



Epilepsy & Seizures:
Information for Adults



Founded in 1954, the Epilepsy Foundation of Minnesota (EFMN) is a non-profit organization that offers programs and services to educate, connect, and empower people affected by seizures.

Together we can...

EDUCATE the community about seizures to reduce the stigma surrounding epilepsy.

CONNECT people with epilepsy to others, and to resources.

EMPOWER people living with epilepsy to reach their full potential.

Our mission

EFMN leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.

Our vision

A world where people with seizures realize their full potential.

INTRODUCTION

If you've been diagnosed with epilepsy, you probably have questions about how it will impact your life. The good news is that medical treatment of seizures is getting better. There's also a lot you can do to maintain your quality of life as a person living with epilepsy and seizures.

In the United States, over three million people live with epilepsy and seizures. Living with seizures is different for different people. For many people, seizures can be easily controlled with medication – however some people may become seizure free without it, after a few years. For others, seizures are a lifelong challenge.

I have epilepsy. Now what?

The first step is getting medical help. Learn all you can about your epilepsy and the type(s) of seizures you have. Then work with your health care team to find treatment to help control your seizures.



EPILEPSY AND SEIZURE BASICS

What is a seizure?

Our brains use tiny electrical signals to control everything we think, feel, and do. A seizure happens when a person's brain is overloaded by an abnormal amount of electrical activity. Some doctors describe a seizure as a "storm in the brain." While a seizure is happening, it causes temporary changes in how a person thinks, feels, or moves. These changes might cause:

- Loss of consciousness
- Convulsions (whole body shaking)
- Confusion
- Brief periods of staring
- A sudden feeling of fear or panic
- Uncontrolled shaking of an arm or leg

Are there different types of seizures?

Yes. There are many types of seizures. The type of seizure your child has depends on where the abnormal activity happens in the brain – and how much of the brain is involved.

- **Generalized seizures** happen in the entire brain.
- **Partial (or focal) seizures** begin in one specific part of the brain.

What is epilepsy?

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

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

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.

What causes epilepsy?

For about half of adults diagnosed with epilepsy, doctors are able to find a specific cause. Common causes vary depending on the person’s age. For the other half of adults diagnosed with epilepsy, the cause is unknown. For young and middle-aged adults, common causes of epilepsy include:

- Head injuries
- Brain infections
- Brain tumors

For adults over age 65, common causes include the ones listed above and also:

- Stroke
- Alzheimer’s disease

When the cause of someone’s epilepsy can’t be identified, genetic (inherited) factors may play a role. Researchers have found that some genetic problems may cause epilepsy, while other genetic problems may change the way a person’s brain works.



What is the most common treatment for epilepsy?

Medication is the most common treatment for epilepsy and is almost always the first treatment to attempt. Seizure medications will successfully control seizures for about seven out of ten people with epilepsy.

Many medications can be used to prevent seizures. These are sometimes called “anti-epilepsy drugs” (AEDs) or “anti-seizure medications.” To choose the best medication for you, your doctor will look at:

- The type(s) of seizures you have.
- Your age and sex.
- Possible side effects of the medicine.
- Any other health problems you may have.

If you start taking a seizure medication, be sure to ask your doctor or nurse:

- Common side effects.
- Any side effects that are considered more serious or dangerous.
- How long it will take to know if the medication is working.
- What to do if you forget to take the medication on time.
- If there are other medications you should not take (such as aspirin or certain birth controls).
- Whether it’s okay to switch between different versions of your medication, like going from brand name to generic.

Epilepsy and bone health

Some seizure medications may have side effects if you take them for a long time. One common side effect of certain medications is weakened bones (osteoporosis). Ask your doctor if you should take vitamin D and calcium supplements to help keep your bones strong. Let your dentist know if you are taking seizure medication – there can be dental side effects to some medications.

What if medications don’t work?

You may need to try different medications before finding the one that works best. In some cases, a combination of medications is the best treatment. If you’ve tried several medications and you’re still having seizures, talk with the doctor or nurse about other options that could work for you, including dietary therapies, medical devices, or surgery.



WORKING WITH YOUR HEALTH CARE TEAM

Getting good medical care for epilepsy and seizures is a team effort, and you are the most important member of the team. Your knowledge and experiences can help your doctor figure out what is going on and find the best treatment for your epilepsy.

Who can help with my epilepsy?

Most people with epilepsy see a **neurologist**, a doctor who specializes in diseases of the brain and nervous system. To manage epilepsy, a neurologist will usually prescribe seizure medication and see you for regular office visits.

For some people, a regular primary care doctor can manage their epilepsy. This can be the best option for people who have seizures that are easily controlled with medication, or for people who live far away from a specialist's office.

If your epilepsy is difficult to treat, your doctor may refer you to an epileptologist (a neurologist who specializes in epilepsy) or an epilepsy center. An epilepsy center has epileptologists, psychologists, pharmacists, nurses, care navigators, and other specially-trained professionals who can work together to give you the care you need.

Find a doctor who's right for you

You and your doctor will work closely together to manage your epilepsy and seizures. It's important that you feel comfortable asking questions and talking to your doctor about your seizures and your life.

How can I make the most of medical visits?

Follow these tips to help you and your doctor make the most of your visit:

- Ask a family member or friend to go with you. This person can help you take notes and support you as you ask questions.
- Be prepared to describe your seizures. You may also want to ask a family member or friend to tell your doctor what happens during your seizures, especially if you lose consciousness.
- Bring your seizure diary so your doctor can see how often you have been having seizures and when they are most likely to occur.
- Bring a list of questions. Use a notepad and pen to write down the answers.
- Ask your doctor to write down important information, like changes in your medicine or any dangerous side effects to look out for.
- If you don't understand, keep asking. It's alright to ask your doctor to clarify something. Asking a nurse to explain complex information can also help.

It's also a good idea to keep copies of all your medical records, such as test results and medicines you've tried. If you ever switch doctors, your new doctor will need this information.

Will I be able to start a family?

Most women and men with epilepsy are able to have children. If you have epilepsy, your children may have a slightly higher chance of developing epilepsy compared to children whose parents don't have epilepsy. Still, it is much more likely that your children will not develop epilepsy.

Pregnancy and childbirth

Most women with epilepsy can have healthy pregnancies and normal deliveries — but you will need to take some extra steps to stay healthy, control seizures, and keep the baby safe.

Before you get pregnant:

- Ask your doctor about your seizure medication. Having a seizure while pregnant is dangerous for you and your unborn baby, and some seizure medications may increase a baby's risk for birth defects (physical or mental development). Talk to your doctor about the risks and benefits of the medication you take. Ask if you can try taking a lower dose that will still control your seizures.



- Take folic acid every day. All women who are trying to get pregnant need to get an extra 400-800 micrograms (mcg) of folic acid every day. Folic acid is a vitamin that reduces your baby's risk of having certain birth defects. Take folic acid before and during your pregnancy to protect your baby.

While you are pregnant:

- Get blood tests. Pregnancy can change how your body absorbs seizure medicine. Blood tests can help you and your doctor make sure you're taking the right amount of medicine.
- Ask about vitamin K. Some seizure medications can stop your body from absorbing vitamin K, a vitamin that helps blood clot. If your unborn baby isn't getting enough vitamin K, there are shots that can be given after delivery.
- Talk to your doctor about breastfeeding. Breastfeeding is very healthy for you and your baby, and most women with epilepsy can breastfeed. You may need to take some extra steps so your baby doesn't get too much seizure medication in your breast milk, such as breastfeeding right before you take medication.

TALKING ABOUT YOUR EPILEPSY

It can be scary to tell people you have epilepsy. Go at your own pace — you don't need to tell everyone right away. Try these tips when you're ready to start a conversation:

Tell your family members and friends

- Remember that true friends will support you. They'll want to know about your epilepsy and how they can help.
- Your friends may have some wrong ideas about epilepsy. Remind them that epilepsy is just a medical condition — it doesn't change who you are.

- Make sure your family and close friends know what to do if you have a seizure. Teach them basic seizure first aid. Visit efmn.org/firstaid for details.
- If you have a seizure response plan, give a copy to people with whom you spend time.

Explain epilepsy to your children

- Make sure your children know that epilepsy is a medical condition, like asthma or diabetes. Encourage them to ask questions about your epilepsy.
- Reassure them by saying that a seizure isn't usually dangerous, even though it may look scary.
- Give age-appropriate information. Older children may want to know more details or find out how they can help you.

MANAGING YOUR EPILEPSY

Every person with epilepsy is different. Your health care team can help you find the best treatment for seizures, but it's up to you to find a lifestyle that works for you. Taking steps every day to manage your epilepsy will help you live as well as possible.

Learn what can trigger your seizures

A seizure trigger increases the likelihood of a seizure. Seizure triggers are different for everyone and can include:

- A specific time of day or night
- Not getting enough sleep
- Feeling stressed
- Missing meals
- Eating certain foods
- Being sick or having a fever



- Flashing lights
- Missing one or more doses of seizure medications
- Menstrual cycle (period)

Learning to identify seizure triggers can help you take steps to prevent seizures. If the trigger is something you can't change, like the time of day, being aware of it can still help you be prepared.

Keep a record of your observations

Keeping track of your seizure activities in a **seizure diary** can be one of the most important tools for managing your epilepsy. It can help you figure out what your triggers are, and it lets your doctor know how well your treatment is working.

Record as much as you can about your seizures, including:

- When your seizures happened
- What type of seizure you had
- What happened right before each seizure
- Any side effects you're having from treatment

Healthy Living

Healthy living is beneficial to everyone – but for people with epilepsy, it's even more important to make healthy choices. Simple changes can make a significant difference in helping control your seizures.

- Get enough sleep. Getting enough sleep lowers your risk of seizures. Try to stick to the same bedtime and wake up schedule every day.
- Eat a healthy, balanced diet. As much as possible, eat meals and snacks at regular times. For some people, missing a meal may make a seizure more likely to occur. If you are on a dietary therapy to help control your seizures, be sure to follow all of your doctor's instructions.
- Stay physically active. Staying active may reduce your risk of seizures. Most people with epilepsy can enjoy many types of physical activity, such as walking, jogging, biking, and playing sports like soccer or basketball.
- Pay attention to your mood. When you have epilepsy, you may be at risk of developing depression, especially since some seizure medications make depression more likely. You and your loved ones can watch for signs of depression, such as:
 - Feeling tired, sad, or hopeless
 - Having trouble sleeping or sleeping too much
 - Having trouble concentrating
 - Thinking about committing suicide

If you think you might be depressed, talk to your doctor right away. Don't stop taking your medicine unless your doctor says it's okay. You may also choose to see a counselor or join a support group. It's important to have someone you can talk to about how you're feeling.

SAFETY AND INJURY PREVENTION

There are many things you can do to help keep yourself safe and lower your risk of getting injured during or after a seizure.

Stay safe at home

To prevent injuries from falling during a seizure:

- Pick up or put away things you could trip over, like power cords or children's toys.
- Make sure that steps have handrails.
- Put gates around radiators and fireplaces.
- Install thick, soft carpets instead of hard flooring.
- Pad sharp corners of tables and other furniture.

To prevent burns and cuts in the kitchen:

- Use plastic or non-breakable dishes and cups.
- Use the microwave instead of the stove when you're home alone.
- If you cook food on the stove, use a back burner.
- Try using a food processor instead of knives to chop your food, or buy pre-sliced foods.
- Use a cup with a lid and spout for hot drinks.



To prevent drowning and stay safe in the bathroom:

- Take showers instead of baths. Consider using a shower seat with a safety strap.
- Place an “occupied” sign on the door instead of locking it, so someone can reach you in case you need help.
- Hang the bathroom door so that it opens out, not in, to ensure someone can get in easily if you need help.

To stay safe while sleeping:

- Sleep in a bed that’s low to the floor. You may want to install a guardrail or put cushions around your bed.
- Try not to sleep on your stomach, and limit the number of pillows you use. This can make it easier to breathe if you have a seizure at night.
- Share a bedroom, or place a monitor in your room so someone else can hear if you have a seizure during the night.

Be active – safely!

Getting plenty of physical activity is good for your mind, body, and spirit.

People with epilepsy can usually enjoy many types of exercise. Talk to your doctor to make sure the activities you want to do are safe for you. Follow these tips to stay safe while exercising:

- Take breaks and avoid exercising during the hottest part of the day. For some people, getting very tired or overheated can make a seizure more likely. Some seizure medications can also make it harder for your body to cool off by sweating.
- When riding a bike, always wear a helmet.
- Always wear a life jacket for boating and other water activities.
- Having a seizure in the water is very dangerous, so never swim alone. Make sure there’s a lifeguard – or a friend who’s a good swimmer – who can help if you have a seizure. Keep in mind that swimming in open water, such as a lake or the ocean, is more risky than swimming in a pool.

Make a seizure action plan

A **seizure action plan** is a document that lets people know what to do when you have a seizure. Ask your doctor about whether it would be a good idea for you to make one. A seizure action plan usually includes:

- Notes about the types of seizures you have, how often seizures happen, and how long they usually last.
- First aid instructions, like how to protect you from choking or getting injured.
- A list of seizure medications you take, including rescue medicine (medication you only take in certain situations, like when you’re having more seizures than usual).



- Information about what to do if a seizure doesn't stop (status epilepticus).
- Instructions about when to call 911.
- Notes about the location of the nearest hospital.
- Emergency contact information for your family and doctor.

Have your doctor review and approve any seizure action plan you create. Remember to update the plan if any information changes such as changes to your medication. Give copies of your seizure action plan to people you spend time with, such as friends, relatives, and coworkers. You may also want to carry a wallet-sized card with your seizure information that's easy for people to access, or wear a medical bracelet.

Ask your doctor about your risk for SUDEP

SUDEP (sudden unexpected death in epilepsy) is when a person with epilepsy dies unexpectedly and without a clear cause of death. SUDEP is uncommon, and can be scary to think about. The causes of SUDEP are unknown.

The best way to lower your risk of SUDEP is to have as few seizures as possible. You can do this by:

- Making sure you always take your seizure medication as prescribed and follow your treatment plan.
- Identifying and avoiding seizure triggers as much as possible.
- Telling your doctor if you think you need more or different treatment to control your seizures.
- Working with your doctor to create a seizure response plan.
- Asking your doctor about how to improve your safety at night.

DRIVING AND WORKING

Can I still drive?

It depends. Driving laws vary by state. In some states, people with epilepsy can drive after they have been seizure-free for six months to a year. You may need to ask your doctor to sign a form saying it's safe for you to drive.

If you can't drive because of your seizures, there are many other ways to get around. For example, you can take public transportation to work or get a ride from a coworker. Even though it can be challenging to live without driving, it's very important to drive only if your doctor says it's safe. If you have a seizure while driving, you could hurt yourself or someone else.

Can I still work?

Yes. People with epilepsy have many different types of jobs. There are only a few jobs — like operating dangerous machinery or driving a school bus — that people with epilepsy usually can't do. You may also need your employer to make accommodations (changes) to help you do your job.

Know your rights

Because of the Americans with Disabilities Act (ADA) and other laws, your employer can't discriminate against you because of your epilepsy. Your employer must provide "reasonable accommodations" to help you do your job. You don't have to tell your employer that you have epilepsy. But you may want to, especially if there's a chance you could have a seizure at work.

Speak up if you need accommodations

Make sure you can be safe and do your best at work by asking for the accommodations you need. For example:

- If flashing lights trigger your seizures, you could ask your employer for a flicker-free computer monitor.
- If you need to take public transportation, you could ask your employer to change your schedule so it's easier for you to get to work on time.

If you have questions about your rights and how to talk with an employer about reasonable accommodations, EFMN can help.

Choose a job that works with your epilepsy

If you're looking for a new job, try to choose one that's compatible with your epilepsy. For instance, if you have more seizures in the morning, you may want to find a job where you can work just in the afternoon or evening.

Find help if you can't work

If you have so many seizures you can't work, or if you're disabled because of another medical condition, you may qualify for financial assistance. Contact your local Social Security office, your county Human Services office or EFMN for details.

GETTING SUPPORT

Build a strong personal support team

Your medical team helps treat your seizures, but friends and family members can help you too. Building a personal support team can help you face challenges in everyday life and get you through hard times. Remember, sometimes friends and family want to help but don't know how. They need you to ask them for the support you need. Here are some examples of how you can ask:

- "Could we carpool to the grocery store this week?"
- "My memory hasn't been great lately. Could you remind me to take my medicine in the morning?"
- "I've had a hard day. Do you have some time to talk?"

Get connected to the epilepsy community

Living with epilepsy can be hard — but you're not alone. EFMN can help connect you with other people who have epilepsy and seizures. Many people find it helpful to talk to others who are going through similar things.



Additional Resources

For information on seizure first aid, seizure types, treatment options, driving, SUDEP, safety tips, additional resources, and more, please visit the following:

- efmn.org
- epilepsy.com

24/7 Support

Call 800.779.0777 or info@efmn.org during business hours or 800.332.1000 (en Espanol: 866.748.8008) after hours with any questions or concerns.