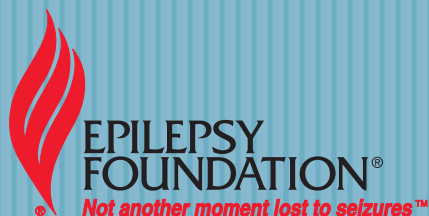


# EPILEPSY



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## You and Your Treatment

Tests • Diagnosis • Management



# EPILEPSY TREATMENT

## About seizures

A seizure is the outward sign of a malfunction in the electrical system that controls the brain. A single seizure can have many causes, such as high fever or lack of oxygen or poisoning; seizures that occur more than once, without a special cause, are called epilepsy (also called a seizure disorder).



Seizures may be convulsions, brief stares, muscle spasms, odd sensations, or episodes of automatic behavior and altered consciousness.

If you have had a seizure and you seek medical help, your doctor will want to know:

- Was the seizure caused by a short-term problem (like fever or infection) that can be corrected?
- Was it caused by a continuing problem in the way your brain's electrical system works?
- Is there anything about the structure of your brain that could cause seizures?
- Was the seizure an isolated event, or does it mean that you have epilepsy?

The doctor will try to find the answers to these questions through:

- A detailed medical history.
- A thorough physical examination, including nervous system function.
- Analysis of blood and other body fluids.

This pamphlet is intended to provide basic information about epilepsy to the general public. It is not intended to be, nor is it, medical advice. Readers are warned against changing medical schedules or life activities based on this information without first consulting a physician.

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- Electroencephalographic (EEG) recordings.
- Magnetic resonance imaging (MRI) and/or computed tomography (CT) scans.

Which tests and how many of them are ordered may vary, depending on how much each test reveals.

## medical history

The most important information about your seizures comes from the detailed medical history. The doctor will want to know what happens from the first hint of a seizure until the end. If you have more than one kind of seizure, each type should be described as fully as possible.

If you're not aware of what happens to you during a seizure, have someone who has seen your seizures come with you when you see the doctor, or ask them to give you a written description.

Don't be afraid to describe any strange feelings you may get from time to time. They may provide clues about your seizures.

## blood tests

Blood tests are often ordered to check on the general state of your body and can be used to determine if your liver, kidneys, or blood cells are functioning normally. Blood tests can also be used to determine if you have infections, vitamin deficiencies or whether you have been exposed to any poisons, such as lead.

If the doctor thinks your seizure might have been caused by infection or bleeding in the brain, he or she may order a spinal tap (or lumbar puncture). This procedure removes a small amount of fluid from the spinal canal so it can be analyzed.

These tests are designed to find out

whether your seizure had an underlying cause that may be treated directly.

If you are already taking medications to stop seizures, your doctor may wish to check

the concentration of the medicine in your blood. This is called a "blood level." It is important to remember that for all anti-seizure medicines, the "normal" blood level is zero, since none of the drugs are normally found in your body.



The goals of treatment are to find a dosage of medicine which stops seizures and doesn't cause side effects. The dosage that does that for you is your personal "therapeutic level." The dose that works for you may be very different from the dose of the same medicine that works for someone else. Because of this variation from person to person, drug levels alone cannot tell whether your dose of medicine is too low, too high or just right. A dose of medicine which makes you feel sick because it is too much will give a drug level that is "toxic" for you. The drug level that may make one person "toxic" may be the concentration that is just right for someone else.

## electroencephalograph (EEG) tests

The electroencephalograph (EEG) is a machine that translates the electrical activity of the brain into a series of wavy lines.

An EEG test will probably be ordered to see whether there are any continuing irregularities in your brain's electrical activity that may produce seizures.

Small metal discs with thin wires, called electrodes, are pasted on the scalp. They are connected to a computer which records the results of the test.

The electrodes pick up tiny electrical charges which are produced by activity of nerve cells in the brain. The charges are amplified and recorded on the computer monitor. The result is a series of wavy or jagged lines. The recording may also be printed out on paper.



Normal electrical activity in the brain makes a recognizable pattern. Seizures, which are rarely seen in routine EEGs, produce very specific, abnormal patterns. Even without your having a seizure, doctors can recognize abnormal patterns that are markers for the risk of seizures. The patterns are called different names. Common names for these abnormal patterns are spikes, polyspikes, sharp waves and spike and wave complexes. These patterns can tell your doctor a lot about your seizures, including the part of the brain where your seizures start, and may even suggest which medicine might be best for you.

Having an EEG is a painless, safe procedure. The machine can't read your mind. It has safety features to prevent you from getting an electric shock. It doesn't measure intelligence or reveal mental or emotional illness.

## Having an EEG

EEG tests may be given in special laboratories or in hospital outpatient departments. Sometimes the person having the test will be

told to stay up late the night before and to avoid caffeine drinks on the morning of the test.

The test itself may be given in a small room separated from the EEG machine and the technologist. This is done to give the person having the test a quiet, relaxing environment.

Some clinics have small TV cameras set up in the test area to videotape the person's movements during the test. The movements recorded on the videotape, when combined with the EEG recording, may give additional clues about the kind of seizure the person is having.

Before the test, the EEG technologist applies the small metal disks to several places on the scalp (hair should be washed on the morning of the test with no additional chemicals, hair sprays, cleansers, cosmetics, or setting gels applied). A special glue is used to attach the electrode disks. It washes out afterwards. Sometimes a cap with the wires already attached is used instead.

Some EEG tests are made with the patient sitting in a chair. Others are performed with the patient lying down on a couch or a bed. During the test, the technologist may ask you to breathe deeply through your mouth for a short time. This may produce a slightly dizzy feeling or numbness in the hands or feet, which goes away when you start breathing normally again.

The technologist may shine a flashing light into your eyes, or ask you to open and close them rapidly a few times. You may be asked to sleep or to make other simple responses, depending on the aims of the test.

Children should be told what to expect during an EEG test, and can be encouraged to "practice" on a doll or stuffed animal beforehand.

The average EEG test may last 35 to 40 minutes; one involving a period of sleep will take longer.

A home monitoring variation of the standard test allows people to go on with normal activities while the recording is being made. The patient wears special headgear with electrodes connected to a recorder worn on the belt. A test like this may take several days.

After the test, the results will be sent to your personal physician.

Sometimes the medical history and other tests suggest that a person has epilepsy, but there is no sign of seizure activity on the EEG. A normal EEG does not rule out epilepsy. There may have been no abnormal seizure activity during the relatively short time the test was given, or the abnormal activity may be located in such a small area of the brain that the surface electrodes failed to pick it up. When this happens, the physician may order an extended test of several hours or use special electrodes that can pick up fainter signals.

## Brain imaging

There are a number of tests that give the doctor information about the structure of the skull and the inside of the brain.

These include conventional x-rays and x-rays taken after the injection of dye into the vessels leading into the brain (angiograms). In babies, high-frequency sound waves may also be used to produce a picture of the brain (echoencephalogram). All these tests help the doctor find any brain tumors, blood clots, malformations or scar tissue that might be causing seizures.

Magnetic resonance imaging (MRI, fMRI) techniques use magnetic fields instead of x-rays to produce detailed pictures of the brain.

A magnetoencephalogram (MEG) measures magnetic fields of the brain and can pinpoint the source of signals of seizure activity as well as the site of normal functions such as vision, hearing, or sense of touch.

Computerized tomography uses special analysis of X-rays to produce pictures of the brain. These are typically not as detailed as those produced by MRI

but can usually be done more quickly, and can often be done when MRI cannot (such as after medical devices have been implanted). Brain imaging is performed by special equipment that looks somewhat like a very large front-loading washing machine, although there are variations in structure.

Typically, if you have a CT or MRI scan, you will lie on an examination table with your head resting on a curved support directly in front of the machine. You and the table will then be moved gently towards the machine so your head, and sometimes your entire body, is inside its circular opening.

A person having a CT or MRI scan may be given an injection of what's called a contrast medium. This is a fluid that goes up to the brain and makes the scan easier to read. After the injection, some people may feel flushed, have a metallic taste in the mouth, or feel a brief nausea.

The scanning process is controlled and monitored by a technologist in an outer room nearby. Relaxing and keeping as still as possible help to keep the pictures from being blurred.





Children should be told what to expect and shown how this great big round camera will take a picture of the brain.

Another type of machine which produces images of the brain is the positron emission tomography (PET) scanner. It produces color-coded pictures of brain processes at work — including blood flow, use of glucose, for fuel, and use of oxygen.

## Treatment

When the doctor has made a diagnosis, the next step is to select the best form of treatment. If the seizure was caused by an underlying condition that can be corrected, such as a tumor in an area that can safely be removed, then treatment — in this case, surgery — may correct that problem and in many cases the seizures will probably not return. However, most patients will be treated with seizure-preventing drugs for a period of time until the effects of surgery can be assessed.

If epilepsy — that is, a continuing tendency to have seizures — is diagnosed, the doctor will usually prescribe regular use of seizure-preventing drugs. More than twenty medications are available to treat epilepsy. If medicines are not successful in preventing seizures, other methods may be tried, including surgery, a special diet or vagus nerve stimulation (VNS).

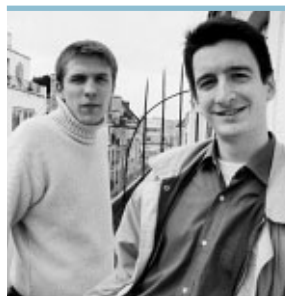
The goal of all epilepsy treatment is to prevent further seizures, avoid side effects, and make it possible for you to lead a normal, active life.

## Treatment with medicines

Most epilepsy medicines are taken by mouth in the form of tablets, capsules, sprinkles, or syrup.

The following are commonly prescribed to prevent seizures: Carbamazepine (brand names, Tegretol, TegretoIXR, Carbatrol); clonazepam (Klonopin); ethosuximide (Zarontin); phenobarbital; phenytoin (Dilantin); primidone (Mysoline); valproic acid (Depakene); and divalproex sodium (Depakote). Several others may also be prescribed.

Newer drugs which are also prescribed for epilepsy include lacosamide (vimpat); felbamate (Felbatol); gabapentin (Neurontin); lamotrigine (Lamictal); levetiracetam (Keppra), oxcarbazepine (Trileptal); rufinamide (Banzel); tiagabine (Gabitril); topiramate (Topamax); zonisamide (Zonegran) and pregabalin (Lyrica). Other new drugs are in development.



A rectal gel form of diazepam (Diastat) may be prescribed for parent or caregiver use in stopping cluster seizures or prolonged seizures in a child or adult. Some doctors may prescribe pills of diazepam (Valium), lorazepam (Ativan), or clonazepam (Klonopin) for the same purpose. Some of these tablets can be dissolved under the tongue, which gets then into the bloodstream more quickly than swallowing them.

A steroid drug, ACTH, may be given by injection to treat children with a type of epilepsy called infantile spasms, or for severe seizures that can't be controlled with other drugs. It is usually given by a doctor who has had special training in using this medicine for epilepsy.

The doctor's choice of which drug to prescribe depends partly on what kind of seizure a person is having. Different drugs control different types of seizures.

People also react to these medicines in different ways. Some experience side effects, others may not. Some people's bodies break down medicines at a faster or slower rate than the average person. Some people's seizures will respond well to a particular drug while someone else will have seizures that continue. With all this variation, it may take some time to find exactly the right dose of the right drug for each person who has a seizure disorder.

Taking medicine on time every day replaces the medicine that your body has used up since the last dose. Taking medicine on time keeps a steady level of the seizure-preventing drug in the body. Taking medicine regularly gives your treatment the best chance of success.

Missing doses, allowing the prescription to run out, or taking fewer pills than prescribed may make the drug level in your body too low to do its job. Then the seizures are likely to start again.

## side effects of medicine

All medicines can cause side effects. Drugs that prevent seizures can cause side effects too, even though many people take them for long periods of time with no unpleasant side effects at all.

Some side effects (like feeling very tired, or nauseated) are more likely to happen when a drug is first started. They may go away later on. Other side effects may happen because one drug you are taking is affecting another one, and the two together are making you feel uncomfortable in some way.

A third possibility is that too much medicine is building up in your blood and the level is becoming "toxic." Feeling very tired, staggering, or slurring your words can all be signs of this.

Some people have an allergic reaction (like a rash) to a drug. The reaction may be caused by only a small amount of the drug. When this happens, a different drug may have to be used instead.

Each drug has its own list of possible side effects. Ask your doctor about the drug you are taking. Ask what to watch out for, and what to do if problems occur.

## how many drugs?

If you are taking several different drugs to prevent seizures (especially if you're still having some seizures and feel very tired all the time), ask your doctor whether treatment with one medicine might control seizures just as well cause fewer side effects.

Of course, you may be one of the people who still needs more than one medicine to prevent seizures. Or, you may be someone who'll continue to have some seizures no matter what. Still, it's well worth checking with your doctor in case a change of treatment can help you. Surgery, the vagus nerve stimulation (VNS) implant, or the ketogenic diet may be treatment options to consider.

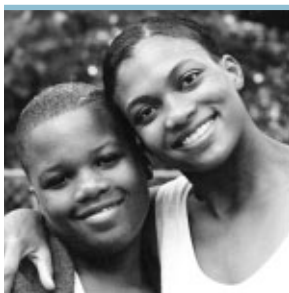
### Helping treatment work

- Ask your doctor ahead of time what to do if you forget a pill.
- Don't stop taking your pills suddenly. It could cause non-stop seizures that would put you in the hospital and might even threaten your life.
- Tell your doctor if you notice any unusual changes in health, feelings, or behavior when you or your child are taking these medicines.

## tests during treatment

The following tests may be ordered when epilepsy is treated with medication:

- Blood and urine tests to make sure that there is enough medicine in your blood to prevent seizures, but not so much as to cause side effects, keeping in mind that one



## treatment during pregnancy

If you're a woman with epilepsy and you plan to have a baby, tell your doctor ahead of time. Ask whether he or she thinks there should be any changes in the epilepsy medicines and vitamins you are taking before you become pregnant. Most babies born to mothers taking epilepsy medication during pregnancy are perfectly normal. However, there is a higher than average risk of birth defects (approximately 4 – 6 percent) when epilepsy drugs are taken during pregnancy. Ask your doctor to discuss the risks with you.

If you take epilepsy medicines and find you are already pregnant, don't make any medicine changes on your own or stop your pills suddenly. You will still need to control seizures while you are pregnant. Check with your doctor. He or she may want to see you more

- Be careful about drinking beer, wine, or hard liquor. Check with your doctor about how these drinks will mix with your medicine.
- Get enough sleep.
- Think about things you want to ask before you see the doctor. Write them down so you don't forget.
- Keep follow-up appointments. You may need to have special tests from time to time to make sure the drugs aren't doing anything to your body that might be bad for you.
- Tell doctors treating you with medicines or surgery for other medical conditions, that you have epilepsy and what medicine you take for it. Write down the names and dosages and times that you take these medications and keep it in a safe place.
- Ask your doctor if there are any cold pills, fever medicines or other drug-store products that you should not use because you take epilepsy medicine.
- If your doctor changes your medicine, don't drive until you know how it's going to affect you.

person may respond quite differently than another to the same blood level.

- Blood and urine tests to see whether the drugs are having any negative side effects on your health. How often these have to be done depends on the drug you are taking and how it makes you feel.
- EEG tests to see whether the medicine is having the hoped-for effect on electrical irregularities in the brain.

The primary aim of these and all tests used to monitor treatment is to give the doctor the information needed to provide the best care in each individual case.

New drugs for epilepsy are being tested in special medical centers. People with severe, uncontrolled seizures who have not been helped by other standard epilepsy medicines may be admitted to these testing programs if they have the kind of seizures the new drugs are designed to control.



often during this time. Some women have more seizures when they are expecting a baby, some don't have as many, and others find it makes no difference.

Be sure to tell any doctor prescribing a birth control method for you that you also take epilepsy medicine. Knowing that will help him or her pick out the right birth control pills for you.

## treatment through surgery

Brain surgery can be a successful way of treating epilepsy. Surgery is most likely to be considered when someone with epilepsy:

- Has already tried the standard medicines without success (or has bad reactions to them).
- Has seizures that always start in just one part of the brain.
- Has seizures in a part of the brain that can be removed without damaging important things like speech, memory, or eyesight.

Surgery for epilepsy is a delicate, complicated operation. It must be performed by a skilled, experienced surgical team. It is usually done at special medical centers rather than at local hospitals. In addition to operations that remove a small part of the brain where seizures begin, other procedures may be done to interrupt the spread of electrical energy in the brain.

People who are going to have epilepsy surgery may have several special tests first. In some cases, electrodes have to be implanted in a separate operation to more precisely locate the source of the seizures. Sometimes these tests take days or even weeks to complete.

Patients may be awake during part of the operation. This is possible because the brain does not feel pain. Having the patient awake

helps the doctors make sure that important parts of the brain are not damaged. Afterwards, some seizure medications may have to be continued, usually for a year or two. Then, if no further seizures occur, the medicine may be slowly withdrawn.

## treatment through diet

A child who has a lot of side effects from anti-seizure drugs, or whose seizures cannot be controlled by them, may be treated with a special restricted calorie diet that tricks the body into burning fat, instead of glucose, for energy.



The diet is very high in fats and low in protein and carbohydrates. It produces a change in the body's chemistry called ketosis, which has the effect of controlling seizures, or reducing their frequency, in two out of three children placed on the diet. Although not all children benefit, parents report that children who do are more alert and active than they were previously.

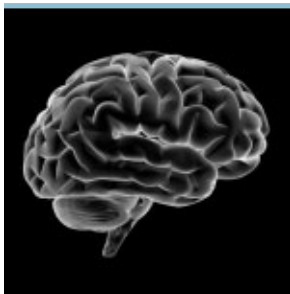
The ketogenic diet must be worked out by a dietitian, weighed out in grams by the family, and followed by a doctor just as if it were a course of drug treatment. **It is not a do-it-yourself diet.** It must be carefully tailored to the individual child, and strictly followed. The diet is usually given in the form of fatty foods and cream, with a 4 to 1 ratio of fat to protein and carbohydrate.

Like other treatments, the ketogenic diet has some side effects which the medical team monitors through blood and urine tests and follow up visits. The diet is primarily used to treat children for a limited period of time, after

which the diet may be slowly tapered and regular food slowly re-introduced. If seizures return, the diet may be re-instituted. Studies are underway to see if the ketogenic diet would work for some adults as well; early results suggest that it may, but the long term effects of such a high fat diet are unknown. Also under active study is to determine whether less restrictive high fat, low carbohydrate diets may be of benefit to children or adults

## treatment through vagus nerve stimulation

Vagus nerve stimulation (VNS) is another form of treatment that may be tried when medications fail to stop seizures. It is currently approved for use in adults and children over the age of 12 who have partial seizures that resist control by other methods. The therapy is designed to prevent seizures by sending regular small pulses of electrical energy to the brain via the vagus nerve, a large nerve in the neck.



The energy is delivered by a flat, round battery, only a little bigger than a half-dollar, which is surgically implanted in the chest wall. Thin wires (electrodes) are threaded under the skin and wound around the vagus nerve in the neck. The battery is programmed by the health team to send a few seconds of electrical energy to the vagus nerve every few minutes or less. If the person with the system feels a seizure coming on, he or she can activate the discharge by passing a small magnet over the

battery. In some people, this has the effect of stopping the seizure. However it is not necessary to have a warning for the VNS to be helpful, since it's main effect results from the long-term, programmed stimulations.

Side effects of VNS treatment are mostly hoarseness and, sometimes, discomfort in the throat. There may be a change in voice quality during the actual stimulation. Although complete seizure control is seldom achieved, the majority of people who have the VNS implant experience fewer seizures. In some its effectiveness increases with time, and patients report an improved quality of life. As with surgery and the ketogenic diet, it is usually necessary to continue with antiepilepsy medication in addition to VNS therapy.

## other treatments

**Vitamin therapy.** Unfortunately, when it comes to epilepsy, high doses of vitamins do not usually do any good. This is often a disappointment to people who would like to have what they think of as a more “natural” kind of treatment than taking medicines every day. Special diets (except for the ketogenic diet described above) don't seem to have any antiseizure effects either although some of these are currently being studied.

**Help with how you feel.** Some people with seizures may need other kinds of treatment—like counseling for emotional problems or help with anxiety or depression, help with finding jobs, or special education services. This type of treatment may help you cope with this disorder and get on track to a more normal life. But the first priority is to get up-to-date medical care and the best seizure control possible.

The Epilepsy Foundation nationwide provides free information about seizures and epilepsy and makes referrals to sources of help. For more information about the Epilepsy Foundation nearest you, contact:

**Epilepsy Foundation**

1-800-332-1000

or visit our website at

[www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

# NOTES