

# Treatment Options

for People Living with  
Epilepsy and Seizures



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### **About the Cover:**

Cover artwork was created by Melinda H., a Studio E participant with the Epilepsy Foundation Heart of Wisconsin. 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 it's 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 their treatment or activities based on this information without first consulting their health care provider.



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**If** you've just learned that you have epilepsy, the next step is for you and your health care provider to talk about a treatment plan. The goal of any epilepsy treatment is to make sure you can live a normal, active life — without seizures or side effects caused by treatment.

## **What's the most common treatment for epilepsy?**

Medicine is the most common treatment for epilepsy. Seizure medicines will successfully control seizures for about 7 out of 10 people with epilepsy.

There are many different medicines that can be used to prevent seizures. These are sometimes called “anti-epilepsy drugs” (AEDs) or “anti-seizure medications.”



## How will my doctor choose a medicine to treat my epilepsy?

Because there are so many different kinds of seizure medicines, it can take some time for you and your doctor to find the medicine and dose (amount) that works best for you. You may even need to take more than one medicine.

To find the right medicine (or medicines) for you, your doctor will:

- Make sure that the medicine treats the type of seizures you have. Different medicines work better to prevent different types of seizures.
- Watch to see how your body reacts to the medicine. A medicine that causes no side effects in one person may cause serious side effects in another. Your doctor will try to find the medicine that causes the fewest side effects for you while still preventing seizures.
- Find the dose that works for you. People's bodies break down medicines differently, so some people need more or less medicine than others.

You may need to try more than one medicine. And that's totally normal. Stick with it!

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Once I was diagnosed with epilepsy, I started taking medicine. It took a while for my doctor and me to find the right drug, but once we had, I did really well.

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**Communication is key.** Talk with your doctor often if you're trying out a new medicine. You should never feel like you have to live with uncomfortable side effects just because you aren't having seizures. Remember, the end goal is no seizures **and** no side effects.

## What do I need to know about my seizure medicine?

It's important to learn about the seizure medicine you're taking so that you take it safely. Make a list of questions to ask your doctor.

### For everyone:

- What should I do if I forget a dose?
- What are some common side effects?
- Are there serious side effects that I should call you about right away?
- How long will it take for us to know if it's working?
- Are there any over-the-counter medicines (like aspirin or ibuprofen) that I can't take while I'm on this medicine? What about dietary supplements (like vitamins or iron supplements) or natural remedies (like herbal supplements or special teas)?
- Can I drink alcohol while taking this medicine?

## For women:

- Will my menstrual cycle (period) affect the medicine?
- Will the medicine make my birth control pills less effective?
- Do I need to make any changes if I'm planning to get pregnant?

Don't be afraid to ask anything else that comes to mind.



## What are “as needed” medicines?

Most seizure medicines are taken every day to prevent seizures from happening. “As needed” medicines (also called “rescue medicines”) are used to help stop a seizure or series of seizures that won't stop on its own (called a “prolonged seizure” or “cluster seizure”). These medicines are not a replacement for daily seizure medicine.

It can help to **write your questions down ahead of time**, before you visit the doctor. Use these other tips to make sure you get the information you need:

- Take notes during your appointment.
- Make sure you leave with clear instructions on how to take your medicine.
- Take a family member or close friend with you to the appointment. This way you'll have someone to help you take notes — and to make sure you get answers to all the questions on your list.
- Speak up if something doesn't make sense to you. Keep asking until you get an answer you understand.
- Keep in mind that your doctor's nurse or physician assistant may be able to answer many of your questions.
- Find out what you should do if you have questions once you get home.

## What can I do to stay healthy and safe?

There's a lot you can do to protect yourself if you're taking medicine to treat seizures.

### **Take your medicine as directed.**

- Don't stop taking your medicine (or change your dose) suddenly. If you stop taking your medicine or miss a dose, it may increase your risk of having a very long seizure or a series of seizures that won't stop. This is called "status epilepticus." It's a medical emergency and requires calling 911.
- Ask your doctor if taking generic medicine is all right for you, or if you need the brand name version.

### **Work with your doctor.**

- Follow instructions from your doctor.
- Keep your follow-up appointments.
- Tell your doctor right away about any physical side effects you experience. For example, some medicines may make you feel sleepy or upset your stomach.

- Tell your doctor right away about any changes in your emotions. For example, some medicines may make you feel depressed or anxious.
- Make sure your doctor knows about any other medicines, dietary supplements, or herbal remedies you are taking.
- Ask your doctor about your risk for Sudden Unexpected Death in Epilepsy (SUDEP) and what you can do to lower it. SUDEP is when a person with epilepsy dies without warning and without a clear cause of death.

**Having trouble remembering to take your medicine?** Give one of these strategies a try:

- Fill up a pillbox with a week's worth of medicine in advance.
- Keep your medicine — or a reminder note — near something you use every day, like your keys.
- Set an alarm on your cell phone to go off at the same time every day to remind you to take your medicine.

## Play an active role in your treatment.

Getting good medical care for epilepsy is a team effort. You are the most important member of the team.

- Tell your family members and friends that you have epilepsy. Make sure they know seizure first aid.
- Write down the name and amount of the medicine you take and keep this information with you at all times.
- Tell other doctors and health care providers that you have epilepsy and what medicine you take for it.
- Keep a seizure diary to track your seizures and any other symptoms you experience. Share this diary with your doctor.



## Take care of yourself.

- Get enough sleep.
- Eat a healthy diet and stay active.
- Take steps to manage your stress, like trying different relaxation techniques.
- Talk to your doctor if you feel depressed or anxious. This could be a side effect of your medicine.

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At first I was afraid to tell people I have epilepsy. But now I realize that talking to my friends about what to do if I have a seizure is an important part of protecting myself. My friends always say they're happy I told them — they want to feel prepared.

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## What if medicines don't work for me?

Seizure medicine is the most common treatment for epilepsy, but it's not the only treatment option available.

Your doctor may suggest a different treatment if medicines aren't working — or if you're very sensitive to side effects caused by medicines.

Here are some other treatments for epilepsy.

### Vagus nerve stimulation (VNS)

For VNS therapy, a surgeon does an operation to put a battery in the upper left chest. The battery sends regular bursts of electric energy to the brain through a large nerve in the neck (the vagus nerve).

If you're using VNS and you feel a seizure coming on, you can pass a small magnet over the battery to activate it. For some people, this will make the seizure shorter — or stop it from happening.

VNS can also help people who don't experience a warning before a seizure or who aren't able to use the magnet. Up to 5 in 10 patients who use a VNS device have fewer or less severe seizures than before.

**If medicines aren't working**, your doctor may also refer you to an epilepsy center. Epilepsy centers have teams of experts that specialize in treating seizures. Ask your doctor for more information about whether visiting an epilepsy center makes sense for you.

### **Responsive neurostimulation (RNS)**

For RNS, a surgeon does an operation to put a battery-powered neurostimulator device in the skull. This device is attached to 1 or 2 wires implanted in the brain at the place where seizure activity starts.

The RNS device is a responsive, direct brain-stimulation treatment. This means that it can sense when a seizure is about to happen and send tiny electric signals to the brain to help stop or lessen the seizure.

### **Dietary therapy**

Dietary therapies are used mostly for children, but some may also be very helpful for adults. The most common dietary therapy is the ketogenic diet, a high-fat, low-carbohydrate, low-protein diet that causes chemical changes in the body. These chemical changes may help

control seizures in as many as 2 out of every 3 children who can maintain it. The ketogenic diet must be supervised by a doctor or nurse.

Other less restrictive diets, like the modified Atkins diet and the low glycemic index treatment, have also been tested and help control seizures in some people. These diets are being used successfully by some adults and children and are easier to manage than the ketogenic diet.

Like all treatments for seizures, dietary therapies have risks and can cause serious side effects. Anyone using these diets needs to work with an experienced treatment team. Talk with your doctor to see if one of these diets is right for you.

## Surgery

There are 2 main types of surgery used to treat epilepsy. In one type, the surgeon removes the part of the brain that causes the seizures. In the other type, the surgeon interrupts the pathways the seizure travels as it moves across the brain.

Epilepsy surgery is complicated, and doctors will do a series of special tests before recommending it for you.

**Clinical trials are research studies** run by doctors and other health professionals to see if new treatments work. Volunteering to be part of a clinical trial may offer good treatment options for some people who have epilepsy, although results are never guaranteed. Talk to your doctor if you're interested in learning more about clinical trials.

## Where can I find out more?

Visit [www.epilepsy.com/treatment](http://www.epilepsy.com/treatment) to:

- Look up specific medicines.
- Find more in-depth information on the treatment options listed in this pamphlet.
- Find the local Epilepsy Foundation affiliate near you.
- Get tips on living well with epilepsy.



# Notes

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This publication was made possible with funding from the Centers for Disease Control and Prevention (CDC) under cooperative agreement number 1U58DP003832-03. Its contents are solely the responsibility of the authors and do not necessarily represent the official views of the CDC.

## 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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