

# Do I Have Epilepsy?

**Diagnosing Epilepsy  
and Seizures**



**EPILEPSY  
FOUNDATION**



**About the Cover:**

Cover artwork was created by Ashley N., a Studio E participant with the Epilepsy Foundation of Michigan. Studio E is a multi-week art therapy program open to people with epilepsy. It is provided through a partnership between the Epilepsy Foundation, its affiliates and Lundbeck. Participants use art to creatively express themselves, build confidence and make friends. Living with epilepsy can be challenging and art therapy may be beneficial in working through how the condition impacts an individual's life. Find out more about the program and where its available at [www.epilepsy.com](http://www.epilepsy.com).

**Disclaimer:**

This publication is designed to provide general information about epilepsy and seizures to the public. It is not intended as medical advice. People with epilepsy should not make changes to treatment or activities based on this information without first consulting their health care provider.

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**I**f you've had a seizure — or you think you might have had a seizure — see a doctor as soon as possible. Finding the right treatment for seizures depends on getting the correct diagnosis and that can take time. This pamphlet will help you know what to expect.

## Diagnosing Epilepsy and Seizures

### I had a seizure. Do I have epilepsy?

Not necessarily. Not everyone who has a seizure has epilepsy. In fact, 1 in 10 people will have a seizure at some point, but not all of these people will be diagnosed with epilepsy.

Seizures cause sudden, temporary changes in a person's behavior or awareness. A seizure happens when a person's brain is overloaded by abnormal bursts of electrical activity. Some doctors describe a seizure as an electrical "storm in the brain."

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Sometimes seizures are caused by a temporary problem — like an infection or low blood sugar. If this is the case, you may not have another seizure after you’ve gotten better and you would not have epilepsy. But if there’s an ongoing problem in your brain that causes seizures, you may need treatment for epilepsy.

Sometimes what looks like a seizure isn’t actually a seizure. These other events may be called “seizure imitators” or “nonepilepsy events.” You can read more about seizure imitators later in this pamphlet.



## **What is a seizure?**

A seizure happens when a person's brain is overloaded by abnormal bursts of electrical activity. Some seizures can make you lose consciousness (pass out) and jerk or shake. Other seizures might make you feel strange, see or hear things that aren't there, or move in ways you can't control. Or, a seizure might cause you to just stare and not be aware of what is going on around you.

There are many types of seizures. The type of seizure you have depends on where the abnormal electrical activity happens in the brain and how much of the brain is involved. To learn more about different seizure types, go to [www.epilepsy.com](http://www.epilepsy.com).

## How do I know if I have epilepsy?

Finding out if you have epilepsy is like putting together the pieces of a puzzle. To figure out if you have epilepsy, you will need to see a doctor who will:

- Ask you to describe your seizure
- Ask about your medical history and lifestyle
- Do a physical exam
- Ask you to get some blood and urine tests
- Asking about your medical history

The doctor may also order tests to see what's happening in your brain. You'll find information about these tests later on page 8 of this pamphlet.

“After I had my first seizure, my doctor did a bunch of tests to see if there might be medical condition that caused it. When everything came back normal, he said it might be epilepsy.”



## What is epilepsy?

Epilepsy (also called a “seizure disorder”) is a medical condition. Doctors will usually diagnose epilepsy if:

- A person has one or more seizures
- The doctor thinks the person is likely to have more seizures
- The seizure is not directly caused by another medical condition, like diabetes or a severe infection.

About 1 in 26 people in the United States will develop epilepsy at some point in their lifetime.

Epilepsy is a general term that includes people who have any of the different types of seizures. Some people with epilepsy have just one type of seizure, while other people have more than one type.

There are many possible causes of epilepsy, including head injuries, infections, or other neurological problems (like stroke, tumor, or autism). Basically, anything that harms the brain can cause epilepsy. Some people may have epilepsy from a genetic cause –something they were born with.

It’s not always possible to tell what causes epilepsy. In fact, in 6 out of 10 people with epilepsy, a clear cause can’t be found.

# Making the Most of Your Doctor Visit

At your first visit, the doctor or nurse will ask you questions and examine you. You may also need to give blood or urine for some lab tests. The physical exam and lab tests will tell the doctor if certain parts of your body are working correctly.

## What do I need to tell the doctor or nurse?

Tell them about your current health, any health problems you've had in the past, and any health problems that run in your family. This is called your "medical history," and it's an important part of diagnosing epilepsy.

Be prepared to tell the doctor or nurse if:

- You have a medical condition, like diabetes
- You ever had a head injury
- You had any serious illnesses as a child
- You take any medicines, including vitamins or herbs
- Someone in your family has epilepsy, seizures, or other neurological problems



**Ask a friend or family member to go with you.** Visiting the doctor can be scary and having support can help. Plus, if someone else is there, you'll have help asking questions and taking notes.

The doctor will also ask you questions to make sure that what happened was a seizure — and to find out what kind of seizure it was.

Be ready to answer questions like this:

- Was this your first seizure?
- What was it like?
- What happened before the seizure?
- What happened during the seizure?
- How long did the seizure last?
- How did you feel after it was over?
- How long did it take before you returned to your usual activity?

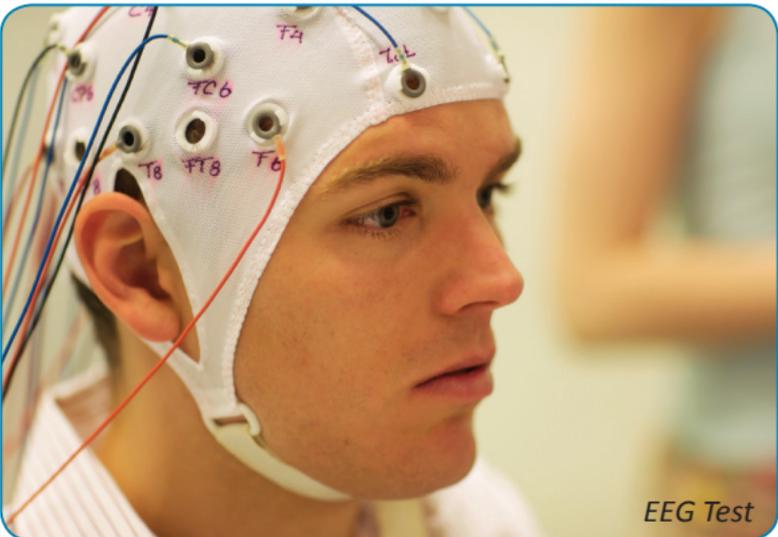
If someone else saw you have a seizure, ask for details about what it looked like. Write down the information and share it with your doctor or nurse.

# Understanding Diagnostic Tests

## What tests will I need?

Besides lab tests, you may need to get one or more tests (called “diagnostic tests”) to help the doctor find out what’s happening in your brain. Some tests show the doctor the electrical activity in your brain. This electrical activity is how your brain “talks” to your body. Other tests take pictures of your brain so the doctor can look for scars or unusual growths.

The most common test used to diagnose epilepsy is called an EEG test. Other tests you might need include a lumbar puncture, a CT scan, an MRI scan, or a PET scan. For some of these tests, you may need to stay still for a while, which can be uncomfortable.



EEG Test

- **EEG (electroencephalogram) test**  
An EEG is a machine that records the electrical activity in your brain. It lets the doctor look for any unusual patterns.

During an EEG test, a technologist will attach electrodes (small metal discs) to your head with sticky paste. The electrodes record your brain activity. The test usually lasts about 30 to 60 minutes, and it's safe and painless.

- **Lumbar puncture (spinal tap)**  
A lumbar puncture is done in your lower back. During lumbar puncture, a needle is inserted between two lumbar bones (vertebrae) to remove a sample of spinal fluid — the fluid that surrounds your brain and spinal cord. This fluid is then tested. This procedure is used to help diagnose serious infections and disorders of the central nervous system.

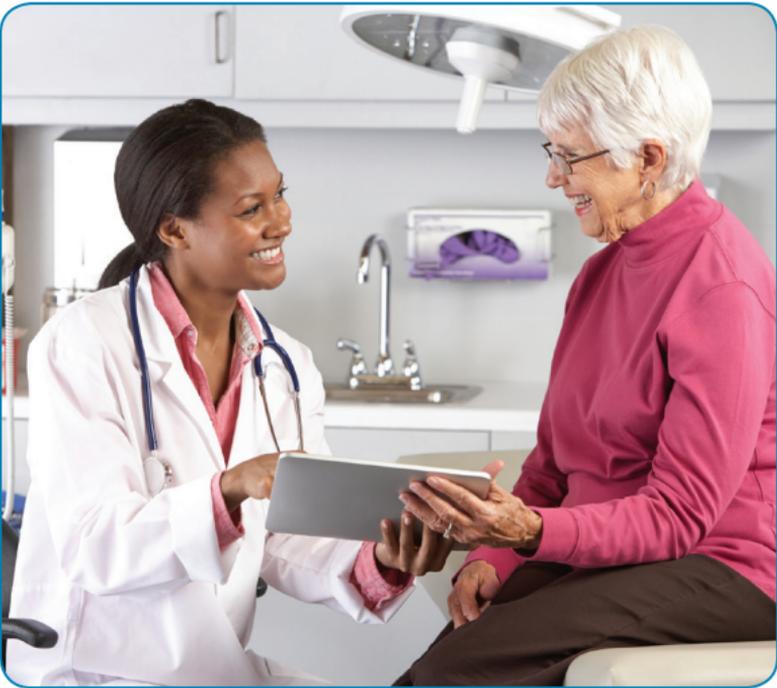
- **CT (computerized tomography) scan**

A CT scan takes pictures of your brain. These pictures can help your doctor see things like scars or a tumor that could be causing seizures. The CT scan uses a low level of radiation, similar to a regular x-ray.

- **MRI (magnetic resonance imaging) test**

An MRI is a machine that uses strong magnets to create an image of your brain. The MRI picture may be clearer than a CT scan and can pick up changes in the brain structure that a CT scan may not. Talk with your doctor about whether an MRI is right for you.





## What Type of Doctor Should I See?

Start by seeing a primary care doctor or family physician. If your primary care doctor thinks you have epilepsy, he will probably refer you to a specialist called a neurologist (“nuh-RAH-luh-gist”).

Neurologists treat medical problems that affect the brain and the nervous system. Usually, the neurologist will do some more tests. If she diagnoses you with epilepsy, she will also help you find the treatment option that’s best for you.

If you have epilepsy and your seizures are hard to control, you should see a neurologist who specializes in epilepsy. This kind of doctor is called an epileptologist.

For help finding a doctor who specializes in treating epilepsy, you can use the “Find a Doctor” feature at [www.epilepsy.com](http://www.epilepsy.com). You can also call the Epilepsy Foundation at 1.800.332.1000. And remember, if you aren’t happy with your doctor, it’s always okay to ask for a second opinion from another doctor.



**If you go to the emergency room** during or after a seizure, be sure to ask whether you need to schedule a follow-up appointment with your regular doctor.

## What If It's Not Epilepsy?

After your physical exam, medical history, and lab tests, you may find out that you didn't have a seizure. You may have experienced what doctors call a "seizure imitator," which is an event that looks like a seizure but isn't one. Some common seizure imitators include:

- Sudden, quick movements that you can't always control, such as a tic
- Fainting (passing out)
- Transient ischemic attacks (mini-strokes), which can cause symptoms like suddenly feeling confused
- Panic attacks

Or you may find out that you don't have epilepsy, even if you did have a seizure. Be sure to ask the doctor about what caused the seizure and what you can do to lower your risk of having another one.

## How can I get the most out of doctor appointments?

Getting good medical care is a team effort, and you are the most important member of the team. Use these tips to make the most of your time at the doctor's office

- Write down questions ahead of time, so you'll remember to ask them.
- Take notes during the appointment.
- Ask a family member or friend to go with you.
- Before you leave, make sure you understand what to do next.
- Get the number to call if you have more questions after you get home.





Don't be shy about asking questions or letting the doctor or nurse know if you don't understand something. Here are some things you might want to ask:

- What type of seizures do I have?
- Can my seizures be treated with medicine?
- Is it likely that I will have more seizures?
- What should I do if I have another seizure?
- How can I keep myself from getting hurt during a seizure?
- What do others need to do if I have a seizure? What is the appropriate first aid response?
- Do you have any information about epilepsy that I can take with me?
- Can I drive?

# Living with Epilepsy and Seizures

## If I have epilepsy, what happens next?

If you are diagnosed with epilepsy, the next step is finding a treatment that works. This may take some time.

The first treatment your doctor will try is medicine. This works for about 7 in 10 people with epilepsy. You may need to try different medicines before finding the one that works best with the fewest side effects. Sometimes, a combination of medicines is the best treatment.

It takes time to know if medicines are working, so it is important to be patient and continue sharing information and asking questions as you work with your medical team to find the right medicine and right dose (amount) for you.

If medicine is not able to control your seizures, you can talk with the doctor or nurse about other options like:

- Special diets
- Medical devices that use painless electrical signals to prevent or control seizures
- Surgery



## Learn more, connect, and get involved.

You have a lot to learn — about seizures, treatment options, and living well with epilepsy. But remember, you aren't alone.

Talk with trusted friends or family members so they can support you. The Epilepsy Foundation has affiliates (regional offices) all over the United States, as well as online communities you can join.

Visit [www.epilepsy.com](http://www.epilepsy.com) or call 1-800-332-1000 to:

- Speak with an information specialist at our Epilepsy & Seizures 24/7 Helpline.
- Learn more about diagnostic tests for epilepsy.
- Look up information about different types of seizures.
- Find detailed information about treatment options.
- Get safety tips for home, work, and school.
- Connect with other people who are living with epilepsy and seizures.







## About the Epilepsy Foundation

The Epilepsy Foundation, a national non-profit with 47 affiliated organizations throughout the United States, has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures. The mission of the Epilepsy Foundation is to stop seizures and sudden unexpected death in epilepsy (SUDEP), find a cure and overcome the challenges created by epilepsy through efforts including education, advocacy and research to accelerate ideas into therapies. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential. **For additional information, please visit [www.epilepsy.com](http://www.epilepsy.com) or call us at 1.800.332.1000.**



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