Ratgeber Epilepsie – Englisch

Epilepsy
Plain and simple

The Guide

1A PHARMA

A Sandoz Brand

In simple terms
Epilepsy

1

Causes

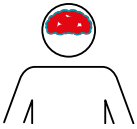
Unknown in one out of two cases. Any disruption in the central nervous system cells can trigger seizures:

- Diseases
- Brain injuries
- Malformations of the brain
- Environmental factors
- etc.

2

Symptoms

Epileptic seizures with different symptoms



Generalised seizure with loss of consciousness, falls or strong muscle spasms

Focal (partial) seizure with unusual feelings or abnormal sensations, e.g sudden tingling on the skin

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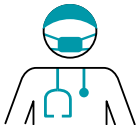

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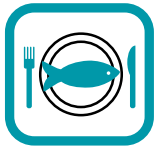
5 Tips for daily life



Special diet, e.g. ketogenic diet

Sport following consultation with the doctor

Remaining vigilant during recreational activities

Where applicable, review of fitness to drive

Information in the event of a desire to have children or pregnancy

Self-management: documentation of seizures

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Important note for readers

The content-related and scientific information in this guide reflects the current state of information at the time of writing (see back page). This guide is intended to provide an initial overview of the topic. It is not, however, a substitute for advice from a doctor. Please always read the package leaflet that comes with your medicines carefully. For the reasons mentioned, 1 A Pharma GmbH cannot guarantee or accept liability for content or information from this guide.

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Dear Reader,

According to the Epilepsy Information Centre (ize) of the German Society of Epileptology, 400,000 to 800,000 people in Germany have epilepsy. Doctors refer to epilepsy when a patient has had at least two epileptic seizures. This Guide provides you as a patient or relative with some preliminary information.

To treat epilepsy, the doctor usually prescribes prescription-only medicines known as antiepileptic drugs. In addition, patients themselves can contribute towards improving the condition in their everyday life. The majority of patients lead an active and largely normal life with targeted treatment. Regular interactions with a specialist are important.

Also talk to a specialist if you have any questions not covered by this guide.

We wish you good health.
The 1 A Pharma Team

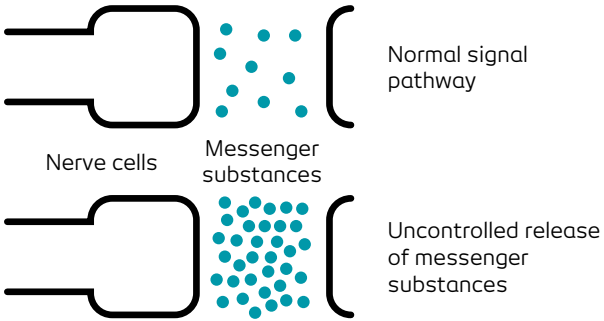
What is epilepsy?

Epilepsy is one of the most common chronic diseases of the central nervous system. According to the Epilepsy Information Centre (ize) of the German Society of Epileptology, about a half to one percent of the population has it. In Germany, that equates to about 400,000 to 800,000 people, in whom different forms of epilepsy occur. Each of them responds differently to drug treatment. In some forms, about nine out of ten patients become seizure-free. In others, this applies to only about one in three patients. In any case, epilepsy places a great strain on patients and their relatives.

To be clear about one thing: epilepsy is not a contagious disease. It is also not caused by mental illness or a mental disability. Epilepsy is a chronic disease of the central nervous system. "Chronic" means that it develops slowly and persists for a long time. In epilepsy, the nervous system is disrupted. Normally, the signals that the nerve cells (or "neurons") in the brain transmit to the muscles are perfectly

synchronised with one another. When there is a disruption, however, they transmit signals to the muscles in an uncoordinated way – in a rapid sequence. This produces movements that are abnormal and uncontrollable. The result is an epileptic seizure. The patient experiences muscle spasms. These result in random rapid movements.

A single epileptic seizure does not mean that someone has epilepsy. This term is used only when a patient has had two or more epileptic seizures.



What are the causes of epilepsy?

Epilepsy can have many causes. Any disruption in the normal activity of nerve cells can trigger seizures. These include diseases, injuries and malformations of the brain. In about half of all seizures, the cause is unknown. Usually, these are what are known as "primary seizures".

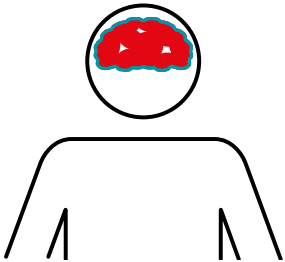
Secondary seizures are caused, for example, by acquired brain damage and tumours, head injuries, strokes or brain inflammation due to infection. A very low blood sugar level, illicit drug withdrawal or alcoholism can also cause secondary seizures.

The extent to which predisposition plays a role has not been clearly explained. It appears to increase the likelihood of having epileptic seizures. In most cases, these are triggered by environmental factors, such as sleep deprivation, fever or excessive alcohol abuse.

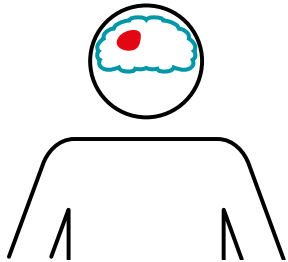
What are the symptoms of epilepsy?

In an epileptic seizure, the nervous system in the brain goes haywire. Abnormal movements, such as jerks or spasms, do not always occur. Sometimes, patients also report unusual sensations or short absences.

Seizures differ. There are more than 30 different forms, including two main groups.



Generalised seizure



Focal (partial) seizure

Generalised seizure

In this case, the nerve cells in many parts of the brain do not do what they are supposed to do. This results in epileptic seizures with loss of consciousness, falls or strong muscle spasms. Sometimes, impairments of consciousness with memory loss occur ("absences"/ "petit mal"); sometimes there are muscle contractions, usually in the back, arms and legs. In other patients, there is repeated jerking on both sides of the body or mixed symptoms. In "grand mal", a "major" seizure, almost all the symptoms occur. The body stiffens and the limbs jerk repeatedly. The patient loses consciousness.

Focal (partial) seizure

About 60% of epilepsy patients have partial seizures. They occur in only one part of the brain. These seizures are frequently named after the area of the brain in which they originate. In a simple partial seizure, consciousness is retained. Unusual feelings or abnormal sensations of various kinds can occur. These include sudden and inexplicable feelings of happiness, anger, sadness or sickness.

An epileptic seizure can last for two to five minutes, but in severe cases it can be as long as twenty minutes.

Experts call warning signs of an epileptic seizure "prodromes". Usually, patients behave strangely and anxiously and complain of inner restlessness and nervousness. This can occur as many as several days before an actual seizure. It should be distinguished from an "aura". This is part of the seizure and leads on to some epileptic seizures. For example, tingling, visual disturbances and sometimes concentration difficulties occur. These can even extend to hallucinations. Other patients notice a feeling of dizziness. As soon as symptoms of an aura occur, some patients recognise that an epileptic seizure is imminent.

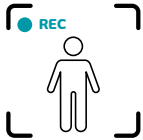
How is epilepsy diagnosed?

To be able to treat epilepsy correctly, an accurate diagnosis is required. Initially, this involves close observation and extensive investigations. The medical history plays an important role in the diagnosis. In this respect, it helps if the patient makes notes beforehand, which he or she then brings along to the doctor. Being accompanied by a relative can also help. This is because the patient often does not remember exactly what happened during a seizure.

The most common examination is the electroencephalogram (EEG). For an EEG, the doctor places electrodes on the patient's scalp. These are used to record brain wave patterns. The EEG result should be interpreted only in conjunction with the other findings. This is because healthy people can also have unusual brain waves. Conversely, the brain wave patterns in epilepsy patients may be normal.

In addition to the EEG, further investigations can be performed when epilepsy is suspected, including video recordings. These help the doctor to assess the seizures in a patient. Magnetic resonance imaging (MRI) generates cross-sections of the human brain. As a result it records even the most minute structural changes. This enables the cause of the epileptic seizures to be ascertained.

EEG



Video recordings

MRI

How can epilepsy be treated?

A person who has more than one seizure a year should be treated. Depending on the patient and the severity of the epilepsy, doctors from different specialties are involved: neurologists, paediatricians, paediatric neurologists, internal medicine specialists, general practitioners, neurosurgeons or epileptologists (epilepsy specialists). Intensive management is possible in large hospitals and outpatient neurology clinics or by community-based neurologists.

Drug therapies

Prescription-only medicines called "antiepileptic drugs" are the treatment of first choice. Medical professionals also call them "anticonvulsants". More than 20 different active substances are now available. They all have different benefits and possible side effects.

Antiepileptic drugs are designed to curb seizures or prevent them from occurring. The active substance and the medicine prescribed, as well as the dosage, depend on the individual.

A variety of aspects play a role here:

- Type of seizures
- Lifestyle
- Age of the patient
- Seizure frequency
- Probability of pregnancy

About 60 to 70 percent of patients can be treated successfully with medicines. They can live a largely normal life. Treatment with one medicine, or "monotherapy", is often sufficient. In other cases, the combining of several antiepileptic drugs is appropriate.

Important

Never stop taking antiepileptic drugs without consulting your doctor - even if you now feel better. Do not stop the drug treatment suddenly, even after consulting the doctor, but rather discontinue the antiepileptic drugs gradually over a prolonged period of time.

What are the possible side effects?
Some patients experience unwanted symptoms initially. These are side effects. They do not occur with every active substance or with every patient. Most subside after a few days. Normally, they can be treated successfully.

The most common side effects of antiepileptic drugs are:

- Sedation, in other words unintended inactivity
- Severe tiredness
- Allergic reactions
- Movement and postural disorders ("ataxia")

What interactions can antiepileptic drugs have with other medicines?
Sometimes, medicines that are taken simultaneously have an effect on one another. Interactions then occur. It is essential to inform your doctors before you start taking an antiepileptic drug if you are already taking other medicines – even ones you have obtained without a prescription. Do the same if you are having a check-up with your dentist. In addition, read the relevant package leaflet and if necessary ask your pharmacist for advice. The best thing is to enter all your medicines in an epilepsy calendar. Ask your doctor about this.

Some antiepileptic drugs can interfere with the effectiveness of oral contraceptives, such as the pill. Women should talk to their doctor about this.

In some cases, patients can come off the medication. The requirement is that they have not had a seizure for several years.

Anyone who stops taking the medication of their own accord is at risk of a relapse. Subjects who were seizure-free expose themselves to seizures again. These can be very serious and progress to what is known as "status epilepticus". This term is used by doctors for a persistent epileptic state or repeated seizures.

Non-drug therapies

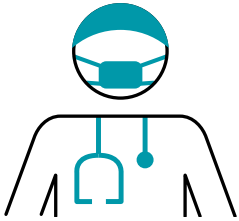
In some patients, epileptic seizures cannot be controlled by medication. Additional non-drug therapy is often of help to them.
Non-drug treatments include:

- Surgery
- Vagus nerve stimulator

Changes in lifestyle can also have a beneficial effect on the disease course.

Surgery

In severe cases in which medicines are unable to control the seizures sufficiently, surgery can help. This depends on the type of seizure and on which region of the brain is affected.

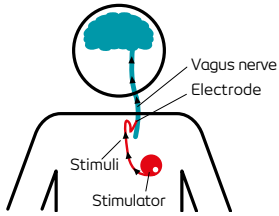


The surgical procedure is preceded by a large number of investigations. For example, the area of the brain from which the seizures originate must be pinpointed. Only once it has been established that there will be no impairment of brain function is surgery performed. This involves the surgeon removing the source in the brain.

Vagus nerve stimulator

A vagus nerve stimulator may also help patients who do not respond to drug therapy. A vagus nerve stimulator is a battery-operated device. It emits electronic stimuli that are transmitted to the brain. Like a heart pacemaker, the device is implanted under the skin of the chest. The doctor then connects it to the vagus nerve in the bottom of the neck. This nerve travels to the brain. As a result, about 40 to 50 percent of patients have only half as many seizures. In some cases, it is

even more successful. Despite the stimulator, however, patients cannot stop taking epilepsy medication completely, although often the dose can be reduced.



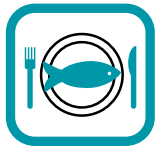
Tips for daily life

For treatment to be successful, it is important for the patient's life situation also to be considered. His or her everyday behaviour can positively or negatively affect the course of the disease. This involves the following areas and life situations in particular:

- Diet
- Sport
- Recreation
- Driving
- Pregnancy
- Self-management

Diet

Diet can affect the course of the disease. This applies in particular to young patients. Some are helped by a strict high-fat, low-protein and low-carbohydrate - or "ketogenic" - diet.



They often experience fewer seizures as a result. A dietitian decides in advance how many calories and how much protein the patient requires daily. Age, height and weight, in particular, play a role here. This usually occurs during a stay in hospital. As the diet continues, regular examinations by a doctor are required. Good co-operation on the part of the patient and, where applicable, the parents is vital.

Alternatively, the modified Atkins diet has proved successful in some older children and adolescents. This provides the body with less fat than the ketogenic diet. Neither the amount of protein nor the daily calorie intake is limited. It does not involve fasting while it is being introduced. The switch should also take place in hospital. Although parents need less training than with the ketogenic diet, constant medical guidance is necessary.

Sport

Sport in many cases improves a patient's well-being. Sport may also have a beneficial effect on the course of the disease. In principle, all sports are permitted. For most people with epilepsy, physical exertion and increased breathing activity do not trigger a seizure. Talk to your doctor about suitable sports.

Recreation

Rhythmic flashes of light can also trigger seizures. These occur, for example, when spending time beside water or visiting a music concert. In such cases, a patient with photosensitive epilepsy should be particularly vigilant and perhaps take along a companion. Suitable precautions against a seizure include, for example, protective helmets or life jackets. These reduce the risk of injury.

Driving

In principle, epileptic seizures that have occurred for the first time or are not controlled by medication impair the mobility of someone who has epilepsy. However, not all epilepsy sufferers are necessarily prohibited from driving. The definitive criteria are laid down in the "Begutachtungsleitlinien zur Kraftfahreignung" ("Guidelines for the Assessment of Fitness to Drive") of the German Federal Highway Research Institute (BASt). As an important prerequisite, the 2017 version states that there should be no "substantial risk of seizure recurrence", in other words no danger of a relapse. Generally, a medical expert assesses fitness to drive.

Pregnancy

Generally, there is no reason for an epilepsy patient not to become pregnant. However, patients should be aware that there is a 5% probability of parents with epilepsy transmitting the risk of seizures to their offspring. It is higher if one parent has an unequivocally inherited form of epilepsy. A specialist and a genetic counselling service can explain this in individual cases.

Some antiepileptic drugs slightly increase the risk of offspring being born with, for example, cleft palate, heart abnormalities, or finger and toe defects. The risk of damage to the unborn child from uncontrolled seizures is greater during pregnancy. In this case, the doctor may decide to change the medication before and during the pregnancy. The change-over should be made in good time. Only then can the correct dose be determined. Only then is it possible to monitor blood levels.

In addition, pregnancy may require a change in the medication dose. This can be decided only by a doctor.

Usually during pregnancy, only one medication is used at the lowest daily dose necessary. During treatment with several antiepileptic drugs, or "polytherapy", blood folic acid levels may be lowered further. Folic acid is one of the group of essential vitamins. The body cannot produce it itself. Humans absorb it in their diet. The probability of the baby developing a facial cleft or neural tube defect is increased when there is a folic acid deficiency. These are malformations of the central nervous system. Doctors therefore usually advise women with epilepsy to take five milligrams of folic acid daily before conceiving and during the first three months of pregnancy. To prevent blood clotting disorders, doctors recommend taking vitamin K1 in the last few weeks of pregnancy. This can also help the newborn baby after birth. At all events, please discuss this with the doctors who treat you.

Epilepsy medications need not be a reason to forego breast-feeding. They pass into the breast milk in only very small quantities. The treating doctor should check the newborn baby regularly for possible drug effects.

Self-management

Self-management has proved successful for many patients. It can protect against new seizures. The patient should, for example, avoid sleep deprivation or heavy alcohol consumption. At the beginning, he or she records all the physical and psychological conditions associated with the onset of seizures. The pattern that this reveals may provide the starting point for a trial of this kind of treatment.

In self-managment, the patient must recognise what triggers a seizure. He or she can then try to do or think precisely the opposite. For example, he/she tries very consciously to relax if anxiety triggers a seizure.

The self-management method is not suitable for counteracting all seizures. It has proven useful particularly

- in partial seizures or
- in partial seizures that begin with an aura.

First aid in seizures

This advice is aimed at the relatives and friends of a person with epilepsy. It helps them to take the right action in the event of a seizure. In severe cases they should call a doctor.

- Keep calm.
- Remove sharp objects. Where applicable, remove the patient's glasses and take any cigarette out of his or her hand. Place something under their head to prevent it from striking the floor.
- Do not try to open the jaw. Do not force objects between the teeth.
- Loosen any tight clothing, particularly around the neck. Place the patient in a stable position on the side after the seizure. Remain with the patient until he or she is fully oriented.
- The patient may be carrying a medical ID card or epilepsy calendar on them with important information about their condition.
- If you are a witness, call a doctor if the seizure lasts more than ten minutes, if it recurs within a period of less than one hour, if the patient does not regain consciousness, or if you suspect a serious injury (call emergency number 112).

Where can I get help?

Deutsche Epilepsievereinigung
Zillestraße 102 • 10585 Berlin
Tel.: 030 3424414
info@epilepsie-vereinigung.de
www.epilepsie-vereinigung.de

A self-help group for people with epilepsy. Information, suggestions, contact addresses, counselling services and much more on the subject of epilepsy.

Deutsche Gesellschaft für Epileptologie e. V.
Epilepsy Information Centre
Reinhardtstraße 27 c • 10117 Berlin
Tel.: 0700 13141300 (12 cents/minute)
ize@dgfe.info • www.dgfe.info

Information for patients with epilepsy and parents of children with epilepsy.

e.b.e. Epilepsie Bundes-Elternverband e. V.
Administrative Office
Am Eickhof 23 • 42111 Wuppertal
Tel.: 0202 2988465
kontakt@epilepsie-elternverband.de
www.epilepsie-elternverband.de
(for parents, carers, teachers, educationalists)
www.epi-surfer.de (for children and adolescents)

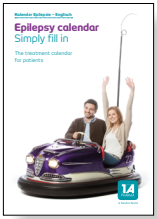
Concerned with the assistance, guidance and support of parents with epileptic children.

Pharmakovigilanz- und Beratungszentrum für Embryonaltoxikologie
Charité University Hospital, Berlin
Campus Virchow-Klinikum
Augustenburger Platz 1 • 13353 Berlin
Tel.: 030 450-525700
www.embryotox.de

Provides information about the tolerability of the most important medicines, including antiepileptic drugs, and the treatment of frequently occurring diseases in pregnancy and during breast-feeding.

Other services of 1 A Pharma

You can order your epilepsy calendar free of charge (while stocks last) by fax on 089 613882525 or over the Internet at **www.1apharma.de/service**



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Einfach verstehen.

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