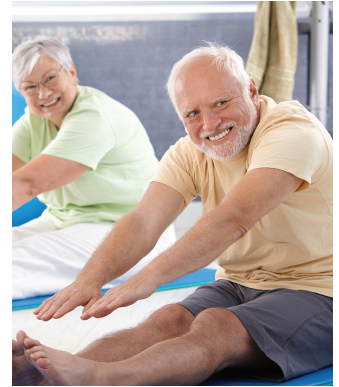


New to Seizures & Epilepsy



1-800-332-1000

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 with their health care provider.

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Improve Your Seizure Control

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. Make sure you 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 makes you likely to have more seizures and is a common cause of breakthrough seizures and emergencies.

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 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 often 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?

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

Focus on your overall wellness. 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.
- Pay attention to your overall emotional health.
- Eat regularly and have a healthy diet.
- Have a strong support system of family and friends.
- 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 care 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.

Some people with certain types of epilepsy find it very hard to control their seizures. They may also have other problems that affect their ability to move, feel, think, talk, and do other things. These other problems are often called comorbidities and can make managing epilepsy more difficult. Being seen at a comprehensive epilepsy center may help you look at all options to improve seizure control and how epilepsy affects your health and quality of life.

Community Education Programs



Epilepsy and Seizure First Aid

Everyone should know what to do when a seizure happens. Epilepsy and Seizure First Aid is available through our local offices and our website, epilepsy.com. Presentations can be tailored to the type of audience.

First Responder Training

The Epilepsy Foundation offers resources and training to help First Responders understand how to recognize and respond to someone having a seizure.

Epilepsy & Seizure Response for Emergency Medical Services (EMS) Personnel describes seizures associated with epilepsy and other causes, outlines appropriate EMS responses to consider for further medical care, and encourages the use of evidence-based guidelines for status epilepticus.

Epilepsy & Seizure Response for Law Enforcement Personnel provides law enforcement personnel with tools to recognize and give appropriate care to people with epilepsy and seizures. Managing other epilepsy-related issues that police may respond to are also highlighted.



Managing Students with Seizures: The Importance of School Nurses

Managing Students with Seizures: The Importance of School Nurses is a program designed to provide the school nurse with information, strategies, and resources that will enable them to better manage the student with seizures by supporting positive treatment outcomes, maximizing educational and developmental opportunities, and ensuring a safe and supportive environment. Programs include a 2-hour course on managing students with seizures, and 1-hour programs targeting rescue therapies, developing IEP and 504 programs, and psychogenic nonepileptic seizures.

Seizure Training for School Personnel

Seizure Training for School Personnel is an interactive course designed to help promote a positive social and educational environment for students living with seizures and epilepsy.

Seizure Training for Childcare Personnel

Seizure Training for Child Care Personnel is a curriculum developed by the Epilepsy Foundation for child care providers instructing them on proper seizure first aid for young children. This program also highlights epilepsy syndromes that are more common in children under the age of 5 and the impact of seizures when providing child care.

Seniors and Seizures: Education for Organizations Serving Older Adults

The Epilepsy Foundation's Seniors & Seizures Training is designed to provide caregivers and staff of adult day care centers, senior centers, long-term facilities, nursing homes, and other senior-serving organizations with strategies to better recognize and respond to seizures among older adults.



Seizures & You: Take Charge of the Facts

Seizures and You: Take Charge of the Facts is an epilepsy awareness program for students in grade K-12 designed to dispel myths and reduce the stigma associated with epilepsy.

How You Can Get the Training

Several of these programs are offered in-person through local Epilepsy Foundation offices. Contact your [local office](#) to learn more. To access courses through the Epilepsy.com Learning Management System, visit <https://learn.epilepsy.com>.

For more information, or to see if a course is available in your area, please call the Epilepsy & Seizures Helpline at 1-800-332-1000.

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Epilepsy & Seizures 24/7 Helpline



What do we do?

The helpline has trained information specialists available to answer your questions about epilepsy and seizures and give you 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.

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

- Treatment options
- Available medicines
- Support groups
- Resources for financial, insurance, and other help
- Seizure first aid and safety issues
- Employment, discrimination, and legal issues
- Emotional support
- Getting connected with local Epilepsy Foundation offices
- Sudden Unexpected Death in Epilepsy (SUDEP)
- 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 comuníquese con nuestra línea gratuita 1-866-748-8008 o visita nuestro sitio web: www.laepilepsia.org.

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. Join our live online events about the latest in epilepsy and issues affecting families.

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.

Clinical Trials Portal

Clinical trials and studies are critical to new therapy development for epilepsy. Please consider joining a current trial or study to aid in the effort of finding new and improved ways of treating seizures and ultimately lead to a cure – visit epilepsy.com/clinical_trials to learn more!

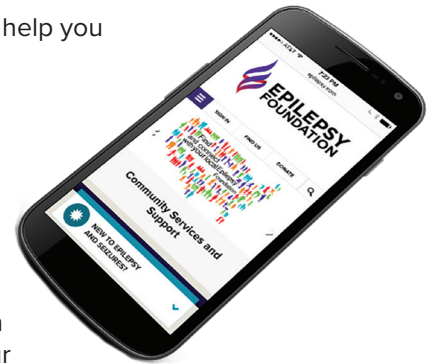
My Seizure Diary

Track your seizures, medicines, and other health events. Having more accurate and up-to-date information helps you and your care team make better decisions about medicines, treatments, and other ways of managing seizures and how they affect your life. See diary.epilepsy.com.

Resources

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

Visit epilepsy.com today.



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 3.4 million people in the United States.

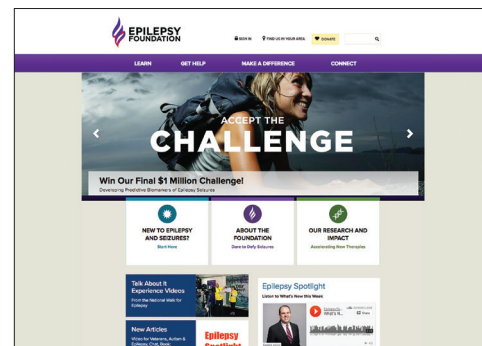
Learn: Whether you have just been told you have seizures or whether you want to learn more to better understand your epilepsy, find basic and in-depth information that meets your needs.

Living with Epilepsy: 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.

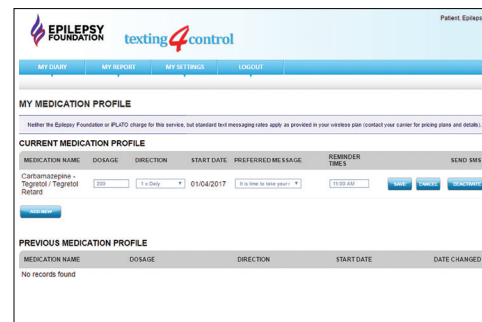
Visit epilepsy.com



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

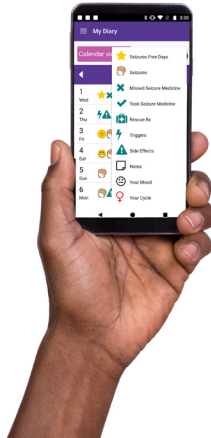


My Seizure Diary

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.
- Share your seizure with a family member, caregiver, or clinician.
- 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



The Importance of Managing Your Epilepsy

Monitor Your Seizures

Recording your seizures or spells will help you and your healthcare team better diagnose and manage your health condition.

Optimize your Treatments

Tracking and identifying your seizures will allow your healthcare team to better choose your treatment path.

Adjust your Treatment

Tracking seizures and side effects helps you know how the treatment works and if a change is needed.

Identify and Manage Side Effects

Recording side effects allows you and your healthcare team to see how the medications are affecting you. This information can help make better treatment decisions.

Identify Seizure Triggers

Knowing and modifying your seizure triggers is a key part of managing epilepsy well. Track these triggers and modify your lifestyle to reduce the frequency and severity of seizures.

Learning More and Getting Involved in Your Epilepsy Care

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.

Be prepared - 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, school problems, or changes in how you feel. Tell them if you feel nervous, sad, depressed, or are having changes in sleep, appetite, or sex drive. This may make you uncomfortable, but your health care team is there to help. They want to know how you're doing.



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
- Are still having seizures
- 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. If you're still having seizures after trying at least two seizure medicines, ask to see an epilepsy specialist.

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 provider 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](https://www.epilepsy.com/managing) to learn more about seizure emergency and seizure response plans.

Know SUDEP Facts



SUDEP is Sudden Unexpected Death in Epilepsy

- SUDEP is the sudden unexpected death of a person with epilepsy.
- While SUDEP is rare, it happens in 1 out of 1,000 people with epilepsy. The risk in children may be lower.
- One way to lessen your risk of SUDEP is to have as few seizures as possible.



Know your risk for SUDEP

SUDEP can happen at any time and with any type of seizure.

It happens most often in people with

- Tonic clonic seizures
- Uncontrolled seizures
- 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 health care provider.**
- **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.



Know how to stay safe

- If you have seizures at night, talk to your health care team about safety.
- Have someone check on you after a seizure or share a room.
- Ask your health care team about seizure alert devices and how to get help after a seizure.

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?

- 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. Here's at least 4 important ones to help you get started:

- **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.



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

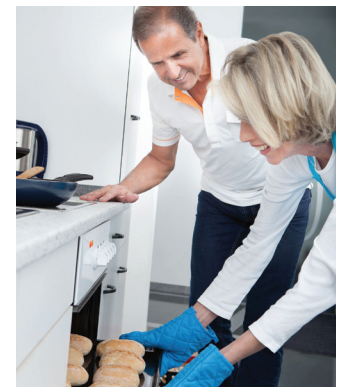
Prevent drowning and injuries from slips and falls in the bathroom:

- 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 will know if you have a seizure and can check on you.
- 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; don't sleep face down.

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. 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

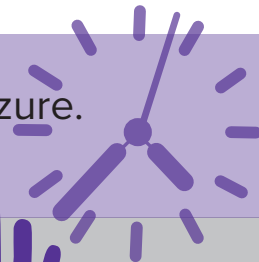
One day, as your child grows, she may ask about your seizures. Use simple language to explain things. Say that you will be okay but that you may need some help sometimes. Show him how to get another adult to help or to call 911 if you do not wake up after a seizure. If you are calm, your child will be 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.

Seizure First Aid

What to do in the event of a seizure

1

STAY with the person and start timing the seizure. Remain **calm** and check for medical ID.



2

Keep the person **SAFE**. Move or guide away from **harmful objects**.



3

Turn the person onto their **SIDE** if they are not awake and aware. **Don't block airway**, put something small and soft under the head, loosen tight clothes around neck.

4

Do **NOT** put **anything** in their mouth. Don't give water, pills or food until the person is awake.



5

Do **NOT** *restrain*.



6

STAY with them until they are awake and alert after the seizure. **Most seizures end in a few minutes.**



Call 911:

- ▲ Seizure lasts longer than 5 minutes
- ▲ Repeated seizures
- ▲ Difficulty breathing
- ▲ Seizure occurs in water
- ▲ Person is injured, pregnant, or sick
- ▲ Person does not return to their usual state
- ▲ First time seizure

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 a medical condition, like asthma and diabetes.
- Epilepsy is a developmental disability when it starts before age 18.
- Often seizures are the main problem for people with epilepsy, but other neurological or developmental problems can be seen too.



What causes epilepsy?

More than half the time, the cause is unknown. When a cause can be found, it is 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. It 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?

- A good description of the event and ideally an eyewitness account or video recording is key to determining if the event was a seizure and what kind.
- A medical history, physical and neurological exam, blood work, and other tests are important. These help diagnose epilepsy and look for other conditions or causes.
- An EEG is one of the most important tests. It records the brain's electrical activity. Some patterns of activity are unique to certain types of seizures.
- Imaging tests (like a CT, MRI, or PET scan) look at the structure and function of the brain. An MRI is needed for anyone with new onset of seizures. PET scans or other advanced imaging may be done later.

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 6 in 10 people may control their seizures with the first or second medicine they try.
- Yet a survey of adults in the community found that 56% still have seizures.
- Regardless of the numbers, if a person does not get control of seizures in the first year or after the first 2 or 3 medicines are tried, they should be seen by an epilepsy specialist.
- Options beyond medicines may be possible.



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 found and removed without hurting vital functions like speech or movement. For other types of surgery, visit epilepsy.com/surgery.

Vagus Nerve Stimulation (VNS) – A small device (generator) is implanted under the skin in the left side of the chest. A small thin wire or electrode goes from the generator and is attached to the vagus nerve in the neck. VNS may be an option if surgery doesn't work or is not right for you. The benefits of the VNS appear to improve over time. For example, about 45% of people have seizures decreased by 50% or more within one to two years.

Responsive Neurostimulation (RNS) – This is another device to treat seizures. It is implanted 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 seizures. RNS also may help people who can't have surgery or when surgery doesn't work well enough. 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.

Deep Brain Stimulation (DBS) – DBS is a new type of device that also helps control seizures when surgery doesn't work or cannot be done. Electrode wires are placed in a specific area of the brain. The device is programmed, like VNS, to give stimulation to interrupt or stop seizures.

Dietary Therapies – Dietary therapies can help control seizures in both children and adults. They are usually used when seizures do not respond to medicine. The most common diet therapy is the ketogenic diet. This is a medically supervised high fat and low carbohydrate diet. There are three other diets that also help control seizures in some people. Most people who use a diet therapy continue taking medicine



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.

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: _____

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 Need More 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 _____