New to Seizures & Epilepsy

EPILEPSY FOUNDATION

epilepsy.com

About the Epilepsy Foundation

The Epilepsy Foundation, a national non-profit with nearly 50 local organizations throughout the U.S., 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 lead the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures, and save lives.** 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 **epilepsy.com**.

"Like" the Epilepsy Foundation on Facebook at **facebook.com/epilepsyfoundationofamerica** and follow us on Twitter at **twitter.com/epilepsyfdn**.

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 with their health care provider.

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epilepsy.com

1-800-332-1000

Seizure & Epilepsy Overview

What is epilepsy?

Epilepsy is a neurological disease that causes people to have recurrent seizures. A seizure is a brief disruption of electrical activity in the brain.

- Epilepsy is not contagious.
- Epilepsy is not a mental illness.
- Epilepsy is not a developmental disability.

What causes epilepsy?

More than half the time, the cause is unknown. When a cause can be found, it is most often one of these:

- Head injury
- Infection of the brain
- Stroke
- Brain tumor
- Alzheimer's disease
- Malformation of an area of the brain
- Genetic factors

Who has epilepsy?

In the United States, 3.4 million people live with epilepsy, and over 150,000 new cases are diagnosed each year. One in 26 people will develop epilepsy at some point in their life. Epilepsy doesn't discriminate. If affects children and adults, men and women, and people of all races, religions, ethnic backgrounds, and social classes. While epilepsy is most often diagnosed either in childhood or after the age of 65, it can occur at any age.

How is epilepsy diagnosed?

Medical history, neurological examination, blood work, and other tests are important in diagnosing epilepsy. Eyewitness accounts of a person's seizures are very important in helping determine the type of seizure(s) a person has. An electroencephalograph (EEG) is a commonly used test to help diagnose seizures. An EEG records the brain's electrical activity during the test. Some patterns of activity are unique to particular types of seizures. In some situations, CT scans, MRIs, and PET scans may be used to look at the internal structure and function of the brain. These tests may help pinpoint causes of seizures and epilepsy.

How is epilepsy treated?

Medication – Drugs used to treat epilepsy are called anti-seizure medication. More than 30 anti-seizure medications are currently approved to treat epilepsy. About 7 in 10 people achieve good seizure control on one or more of these medications. Other treatments are available if medicines don't work.

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Surgery – Certain types of surgery may be used for people whose seizures do not respond to medication. Surgery may be recommended when a seizure focus can be determined and removal of all or part of the affected area can be performed without hurting vital functions like speech or movement.

Vagus Nerve Stimulation (VNS) – A small device is implanted under the skin in the left side of the chest. A lead (small thin wire or electrode) goes from the device under the skin and attaches to the vagus nerve in the left side of the neck. The benefits of the VNS appear to improve over time. For example, after one or two years, up to 4 or 5 out of 10 people who have the VNS may see their seizures decrease by 50% or more.

Responsive Neurostimulation (RNS) – A small device for the RNS is placed under the scalp in a small area of the skull or bone surrounding the brain. One or two wires from the device are placed under or on the surface of the brain where seizures start. The device is able to sense a seizure and sends small pulses of electrical current through the wires to help stop or lessen seizure activity. Like the VNS, the RNS does not cure epilepsy and it may not work right away. Yet it can help stop or lessen the number of seizures a person has by 40% to 60% after one to three years.

Dietary Therapies – Dietary therapies are used primarily in children, but some can also be very helpful in adults with seizures that do not respond to medications. The most common dietary therapy is the ketogenic diet. This is a medically supervised high fat and low carbohydrate diet. It can help control seizures in about 2 out of 3 children who stay on the diet. Other less strict diets may also help to lessen seizures in some people.

Seizures can take many different forms, not just the convulsive type that most people associate with epilepsy.

Types of seizures

Common types of seizures include:

Generalized Onset - Tonic-Clonic (Grand Mal) – Convulsions, rigid muscles, jerking; typically lasts 1 to 3 minutes and followed by period of confusion.

Generalized Onset - Absence (Petit Mal) – Blank stare lasting only a few seconds; sometimes with blinking or chewing motions.

Focal Onset - Impaired Awareness (Complex Partial) – Staring and dazed facial expression; person is not aware of what is going on or will not remember; person may perform repetitive random movements and may not be able to talk normally; typically lasts 1 or 2 minutes and may be followed by confusion.

Focal Onset - Aware (Simple Partial) – Jerking in one or more parts of the body or sensory or perceptual changes that may or may not be obvious to onlookers; the person is aware of what occurs during the seizure.

Atonic (Drop Attacks) – Sudden collapse with recovery within a minute.

Myoclonic – Sudden, brief, massive jerks involving all or part of the body.

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Epilepsy & Seizures 24/7 Helpline

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What do we do?

Trained information specialists are available on the helpline to answer your questions about epilepsy and seizures and provide you with support, guidance, and referrals to national and local resources.

How can we help you?

The 24/7 Helpline provides compassionate telephone support, answers emails and replies to forum posts on the Foundation's online community site - epilepsy.com.

Some of the topics our information specialists respond to most often include:

- Treatment options
- Available medicines
- Support groups
- Seizure first aid and safety issues
- Employment, discrimination, and legal issues
- Emotional support
- Getting connected with local Epilepsy Foundations
- Sudden Unexpected Death in Epilepsy (SUDEP)
- Providing free information packets

Interpreters available for over 200+ languages

Providing HELP, HOPE, and SUPPORT to people with epilepsy and seizures and their families nationwide.

1-800-332-1000

epilepsy.com/helpline

Para obtener información adicional y materiales impresos con información detallada y actualizada comunícate con nuestra línea gratuita 1-866-748-8008 o visita nuestro sitio web: www.laepilepsia.org.

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Epilepsy.com

Epilepsy.com offers ways to learn critical information, skills and resources that will help you manage seizures and epilepsy more easily.

Information

Information is available to help you learn as much as you can about seizures and epilepsy, managing your epilepsy, new therapies, seizure first aid, and more!

Community

Our online community helps you to connect with others who are living with seizures and epilepsy. Read or post messages on a wide variety of topics. You can also join a chat and talk to others in real-time, read powerful stories, or listen to our Hallway Conversations.

Empowerment

Explore the many tools available to help you be in charge of your seizures & epilepsy, work with your health care team, and take action to manage your seizures.

Resources

Search for a local Epilepsy Foundation that works in your area or search the Helpline Resource database to learn about resources available in your area.

Visit epilepsy.com today.

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You and 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. You want answers, and your doctor needs information from you, too! What you tell your doctors and other health care providers is critical – it helps them sort out if you have seizures and what type of epilepsy you have. It also helps them choose which medicine may be best for you.

Do your part by telling the doctor or other health care provider:

- Your history – when and what happened and when you first noticed seizure symptoms
- About your seizures or events
- What medicines you take and any allergies
- About any side effects or other health problems
- How epilepsy affects you and your family
- Your priorities and questions - what's bothering you most

Take an active role in your health care

The traditional approach to medical care is that the doctor asks questions, the patient answers them, and the doctor recommends the treatment. But there's another approach, called patient-centered health care, where the patient and family play a more active role on the health care team.

Making sure you get patient-centered care is especially important when you are coping with a chronic health problem like epilepsy. That's what managing your epilepsy is all about.

Share important information

Epilepsy is often "invisible" to doctors, since seizures don't usually happen during an office visit. That means your doctor is relying on you to say what your seizures are like, how often they happen, and how they affect your life.

Keep a seizure diary to track any seizures or other symptoms you have. Take it to your appointment. When you track your seizures and how you are feeling, you're bringing in critical data that your team will need.

Make a list of all the medicines you take – including any vitamins or herbal remedies – and the amount you take.

Be ready to talk about anything that has changed since your last visit, like a new job. Sometimes you might need to talk to the doctor about a topic that makes you uncomfortable.

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Remember, your doctor can only help if you share all of the relevant information, including if you:

- Don’t always take your medicine
- Are having side effects or aren’t feeling well
- Don’t like your treatment plan
- Want a second opinion from a different doctor

Learn what to do

For your treatment to work, you’ll need to learn new skills — like how to take your medicines, make lifestyle changes, teach others seizure first aid, and prevent injuries. If seizures are not responding to medicines, your health care team may want you to try a special diet or consider testing for surgery or a device.

All this can be overwhelming at times. If you are new to seizures and epilepsy, start with the basics.

- Think about what you need now to get diagnosed properly, stay safe, and follow your treatment plan. Remember, treatment will only work if you can follow the plans.
- Next think about how epilepsy is affecting you and your family. Ask for help. You may need to learn new skills here too – how to talk about epilepsy or cope with the impact it may have on relationships, work, family, and social life.

Ask questions

People work together best when they know what to expect from each other. Talk to your doctors and health care providers about your role, their role, and what to expect from each other.

Also talk to your doctors about new ideas or treatments, other people who should be part of your team, and any other concerns you may have.

Discussions take time. You may need to set up special appointments to talk to different people about your questions, concerns, and next steps in your care.

Talk to your doctors about new ideas or treatments, other people who should be part of your team, and any other concerns you may have.

Stay in touch

Be sure to keep all follow-up appointments. Write them in your calendar, put a note on your fridge, or set a reminder on your phone – whatever will help you remember.

If you don't have time to talk about everything that's on your mind, make another appointment. It's also a good idea to ask what to do if you have questions after you get home. Find out who you can call and when.

You may want to contact your doctor in situations like these:

- If you start having more seizures, or you have seizures that are different from your usual pattern
- If you have unexpected side effects, or bad side effects
- If you have an unexpected problem that develops after surgery
- When you're sick with another illness
- When you're taking a new medicine
- Before surgery or procedures for a different health problem

Getting urgent help

There may be times when you should not wait for a routine call back. Ask your doctor who to call in an emergency, and how to reach them.

- If the problem is urgent and you can't reach your own doctor, you may need to talk to a different doctor or go to an emergency room or urgent care clinic.
- If you have seizures that last too long or happen too close together, someone should call 911 for emergency medical help.

Once your health care team gets to know you, ask for help developing a seizure response plan. This will help you and others have the right information at home – what to do for seizures, when seizures could be an emergency and if anything can be done at home to prevent an emergency. Sometimes a rescue therapy (medicine or device) may be recommended for people who may have long or cluster seizures)

Visit epilepsy.com/managing to learn more about seizure emergency and seizure response plans.

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Improve Your Seizure Control

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Take medication as prescribed

Taking medicines daily can be hard to remember. Sometimes medicine schedules are complex and hard to follow, especially if medicines are taken many times a day. If you're new to seizures, talk to your health care provider about your medicines and what's expected. You'll want to know details of what you take, how often, when, and why. You'll also need to learn some new skills, such as how to take medicines safely and consistently. For example:

- Checking your medicine and pill sizes to know if you have the right one and correct dose.
- Following special instruction for different forms of seizure medicines.
- Setting times to take medicines as prescribed by your doctor or nurse.
- Recognizing side effects and when to call your provider.
- Getting blood tests done if needed.
- Tracking if medicines are working.

Seizure triggers

Some people find that certain situations, habits, health problems, or medications can affect their seizures. For example, not sleeping well or too much stress can make some people more likely to have a seizure. Missing doses of seizure medicine can trigger or make many people have more seizures too.

When you are first diagnosed with epilepsy, it's important to note when you have a seizure and if any triggers can be identified. Some examples of seizure triggers include:

- Missing seizure medicine or stopping them suddenly
- Not getting enough sleep or not good quality sleep
- Stress
- Being sick with another illness or fever
- Flashing lights in people who are photosensitive
- Menstrual cycles or other hormonal changes
- Alcohol or drug use (Too much alcohol can make a person more likely to have seizures, especially the day after drinking.)
- Certain prescription or over-the-counter medicines
- Some herbal products or supplements
- Low levels of certain minerals or substances in the body (for example, low levels of sodium or salt, magnesium, or calcium)

What to do next? What do I do about triggers?

If you find things you think could affect seizures, keep track of them over time and see how often they happen. If they frequently happen before seizures, then it's time to see if you can change or avoid the trigger. Can you change your lifestyle? Avoid the trigger?

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Share your observations with your health care team and talk about what you can do to prevent or lessen your seizure risk this way.

Having healthy daily routines also can help improve seizure control. Here's a few things that can help:

- Keep a regular sleep pattern – go to bed and get up at the same time each day.
- Drink plenty of fluids and stay hydrated.
- Eat regularly and have a healthy diet.
- Exercise in a safe manner; avoid getting overheated, overtired, or dehydrated.
- Look at how you cope with stress – talk with others; give and get support!
- Keep a seizure diary – such as My Seizure Diary or a paper diary – to help you check your progress.

If you find things you think could affect seizures, keep track of them over time and see how often they happen. If they frequently happen before seizures, then it's time to see if you can change or avoid the trigger.

Managing stress

Many people with epilepsy think that emotional stress may affect their seizures. Or maybe stress can affect how you sleep, eat, or feel in general. Some may notice times they feel scared, worried, sad, or depressed separate from their seizures. A few tips to think about:

- Talk about how you feel with your health care providers. Let them know if your mood changes.
- Try deep breathing, meditation, exercise, or other ways to help you relax and manage stress.
- Talk with your health provider if you are having trouble sleeping. Sleep problems can trigger seizures or be a symptom of something else.
- If mood changes continue or last longer than a few weeks, tell your doctor and ask for help.

Menstrual cycles

About half the women of childbearing age who have epilepsy report more seizures around the time of their menses or in the middle of their cycle. Keeping track of when seizures occur can help women find out if there are any connections. Talk with your health care team about monitoring your hormones and other health conditions. For some women, this could lead to other ways to improve seizure control.

Strive to stop seizures

Getting the best seizure control possible is one step towards improving your health and lessening the risk for SUDEP. Don't give up or settle for life with continued seizures. Be proactive and see an epilepsy specialist if you are still having seizures or side effects of medicines.

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In the Event of a Seizure

Focal, Complex partial, temporal lobe

1. Recognize common symptoms

2. Follow first-aid steps

People who've had this type of seizure should be fully conscious and aware before being left on their own. Make sure they know the date, where they are, and where they're going next. Confusion may last longer than the seizure itself and may be hazardous. If full awareness does not return, call for medical assistance.

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In the Event of a Seizure

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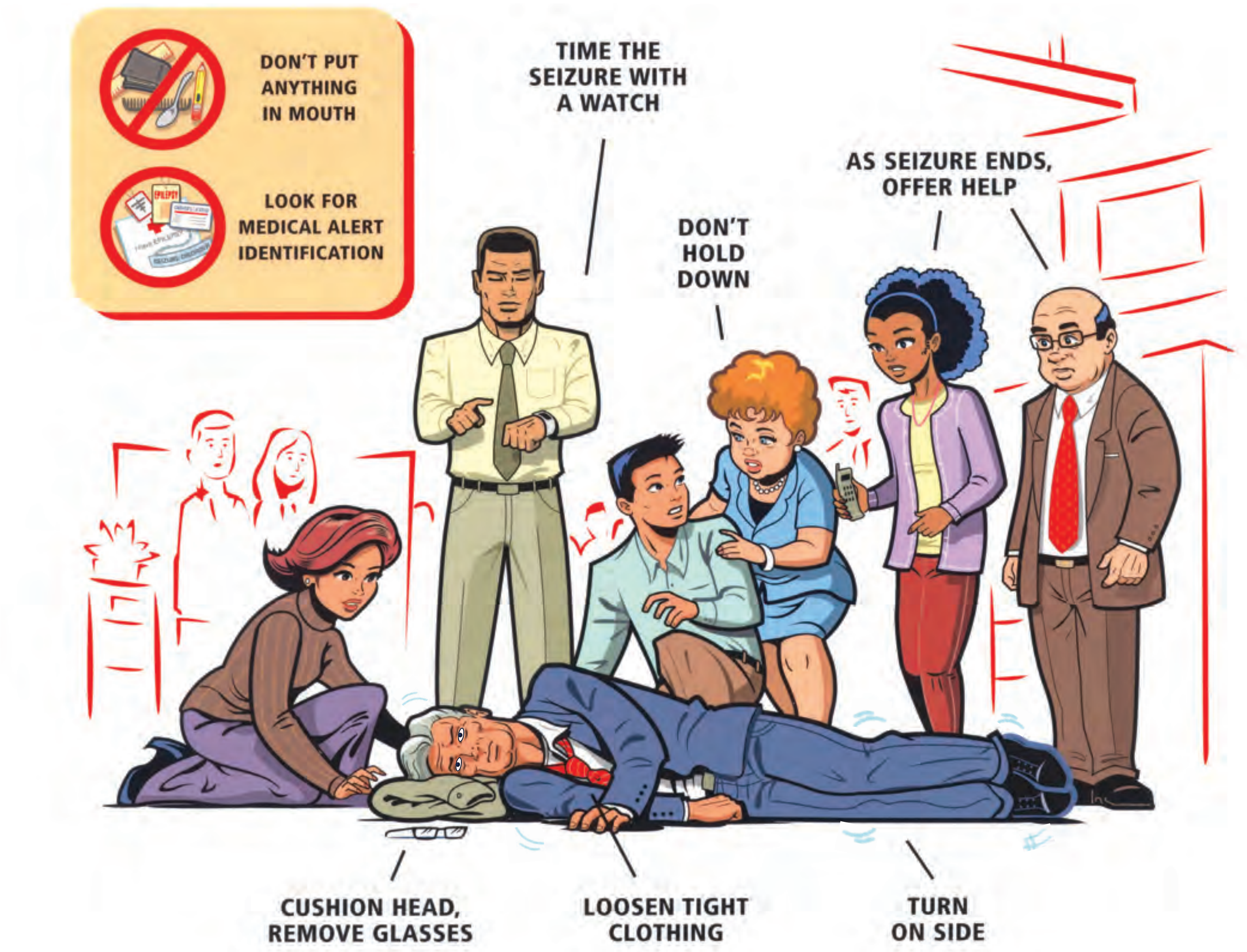
Tonic-clonic, Convulsive, grand mal



Most seizures in people with epilepsy are not medical emergencies. They end after a minute or two without harm and usually do not require a trip to the emergency room.

But sometimes there are good reasons to call for emergency help. A seizure in someone who does not have epilepsy could be a sign of a serious illness.

Other reasons to call an ambulance include:

- A seizure that lasts more than 5 minutes
- No "epilepsy" or "seizure disorder" identification
- Slow recovery, a second seizure, or difficulty breathing afterwards
- Pregnancy or other medical diagnosis
- Any signs of injury or sickness

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DARE TO SAY SUDEP

Know SUDEP Facts

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SUDEP is **S**udden **U**nexpected **D**eath in **Ep**ilepsy

- SUDEP is the sudden unexpected death of a person with epilepsy.
- SUDEP is less common in children, but it is a leading cause of death in young adults with uncontrolled seizures.
- One way to lessen your risk of SUDEP is to have as few seizures as possible.

Know your risk for SUDEP

People with frequent seizures, especially generalized tonic-clonic (grand mal) seizures, are at greatest risk for SUDEP.

Other risk factors may include:

- Epilepsy beginning in childhood
- Young adult age (20-40 years old)
- Having epilepsy for a long time
- Not taking medications regularly
- Having seizures at night

#DareTo take control

- **Take your medicine on time, every day — exactly as prescribed.** People whose seizures aren't controlled have an almost 40 times higher risk of death than those whose epilepsy is under control.
- **Keep a health diary of seizures, test results, and questions for your doctor.**
- **Know your seizure triggers.** For many people, not getting enough sleep, drinking too much alcohol, or feeling stressed can trigger more seizures.
- **Create and share your own Seizure Response Plan.** Get your doctor's input and share it with your family, friends, co-workers, or teachers. Discuss how you can improve your safety at night with your doctor, family and friends.

Talk to your health care providers about SUDEP

Get answers to these questions:

- What is my risk of SUDEP?
- What should I do if I have another seizure?
- How can I prevent more seizures?
- Are there other ways to control seizures and lower my risk of SUDEP?

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- What should I do to reduce my risk of SUDEP if I have seizures at night?
- Should I consider using a device to warn someone that I am having a seizure?
- Should I consider sharing a bedroom?
- What else should I know about?

Some other health conditions may increase your risk of dying or getting injured during or after a seizure. See your primary care physician for regular check-ups to help you stay healthy.

Tell your family & friends about epilepsy and SUDEP

- Your friends and family care about you, so let them know about your risks.
- Make sure they know *Facts to Keep You Safe* and when to call 911. Learn more at epilepsy.com/safetyfacts

#AimForZero

Getting the best seizure control possible is one step towards lessening the risk for SUDEP. Aiming for zero seizures means keep trying. Some people can get complete seizure control with available treatments. Others, especially people with a complex form of epilepsy or one that doesn't respond to medicine, may never reach zero seizures. If you are in the latter situation, you still should not give up. It's just as important for you and your family to do what you can to lessen your risks – lessen the risk of breakthrough seizures, severe or long seizures, triggers, and potential complications. There are many approaches that may vary from one person to the next. Everyone can take these four actions to lessen their risks:

- **Take medication as prescribed** – consistent, regular amounts of medicine are key for seizure medicines to work properly.
- **Get enough sleep** – not enough sleep or poor quality of sleep is a common trigger for seizures.
- **Limit alcohol** – too much alcohol can make a person more likely to have seizures, especially the day after drinking. Some seizure medicines may lower your tolerance for alcohol and you get drunk faster.
- **Strive to stop seizures** – don't give up or settle for life with continued seizures. Be proactive and see an epilepsy specialist if you are still having seizures or side effects of medicines.

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A Seizure Safe Environment

Depending on the type of seizure, people may fall or hurt themselves in a variety of ways. Cuts, burns, bumps, and bruises can happen. More serious injuries can happen too, especially if someone falls and is not aware of what's going on around them.

Here are some general tips that can help lessen your risk of injury. First talk to your health care provider about your type of seizures and risks. Then look at where you are when a seizure may happen and what risks are present in your home, work, school, or play area. Look at your lifestyle too. For example, what types of activities do you like to do? Then look at the following tips and see what makes sense to keep you safe and prevent injuries or accidents.

Home safety

Prevent drowning and injuries from slips and falls in the bathroom:

- Take showers instead of baths.
- Leave the bathroom door unlocked. Make sure someone is close by in case you have a seizure while showering.
- Hang the bathroom door so it opens out, not in. This way someone can get in easily if you need help.
- Use safety glass for mirrors and shower doors.

Take care when cooking:

- Get pre-sliced foods so you don't need to use knives when alone.
- Use the microwave instead of a stovetop when you're home alone.
- If you use a stovetop, use back burners to prevent spilling hot foods.
- Wear long thick oven mitts to take food out of the oven.
- Try not to carry hot dishes. Try sliding them along a counter or use a cart.
- Use cups with lids for hot drinks.
- Use non-breakable dishes, cups, and cookware.

Stay safe from burns and fires:

- Make sure someone is nearby when you use the stove, grills, or fireplace.
- Iron clothes or light candles only when someone is with you.
- Look for appliances that have automatic shut-off switches.
- Put guards in front of radiators, heaters, and fireplaces. Only use space heaters that can't tip over.
- Check your smoke alarms once a month by pushing the test button.

Keep yourself safe while sleeping:

- Sleep in a bed that is low to the floor if you have seizures at night.
- Consider using a seizure alert device so someone can hear if you have a seizure.
- If you have shaking movements during a seizure, move your bed away from furniture or the wall so you don't injure yourself during a seizure.
- Sleep on your back or side; avoid sleeping face down.

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Prevent injuries from falls:

- Pick up or put away things you could trip over, like cords, toys, or shoes.
- Store things you use often where you can reach them easily.
- Put padding on furniture with sharp edges or buy furniture with rounded or soft edges.
- Install soft flooring, like carpets with thick padding.
- Use soft “outdoor carpeting” on hard surfaces like stairs or a deck.

Work safely outside:

- Use a lawn mower that stops when you let go of the handle.
- Make sure that power tools have safety guards and will stop running if you let go.
- Always wear protective eyewear, footwear, and gloves.

Safety and parenting

You have seizures and you have a child. How is this going to work?
You can’t help but wonder, “What happens if I have a seizure while taking care of the baby?”

This is a normal question and one you should talk about with your loved ones and health care team. Then develop a plan to make your home safe for your family and try these simple parenting tips to make life easier.

Remember, what you need to do may vary with the type and number of seizures you have, so talk about these ideas with your doctor or nurse. If you have frequent seizures, especially with loss of awareness, consider having someone help while you care for your baby.

- When childproofing your house like all parents do, take an extra step. Get down on the floor and think what would happen if you fall. What could hurt you or your baby?
- Sit in the middle of the bed, on the couch, or on the floor when holding or feeding your baby.
- Change, dress, and sponge bathe the baby using a portable changing pad on the floor.
- Strap the baby snugly into a stroller with breaks or an infant seat when you feed him.
- When home alone, use a playpen or play yard with doors and gate. If you don’t feel well, put the baby down in this enclosed area.
- Keep baby supplies on each level of the home to avoid climbing stairs.
- Don’t carry hot fluids or dangerous items near the baby.
- If your seizures are sensitive to sleep deprivation, use help to feed the baby at night.
- Always keep your epilepsy medicine (and other medicines) where children can not reach them.
- When walking outside with a child who can wander, consider using a safety harness to keep your child close in case you have a seizure.
- If you feel a warning or seizure, lie down on your side on a soft surface.
- Carry a cell phone with you, even in the house, to call for help if needed.

Telling children about seizures

One day, as your child grows, she may ask about your seizures. Use simple language to explain things. Say that you will be okay but that you may need some help sometimes. Show him how to get another adult to help or to call 911 if you do not wake up after a seizure. If you are calm, your child will be too. As your child gets older, he will have more questions for you. Use age appropriate information to teach your family about seizures and how they can help.

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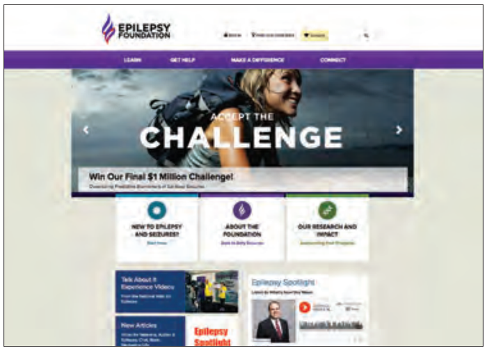
Tools for Managing Seizures

For most people, seizures and epilepsy are chronic problems. Medicines can control seizures for many people, but it takes work. You need to do things like remembering to take your medicine, tracking your seizures, and finding out what triggers your seizures. And if medicine doesn't work, it may take even more work to find other ways to manage your seizures.

Managing your epilepsy, *also called self-management*, includes everything you and your family or supports do to control your seizures, manage how epilepsy affects your daily life, and live life to your fullest potential. It doesn't mean you manage epilepsy by yourself. **It does** mean you work together with your health care team, family, and other supports. Here are some programs to help.

Epilepsy Foundation website

Epilepsy.com is the most comprehensive national resource for anyone who seeks to better understand a medical condition that affects 3 million people in the United States.



Learn: Whether you have just been told you have seizures or whether you want to learn more to better understand your epilepsy, find basic and in-depth information that meets your needs.

Get Help: Find training, tools, online resources, local services, and more that will help you take charge of your health, care, safety, wellness, and life.

Make a Difference: Getting involved and giving back to the epilepsy community can be a powerful way to improve your life. Find ways to get involved in the fight to find new therapies and a cure and to raise awareness about epilepsy
and seizures.

Connect: Connect with others who are living with seizures and epilepsy.

Visit epilepsy.com

Texting4Control

Texting4Control is text messaging support available to people with epilepsy. This service sends reminders to your cell phone to help you remember to take your epilepsy medications, as well as motivational messages to help you stay positive about taking control of your epilepsy.

To sign up, visit www.texting4control.com

MY MEDICATION PROFILE

CURRENT MEDICATION PROFILE

MEDICATION NAME	DOSAGE	DIRECTION	START DATE	PREFERRED MESSAGE	REMINDER TIMES	SEND SMS
Carbamazepine - Tegretol / Tegretol Retard			01/04/2017			

PREVIOUS MEDICATION PROFILE

MEDICATION NAME	DOSAGE	DIRECTION	START DATE	DATE CHANGED
No records found				

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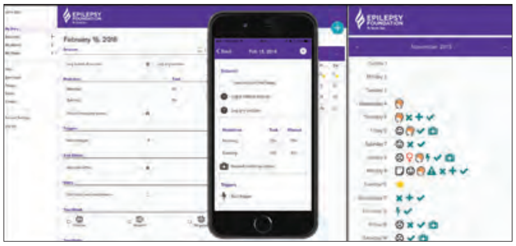
My Seizure Diary

A free online seizure diary with companion smartphone app for people with seizures and epilepsy.



- Monitor your health – track seizures and clusters over time.
- Manage medicines – track side effects and use of rescue therapies.
- Learn what works and when changes may be needed.
- Easy-to-use reminders to prevent missed medicines or appointments.
- Track triggers and lifestyle to lessen risk of breakthrough seizures.
- Organize your health history and personalized seizure response plan.
- Communicate more easily with your healthcare team!

Learn more at epilepsy.com/seizurediary

Epilepsy Foundation acknowledges support from Upshur-Smith for My Seizure Diary

WebEase

- Learn new skills for managing your epilepsy and feel more confident that you know what to do.
- Set goals and get personalized tips to meet them.
- Watch and listen to stories from others living with epilepsy.
- Find helpful resources and explore topics that interest you.
- Watch videos to get tips on how to remember your medication, manage stress, and sleep better.

This free program is just a mouse-click away at webease.org

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My Seizure Response Plan

Name: Birth Date:

Address: Phone:

1st Emergency Contact /Relation: Phone:

2nd Emergency Contact / Relation: Phone:

Seizure Information

Seizure Type/Nickname	What Happens	How Long It Lasts	How Often

Triggers

Daily Seizure Medicine

Medicine Name	Total Daily Amount	Amount of Tab/Liquid	How Taken (time of each dose and how much)

Other Seizure Treatments

Device Type: Model: Serial# Date Implanted

Dietary Therapy: Date Begun:

Special Instructions:

Other Therapy:

continued on back

Seizure First Aid

- ☐ Keep calm, provide reassurance, remove bystanders
- ☐ Keep airway clear, turn on side if possible, nothing in mouth
- ☐ Keep safe, remove objects, do not restrain
- ☐ Time, observe, record what happens
- ☐ Stay with person until recovered from seizure
- ☐ Other care needed: __________________________________

Call 911 if...

- ☐ Generalized seizure longer than 5 minutes
- ☐ Two or more seizures without recovering between seizures
- ☐ "As needed" treatments don't work
- ☐ Injury occurs or is suspected, or seizure occurs in water
- ☐ Breathing, heart rate or behavior doesn't return to normal
- ☐ Unexplained fever or pain, hours or few days after a seizure
- ☐ Other care needed: __________________________________

When Seizures Require Additional Help

Type of Emergency (long, clusters or repeated events)	Description	What to Do

"As Needed" Treatments (VNS magnet, medicines)

Name	Amount to Give	When to Give	How to Give

Health Care Contact

Epilepsy Doctor: ________________________ Phone: ________________

Nurse/Other Health Care Provider: ________________________ Phone: ________________

Preferred Hospital: ________________________ Phone: ________________

Primary Care: ________________________ Phone: ________________

Pharmacy: ________________________ Phone: ________________

Special Instructions: ____

____

My signature ________________________________ Date ______________

Provider signature ________________________________ Date ______________