Ratgeber Epilepsie – Englisch

Epilepsy
Simply explained

The guide

1A PHARMA

A Sandoz Brand

Simply explained
Epilepsy

1 Causes

Causes of epilepsy are changes in the brain, e.g. resulting from:

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

In many cases, however, the causes of epilepsy remain unknown.

2 Forms and symptoms

Epileptic seizures can be accompanied by a variety of symptoms. A distinction is made between the following types of seizure:

Generalised seizures are not limited to just one region or half of the brain. In addition to causing a clouding of consciousness, they can also affect the movement of the person with the condition.

Focal (partial) seizures only affect a specific region of the brain, but can spread from there. They can occur with or without affecting consciousness.

3 Drug therapy

Generally with prescription-only medicines ("antiepileptic drugs"). More than 20 active substances are available. Dosage and active substance depend on the individual.

4 Non-drug-based therapies

As an add-on to or in the event of unsuccessful drug-based treatment. Surgery or stimulation methods are also available. A targeted change in diet can help, especially in the case of children and adolescents.

Targeted diet, e.g. ketogenic diet

Surgery

5 Tips for daily life

Sport following consultation with a 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 most up-to-date facts available at the time of editing (see back page). This guide is intended to provide an initial overview of the topic. It is not, however, a substitute for medical advice. Please always read the package insert that comes with your medications 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 German Society for Epileptology, 400,000 to 800,000 people in Germany have epilepsy. This guide provides those with the condition or their relatives with some initial information.

To treat epilepsy, the doctor usually prescribes prescription-only medicines known as antiepileptic drugs. In addition, those with the condition can use self-help tips. The majority of patients lead an active and largely normal life with targeted treatment. Communicating regularly with a specialist is important. You should also talk to the specialist if you have any questions not covered by this guide.

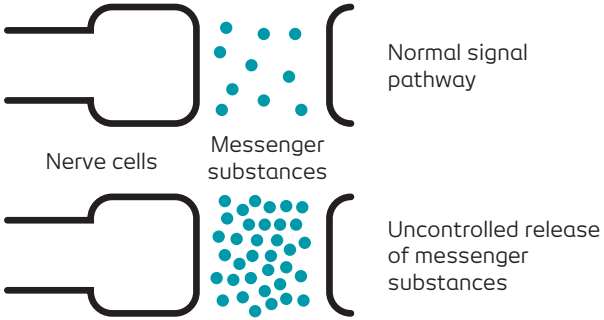
Best wishes
The 1 A Pharma Team

What is epilepsy?

Epilepsy is one of the most common chronic diseases of the central nervous system. According to the epilepsy information centre (or 'ize') of the German Society for Epileptology, around a half to one percent of the population has it. However, there are different forms of epilepsy. They all respond to drug treatment with different degrees of success. In some forms, about nine out of ten patients become seizure-free. For other forms, it is only one in three. In any case, epilepsy places a great strain on patients and their relatives.

But what exactly causes an epileptic seizure?
An epileptic seizure is caused by a disruption in the nerve cells (called "neurons") in the brain. Normally, the signals that the nerve cells in the brain transmit to the muscles are perfectly synchronised with one another. When they are disrupted, however, they transmit signals in an uncoordinated fashion – in rapid succession. The effects can vary in nature;
for example, people report muscle twitching, a loss of sensation, a clouding of consciousness and abnormal

behaviour, but speech and hearing centre problems also occur.



A single epileptic seizure does not mean that someone has epilepsy. This is only considered to be the case when a patient has at least two seizures more than 24 hours apart.

What are the causes of epilepsy?

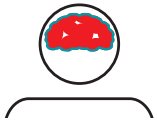
Any disruption in the normal activity of nerve cells in the brain can trigger seizures. This is usually caused by changes in the brain, for example as a result of illness, damage or malformations. In some cases, however, the cause of the condition remains unknown.

"Primary epilepsy" is a condition that occurs in its own right. If, on the other hand, the epilepsy is the result of another condition, it is called "secondary epilepsy". Secondary epilepsy is caused by acquired brain damage such as brain tumours, traumatic brain injuries, strokes or brain inflammation due to infection. Under certain circumstances, e.g. high fever, poisoning, large blood sugar fluctuations or in connection with acute brain damage, there may be isolated epileptic seizures that do not recur after they have passed. Such seizures are called situational seizures.
Genetic causes can also play a role. For those with the condition, they increase the likelihood of epileptic seizures occurring.

What are symptoms of epilepsy?

Epilepsy is characterised by the repeated occurrence of epileptic seizures. During an epileptic seizure, the brain experiences a temporary loss of function as a result of short discharges from nerve cells. Abnormal movements, such as twitching or stiffening, do not always occur. Sometimes, patients also report unusual sensations or brief absences.

Seizures are split into two main groups depending on where they originate:



Generalised seizure

Focal (partial) seizure

Generalised seizure

In this case, nerve cells throughout the brain do not do what they are supposed to do. A generalised seizure can occur both with and without movement being affected. "Absences" occur without the muscle stiffening. These are spontaneous lapses of consciousness, meaning that those affected can usually recover quickly. The "tonic-clonic seizure", on the other hand, is an example of a seizure affecting the muscles. The tonic phase causes the arms and legs to tense, whereas the clonic phase causes rhythmic muscle jerking. In addition, breathing may stop, the skin may change colour and there may be increased salivation.

Focal (partial) seizure

Focal seizures only occur in one part of the brain, but can also spread from there, i.e. "generalise". They can happen both with and without affecting consciousness. Those affected can describe the symptoms themselves, depending on whether or not they remain conscious. If they lose consciousness, they often appear absent to onlookers.

An epileptic seizure usually lasts no longer than two 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. A prodrome is distinct from an "aura". This precedes some epileptic seizures. It can cause dizziness, tingling, vision problems or a strange feeling in the abdomen that is difficult to describe. 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, a diagnosis is required. Initially, this involves close observation and intensive investigations. The medical history plays an important role in the diagnosis. In this respect, it helps if the patient makes notes beforehand and takes them 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, other examinations are carried out if epilepsy is suspected. These include magnetic resonance imaging (MRI), which produces cross-sectional images of the human brain. As a result, it records even the most minute structural changes. Video recordings can also help the doctor to assess a patient's seizures.

EEG

MRI

Video recordings

How can epilepsy be treated?

A one-off seizure does not necessarily need to be treated. Treatment may be advisable, however, depending on seizure frequency. The individual patient and form of epilepsy may mean doctors from different specialties becoming 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-based therapies

Prescription-only medicines called "antiepileptic drugs" are usually 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 curtail 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 and frequency of seizures
- Age and lifestyle
- Use of additional / other medicines
- Probability of pregnancy

About 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.

What are the possible side effects?

Some patients may experience undesirable accompanying 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:

- Tiredness
- Dizziness
- Double vision
- Hypersensitivity to the medicine

What interactions can antiepileptic drugs have with other medicines?

Sometimes, medicines that are taken at the same time can have an effect on one another. Interactions then occur. If other medicines are being taken, it is essential to talk to a doctor before starting to take them - even if they are over-the-counter medicines. The same also goes for visits to the dentist. A glance at the package leaflet or asking a pharmacist for advice can also be helpful. All medications can be noted down in an epilepsy calendar.

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. People who were seizure-free may start having seizures again. These can be very serious and progress to what is known as "status epilepticus". Doctors use this term to describe an epileptic seizure that lasts longer than 5 minutes; this needs to be treated quickly.

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.

Non-drug-based therapies

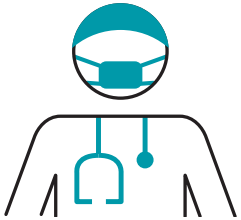
Some patients are unable to achieve control of their epilepsy by taking medication alone. Additional non-drug therapy is often of help to them.
This includes:

- Surgery
- Stimulation methods (vagus nerve stimulation, deep brain stimulation)
- Diet

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

Surgery

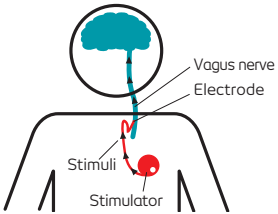
In severe cases in which medicines are unable to control the seizures sufficiently, surgery can help. This depends on the type of seizure and on which region of the brain is affected.



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 area of the brain that is causing the seizures.

Stimulation methods

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 on the chest. The doctor then connects it to the vagus nerve at the bottom of the neck. This nerve travels to the brain. As a result, about one in four 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. The dose can often be reduced, though.
Deep brain stimulation, another technique, is not common in Germany and should only be used at special treatment centres.

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 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. Initiation usually takes place 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.

Less strict diets such as the modified Atkins diet have 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. The switch should also take place in hospital. Although parents need less training than with the ketogenic diet, constant medical monitoring is necessary.

Tips for daily life

If treatment is to be successful, it is important to take your circumstances into account. Your everyday behaviour can positively or negatively affect the course of your condition. This involves the following areas and circumstances in particular:

- Sport
- Recreation
- Driving
- Pregnancy

Sport

In many cases, sport improves a patient's well-being. Studies show that sport does not lead to an increase in seizures, but rather to a decrease in them. For most people with epilepsy, physical exertion and faster breathing do not trigger a seizure. In principle, all sports are also allowed. However, talk to your doctor about suitable types of sport.

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 impede a patient's mobility. However, not all epilepsy sufferers are necessarily prohibited from driving. The definitive criteria are laid down in the so-called "Begutachtungsleitlinien zur Kraftfahreignung" ("Guidelines for the Assessment of Fitness to Drive") of the German Federal Highway Research Institute (BASt). As an important prerequisite, it states in the 2019 version that there should be no "significant risk of seizure recurrence", in other words no danger of a relapse. A medical expert usually assesses fitness to drive.

Pregnancy

Generally, there is no reason for an epilepsy patient not to become pregnant. The good news is that around 95% of the children of people with epilepsy do not develop epilepsy themselves. However, there is a higher risk if one parent has a clearly hereditary form of epilepsy. A medical specialist and a genetic counselling service can clarify this in individual cases.

Pregnancy may require a change in the medication dose under certain circumstances. The change-over should be made in good time in order to establish the correct dose. Ideally, pregnancy should be planned. Talk to your doctor as early on as possible.

This will allow the doctor to adjust medication doses and combination therapies to meet pregnancy and childbirth needs. Fortunately, about 2/3 of women remain seizure-free during their pregnancy.

Folic acid deficiency, which can also be caused by antiepileptic drugs, increases the risk of malformations. Folic acid is one of the group of essential vitamins. The body cannot produce it itself. Humans absorb it in their diet. Folic acid deficiency increases the likelihood of malformations in babies. These are malformations of the central nervous system. Doctors therefore usually recommend that women with epilepsy take folic acid daily before they become pregnant and during the first three months of pregnancy. In any case, 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.

First aid for 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.

- Remain calm and briefly look at the clock to estimate the length of the seizure.
- If necessary, move the person having the seizure out of harm's way and minimise the risk of injury from sharp objects.
- Place something underneath their head to prevent it from hitting the floor.
- Do not try to hold the person down or open their jaw.
- Loosen any tight clothing - especially around the neck - and remove spectacles, if necessary.
- After the seizure, place the patient in a stable position on their side. Reassure them. If possible, you can also cover them and remove potential saliva with a tissue.
- Call the emergency number if the seizure lasts longer than 3 minutes, if it happens again within less than an hour, if you suspect serious injuries or if you are not sure whether the person has epilepsy or is having an epileptic seizure.

Where can I get help?

Deutsche Epilepsievereinigung e.V.
[German Epilepsy Association]
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.
[German Society for Epileptology]
Epilepsy information centre
Reinhardtstraße 27 c • 10117 Berlin
Tel.: 030 23132301 (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. [epilepsy parents' association]
Administrative Office
Bommerfelder Ring 29 • 58452 Witten, Germany
Tel.: 02302 2052859
kontakt@epilepsie-elternverband.de
www.epilepsie-elternverband.de
(for parents, carers, teachers, educationalists)
www.epi-surfer.de (for children and adolescents)

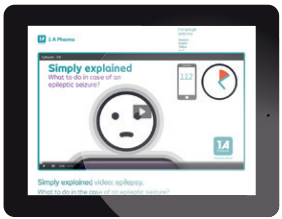
Deals with the assistance, guidance and support of parents with epileptic children.

Pharmacovigilance and Advisory Centre for Embryonal Toxicology
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 also order the other free services related to epilepsy (while stocks last) online from the webshop at **www.1apharma.de**



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