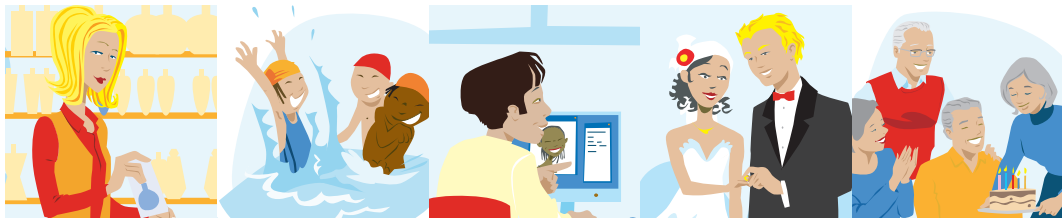


What is Epilepsy?

Information for people with epilepsy,
family members and friends



Other booklets and information
available from



- Living Well with Epilepsy
- Children, Adolescents and Epilepsy
- Women and Epilepsy
- Elderly and Epilepsy
- Epilepsy Diary & Information Booklet

- Baby Sitter Information
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You can live well with Epilepsy...

Epilepsy is the most common disorder of the nervous system in the world and affects about 50 million people. However, in spite of the large numbers of people who have epilepsy, many people with the condition still face prejudice from others, often through lack of knowledge about what having epilepsy really means. Yet more people with epilepsy are realising they can live, work, have leisure occupations, enjoy normal relations and be active members of society if their seizures are well controlled.

It may be difficult to come to terms with the fact that you or your loved one has epilepsy, and you will probably be asking questions on how or why you have this condition. Try not to dwell too much on this, instead, start to focus on what you can do to better manage your epilepsy.

Just making some small changes to the way you manage your epilepsy, could make a significant improvement to your day-to-day quality of life. This booklet is a start. In here you will find out more about epilepsy, the type of seizure you have, why it is important for your doctor to know this and how the type of seizure can affect the treatment you receive. There is a **“Notes”** section at the back of this booklet for you to jot down any points you wish to ask your doctor at your next visit.

You may also find the **“Epilepsy Diary”** helpful in monitoring your seizure control and checking for any side effects. It can help to remind you to talk with your doctor about them, to explore the best treatment options available for you, and the possibility of stopping your seizures. Of course your doctor cannot give you any guarantees, because everyone’s epilepsy is different and the way you respond will also be different to another person. Most importantly, you will have started to explore your treatment options together with your physician.

What is Epilepsy?

Epilepsy is a disorder of the nervous system that can affect people of any age, sex, race, social class or nationality. Epilepsy can be caused by injury to the brain, due to trauma – such as a car accident or a head injury, a high fever caused by an infection, or as they get older some people develop epilepsy due to vascular disease, strokes, tumours and Alzheimer's disease. However, for many people, the cause of their epilepsy is never known.

Epilepsy is diagnosed when there are repeated seizures (sometimes called fits) during a certain period in a person's life. If you only have one seizure it is often not epilepsy.

What is a seizure?

A **seizure** is the result of a temporary disturbance to the brain's electrical activity. This results in the brain's messages becoming temporarily halted or mixed up. The number of seizures can vary from less than one a year to several per day. Seizures can happen at any time. They generally last only a matter of seconds or minutes, after which the brain cells return to normal.

Our brains are responsible for most of our bodily functions, so what someone experiences during a seizure will depend on the part of the brain affected and how widely and rapidly it spreads. For this reason, there are many different types of seizure, and everyone will experience epilepsy in a way that is unique to them.

Seizures are classified into two types - generalised and partial seizures.

- Generalised seizures involve most or all of the brain.
- Partial seizures involve a limited part of the brain, and can be either Simple or Complex.



Simple partial seizures

These seizures do not result in the person losing contact with their surroundings (consciousness is not affected). As the brain controls most of the body's function, if a seizure occurs it usually affects the organ controlled by that part of the brain. So, for example, seizures affecting part of the brain controlling:

- The **muscles** can cause rhythmic shaking of a part of the body
- The **sensory** organs such as:
 - Nerves: can cause tingling sensation or pins and needles in the part of the body which may or may not spread to other parts.
 - Eyes: may cause the person to see lights, objects, animals or other people.
 - Ears: may result in the person hearing sounds, voices or melodies.
 - Nose: often difficult to describe but generally disagreeable smells.
- The **digestive system**: may cause feelings of nausea..
- The **memory or emotions**: can cause the sensation of déjà vu (the feeling you have done or been in a situation before), strange thoughts, feelings of fear, wellbeing or anxiety.
- The **heart, lungs, glands** or temperature may cause rapid heart-beat, altered breathing rates, sweating, fever or chills.



Some people may have a warning, called an **aura** (a simple partial seizure) just before losing consciousness or becoming less aware of their surroundings (complex partial seizure). An aura usually lasts just a few seconds but can be longer.

Complex partial seizures

People affected by this type of seizure lose contact with their surroundings (lose consciousness). They can become immobile, with a fixed stare and unable to respond. They often chew or swallow, or move their hands. Sometimes, they may move as if they were conscious (in contact with their surroundings) but will act strangely, not reacting when spoken to or reacting inappropriately.

Generalised seizures

- **Tonic-Clonic** seizures: can produce an abrupt loss of consciousness, with the whole body going rigid at the start (the tonic phase) and, then, jerking of the arms and legs (the clonic phase). The person may bite their tongue, urinate or hurt themselves in the fall or with the jerking movements. Once the seizure is over, they will gradually recover.
- **Absence** seizures: are very short (lasting only a few seconds) but can happen many times during the day. When a person has this type of seizure they may become still and unresponsive with a fixed stare. They recover immediately and, on many occasions, these types of seizure may go unnoticed, due to their being so short-lived. This type of seizure often begins in childhood or adolescence, and the main inconvenience is the fact that they occur very frequently which can lead to loss of attention and learning problems for the child or adolescent.
- **Myoclonic** seizures: cause a sudden jerk of the body or limbs (arms or legs), which may cause the person to drop the things they have in the hands.
- **Atonic** seizures: cause a sudden loss of muscle strength and consciousness resulting in the person falling to the floor. They recover immediately, however the seriousness comes from the risk of injury from hitting their head or falling to the floor.



Although the vast majority of seizures do not cause accidents, their existence causes uncertainty and insecurity in people with epilepsy, their family and friends. A series of relatively simple recommendations are sufficient to reduce the risk of injury. It is important to follow this advice especially if you have seizures that are more frequent or severe.

How is Epilepsy treated?

The aim of epilepsy treatment is to stop seizures completely but without causing problems (reactions to the medication).

Most people with epilepsy are prescribed **Antiepileptic drugs** to re-establish the electrical balance of the brain. There are several antiepileptic drugs available today (see Table 2). They are used to control or, for some patients, even stop seizures by reducing the sensitivity of the neurons that cause them.



The choice of treatment with an antiepileptic drug is not a random decision. It will depend on various factors, including

- your age,
- type of epilepsy,
- your response and tolerance to the medication,
- medicines you may also need to take (e.g. contraceptive pill, medicines for high blood pressure or high cholesterol etc.).

Treating epilepsy isn't easy. Quite a lot of people continue to have seizures despite trying many of the different medications and treatments currently available. However, with the choice of drugs available, it is possible that around seven out of 10 people with epilepsy could become seizure-free, once the most appropriate drug and the correct dose for them have been identified, even if this could take some time to achieve.

Only your doctor can establish the type of treatment and the correct dose for you. It is important that you take your medication as instructed to give yourself the best chance of controlling the seizures and being able to live your life.

Almost all AEDs have two names :

- **Generic**, or basic chemical name, e.g., sodium valproate
- **Brand**, or manufacturer's name, e.g., Epilim.

You may come across some of the following, though the Brand name may change in different countries :

Convulex	Valproic acid
Diamox, Diamox SR	Acetazolamide
Emeside/Zarontin	Ethosuximide
Epanutin	Phenytoin
Epilim, Epilim Chrono	Sodium valproate
Frisium	Clobazam
Gabitril	Tiagabine
Keppra	Levetiracetam
Lamictal	Lamotrigine
Mysoline	Primidone
Neurontin	Gabapentin
Nootropil	Piracetam
Phenobarbitone	Phenobarbital
Rivotril	Clonazepam
Sabril	Vigabatrin
Tegretol, Tegretol Retard	Carbamazepine
Trileptal	Oxycarbazepine
Topamax	Topiramate
Zonegran	Zonisamide

About Your Treatment



Your neurologist will usually advise that the treatment starts slowly, with steady increases in the dosage of the medication. This is to allow your body to adjust to the medication and limit the side effects from the medication. If side effects appear your doctor may decide to reduce the dose for a short time before increasing the dose more slowly.

Anti-epileptic drugs may be taken once, twice or three times a day, depending on the medication and are generally taken at meal-times. The medicine should always be taken at the same time every day. If you have forgotten to take a dose then try to take it as soon as possible.

If the seizures continue or the side effects become difficult to bear, your doctor may decide to change your medication to one that is more suitable for you. For many people with epilepsy, their first antiepileptic drug will sufficiently control their seizures. However, people unable to tolerate a drug or whose seizures have not been controlled may need to change their anti-epileptic drug, or add a second one. Your neurologist will advise you if this is necessary for you.

Medication side effects

Any type of medication, not just anti-epileptic drugs, can have side effects. These side effects can range from mild to severe. It can be easy to become used to your epilepsy treatment without realising how it is affecting you. In order to help your doctor identify the treatment that may be best for you, it is important to be aware of the number of seizures you are having (if any), and also how these drugs make you feel. Many people accept having treatment side effects as being part of having epilepsy. But this needn't be the case.

EXAMPLES OF SHORT-TERM EFFECTS

Some side effects happen at the start of taking anti-epileptic drugs, while the body is adjusting to them.

- Sleepiness / fatigue
- Feeling unsteady, 'woozy' or dizzy
- Irritability
- Allergic reaction / skin rash (these may not disappear)

Some of these effects may lessen or disappear completely over time.

EXAMPLES OF LONG-TERM EFFECTS

More troublesome side effects can happen when certain drugs are taken for a long time. They may include the following

- Poor memory and concentration
- Slow speech, word-finding difficulties
- Swollen gums
- Acne
- Weight gain / loss
- Hair loss or thinning / excessive hair growth in unusual places

You should always inform your doctor if you suffer from these or any other side-effects. Never stop or change the dose of drugs yourself.

Importance of Regular Reviews with your Specialist

Inform your doctor if you find that you have problems with the medication, or if you notice:

- side effects that are having an impact on your day to day life,
- an increase in seizures,
- a new type of seizure,
- your seizures last a longer time.

Your doctor may decide an appointment with an epilepsy specialist is appropriate. This will be an opportunity for you to find out about any treatment options that could offer improved seizure control and fewer side effects.

Even if you and your specialist decide not to change your medication, there may be ways of reducing the side effects you are experiencing, or the control you have over your seizures. Your doctor should be able to discuss those options with you.

You should not change the dose or stop your medication yourself as there is the risk of increasing the frequency and seriousness of the seizures.

Unfortunately, 3 out of 10 people with epilepsy will have seizures that cannot be controlled by medication. Their epilepsy specialist may consider other options, including surgery to help control their seizures.

Other Treatment Options

- **Vagal nerve stimulation** - uses a device similar to a pacemaker implanted under the skin, which stimulates the vagal nerve to reduce epileptic seizures.
- **Ketogenic diet** is a diet high in fats and low in proteins and carbohydrates (similar to the Atkins Diet). It is a very strict diet lasting 6-8 weeks initially before an assessment of its effectiveness can be made. As it can cause lower levels of vitamins B, C, and D, and calcium, supplements of these are required. The diet can lead to a number of side effects which prevent people from continuing with this. It is vital that it be carried out in collaboration with a dietician or endocrinologist.
- **Surgery** – the part of the brain that causes the seizures and sometimes also some of the surrounding brain tissue is removed, often with very good results. Before proceeding to surgery, epilepsy specialists will make every possible effort to ensure that removing the part of the brain responsible for the seizures does not lead to an important loss of brain function

Taking Control of your Epilepsy

Epilepsy does not mean that your life has to drastically change. Just like everyone else, maintaining a healthy and well-balanced lifestyle is important. As a person with epilepsy there are just a few additional measures to take. Some simple tips to do so:

- Remember to **take your antiepileptic medication** at the right time – one of the most common causes of uncontrolled seizures is people's failing to take their medication correctly. Medicines are removed from the body at a different rate depending on the type of drug, which means that if you forget to take them, the amount of medicine in the blood may not be sufficient to control your seizures.
- **Sleep well** - lack of sleep increases the risk of epileptic seizures, especially in people with certain generalised epilepsies. A regular sleep pattern, ensuring enough rest, is recommended, and estimated to be between seven and ten hours a night (depending on your age).
- Try to **limit your workload and stress** – stress can trigger seizures so activities that help to reduce your stress levels can help. Try to take time and pleasure in preparing good food for yourself, your family and friends.



Only certain high-risk sports are not advised if you have epilepsy (mountain climbing, paragliding, hang-gliding, diving etc). The majority of well-run leisure activities and sports are possible and highly recommended. You will have many activities to choose from and will have the opportunity to meet new people. If your seizures are well controlled and you are able to tolerate your treatment there should not be any effect on your sporting performance.



- Try to **avoid stimulants** such as coffee, alcohol or drugs and noise, especially if they trigger your seizures. Excessive use of alcohol is toxic for the neurons and can also affect sleep patterns, which may lead to further seizures. Some drugs may affect the way your epilepsy medicine works which could increase the risk of seizures. If you are being put on other medication for other illnesses remember to inform your epilepsy specialist.
- Arrange a **regular review** with an epilepsy specialist if you notice any change in the type of frequency of the seizures you experience. Also do not be afraid to talk to your specialist of things that are affecting you – they could be a reason for any change in the seizures you are experiencing. Make a note of anything you wish to discuss.

