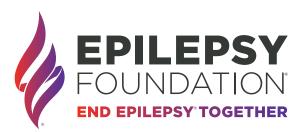
# New to Seizures & Epilepsy











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.

TThis publication is supported by the Centers for Disease Control and Prevention of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award totaling \$12,500 with 100 percent funded by CDC/HHS. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, CDC/HHS, or the U.S. Government.

# 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 for people affected by seizures and the epilepsies

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**.

## 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!

#### **Epilepsy Toolbox**

Our toolbox is the place to find resources, such as forms and posters, for managing your epilepsy and other needs, helping your loved one, and teaching others about epilepsy and seizurs. Visit the Toolbox at epilepsy.com/toolbox.

#### 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.

# Community Education Programs



#### Seizure First Aid Certification

Everyone should know what to do when a seizure happens. Seizure Recognition and First Aid Certification is a formal training offered by the Epilepsy Foundation that teaches people:

- · How to recognize signs of a seizure
- · How to respond with proper seizure first aid
- When to call for help

This course is designed for people who:

- Have a family member, loved one, or friend with seizures
- · Have a job where you provide care for people with seizures
- Have a job where you work with the public or work with someone who has seizures.
- · Coach or lead groups
- Work, play or live in areas or settings where seizures could occur

Participants who successfully complete the course will receive a twoyear certification that can be renewed in the future.

To learn more about the seizure first aid course, and of upcoming dates, visit: epilepsy.com/firstaid.



#### Seizure Training for School Nurses

Seizure Training for School Nurses: Caring for Students 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.

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To learn more about the school nurse course, visit epilepsy.com/school-nurse-training.

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### 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.

Classroom teachers, special education teachers, librarians, teacher assistants, school bus drivers, aides, and other staff members or volunteers in grades K-12 can all benefit and can receive continuing education units.

To learn more about the the school personnel course, visit: epilepsy.com/schoolpersonneltraining.

## How You Can Get Training

#### **Epilepsy Learning Portal**

The Epilepsy Learning Portal is your one-stop shop to access the Epilepsy Foundation's online and on-demand trainings about epilepsy and seizures. Here are some of our most popular classes. Many classes offer continuing education credits. Visit the site at **learn.epilepsy.com**.

#### **Local Epilepsy Foundation Offices**

Several programs are offered through local Epilepsy Foundation offices. To find your local office, visit **epilepsy.com/local** to find an office in your area.

For more information, or get help finding a local office in your area, please call the Epilepsy & Seizures Helpline at 1-800-332-1000.



## 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.

# 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

**Learn.epilepsy.com** is your one-stop shop to access the Epilepsy Foundation's online and ondemand trainings about epilepsy and seizures.

**Medications** is the place to learn about the different medications available that can help prevent or stop seizures. epilepsy.com/medications

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**SUDEP** is the sudden, unexpected death of someone with epilepsy, who was otherwise healthy. People who continue to have seizures are at greater risk of a number of complications, which is why preventing seizures and other problems is so important. Learn about SUDEP at epilepsy.com/sudep.

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**Triggers** can sometimes lead to seizures. Keeping track of any factors that may come before a seizures can help you recognize when a seizures may be coming. Learn about triggers at epilepsy.com/triggers.

**Toolbox** is the place to find resources for managing your epilepsy and other needs, helping your loved one, and teaching others about epilepsy and seizures. epilepsy.com/toolbox

### Managing Epilepsy Well Programs

HOBSCOTCH (Home Based Self-Management and Cognitive Training Changes Lives)

Delivered in person and by phone, HOBSCOTCH teaches people with epilepsy memory skills and uses problem-solving therapy to improve memory and attention

**PACES in Epilepsy** (Program for Active Consumer Engagement in Self-Management)

Delivered in person in a community setting or by phone, PACES improves self-management, confidence, depression, and quality of life in people with epilepsy.

**SMART** (Self-Management for People with Epilepsy and a History of Negative Health Events)

Starting with an in-person group session and continuing for 8 weeks using a teleconferencing or video conferencing program, SMART provides educational and behavioral interventions to enhance epilepsy self-management.

EPILEPSY

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**TIME** (Targeted Self-Management for Epilepsy and Mental Illness)

Serving adults who have both epilepsy and a serious mental illness, TIME uses 12 weekly group sessions to provide education, behavioral modeling, and group support aimed at reducing depressive symptoms.

Project UPLIFT for Epilepsy (Using Practice and Learning to Increase Favorable Thoughts)

An 8-week program delivered over the phone, UPLIFT for Epilepsy usesognitive behavioral and mindfulness therapies to reduce depressive symptoms and improve depression self-management.

Learn more at epilepsy.com/mew

## 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.



#### 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

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.

## 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 for tools to help you manage your seizures.

## **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.













## 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 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 them.
- 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..

Visit epilepsy.com/safety for more information on staying safe

# Seizure First Aid

How to help someone having a seizure

1

**STAY** with the person until they are awake and alert after the seizure.

✓ Time the seizure ✓ Remain calm

√ Check for medical ID



2

Keep the person **SAFE**.

✓ Move or guide away from harm



3

Turn the person onto their **SIDE** if they are not awake and aware.

✓ Keep airway clear

✓ Loosen tight clothes around neck

✓ Put something small and soft under the head



Call **911** if...

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

Do **NOT** 

- X Do **NOT** restrain.
- X Do **NOT** put any objects in their mouth.
  - ✓ Rescue medicines can be given if prescribed by a health care professional

Learn more: epilepsy.com/firstaid



epilepsy.com

24/7 Helpline: 1-800-332-1000

# Seizure & Epilepsy Overview

#### What is a seizure?

A seizure is sudden surge of electrical activity in the brain. Seizures are not a disease in themselves. Instead, they are a symptom of many different disorders that can affect the brain.

- Some seizures can hardly be noticed, while others are totally disabling.
- About half of people who have one seizures without a clear cause will have another one.
- If there is a known cause for your seizures, you are twice as likely to have another.
- Seizures are not contagious.

## What is epilepsy?

Epilepsy is a neurological disease that causes people to have recurrent seizures.

- · Epilepsy is not contagious.
- Epilepsy is a medical condition, like asthma and diabetes.
- 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 or MRI) may be done to look at the brain structure, while others (like PET) may be done to measure function of the brain if seizures fail to respond to initial treatments.







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## 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.
- 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.



**Devices** - A device may be used for people whose seizures are difficult to control. A small device is implanted which delivers an electrical signal to change what a nerve or the brain does. There are different types of devices and each work differently.

**Dietary Therapies** - Dietary therapies can help control seizures in both children and adults when medicines alone do not work. There are four major dietary therapies used: Ketogenic Diet, Medium-Chain Triglyceride diet (MCT), Modified Atkins Diet (MAD), and Low Glycemic Index Treatment (LGIT). All are low in carbohydrates (like sugar, pasta, and bread) and high in fat (like butter, oils, bacon, and avocados).

To learn more about treating seizures and epilepsy, visit epilepsy.com/treatment.

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.

Tonic - Sudden stiff or tense body, arms, or legs; person may fall; lasts around 20 seconds.

**Epileptic Spasms** (Infantile Spasms) - Brief 1-3 second events of arm, leg, and head pulling into or extending from the body; Often happen in clusters every 5-10 seconds over a 5-10 minute period.

To learn about the different seiuzure types, visit epilepsy.com/seizuretypes.

# SEIZURE ACTION PLAN (SAP)

How to give \_





Name:			Birth Date:		
Address:			Phone:		
Emergency Contact/Relationship			Phone:		
Seizure Informat	tion				
Seizure Type How Long It L		How Often	What Happens		
How to respon	d to a seizure	(check all t	hat apply) 🗹		
☐ First aid – Stay. Safe. S	Side.	□ No	otify emergency contact at		
☐ Give rescue therapy according to SAP			☐ Call 911 for transport to		
☐ Notify emergency contact		□ O:	☐ Other		
First aid for any seizure			When to call 911		
☐ STAY calm, keep calm, begin timing seizure			<ul> <li>Seizure with loss of consciousness longer than 5 minutes, not responding to rescue med if available</li> </ul>		
☐ Keep me <b>SAFE</b> – remove	-		☐ Repeated seizures longer than 10 minutes, no recovery between		
don't restrain, protect hea		,	them, not responding to rescue med if available  Difficulty breathing after seizure		
don't put objects in mout		,	Serious injury occurs or suspected, seizure in water		
$\ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ \ $			When to call your provider first		
☐ Swipe magnet for VNS			☐ Change in seizure type, number or pattern		
☐ Write down what happens			<ul> <li>Person does not return to usual behavior (i.e., confused for a long period)</li> </ul>		
		_	☐ First time seizure that stops on its' own		
			Other medical problems or pregnancy need to be checked		
When rescu	<b>ue therapy</b> ma	y be nee	ded:		
WHEN AND WHAT TO D	0				
•					
Name of Med/Rx					
How to give					
If seizure (cluster, # or len	gth)				
Name of Med/Rx					
How to give					
If seizure (cluster, # or len	gth)				
Name of Med/Rx			How much to give (dose)		

Care after seiz							
What type of help is needed? (describe)  When is person able to resume usual activity?							
Special instruc	tions						
First Responders:							
Emergency Department	t:						
Daily seizure m	nedicine						
Medicine Name	Total Daily Amount	Amount of Tab/Liquid	How Taken (time of each dose and how	/ much)			
Other informat	ion	·					
Triggers:							
Important Medical History							
Allergies							
Epilepsy Surgery (type, da	te, side effects)						
Device: ☐ VNS ☐ RNS	S □ DBS Date Implant	ed					
Diet Therapy ☐ Ketogen	ic $\square$ Low Glycemic $\square$	Modified Atkins □ O	ther (describe)				
Special Instructions:							
Health care contacts	<u> </u>						
Epilepsy Provider:			Phone:				
Primary Care:			Phone:				
Preferred Hospital:			Phone:				
Pharmacy:			Phone:				
My signature			Date				
Provider signature			Date				



