THE PATH TOWARD PREPARED

A GUIDE TO LIVING WITH EPILEPSY AND FREQUENT SEIZURE EPISODES
PREPARING FOR THE UNPREDICTABLE

If epilepsy were defined with one word, it’d probably be “unpredictable.” Not knowing when seizures will strike, or why, can leave even the most prepared person feeling uneasy. The good news? There may be ways to control aspects of epilepsy so you can live each day to the fullest.

**MILLIONS OF PEOPLE LIVE WITH EPILEPSY**

Epilepsy can affect anyone—both males and females of all races, ethnic backgrounds, and ages. At least **3.4 million people in the United States** live with epilepsy. In fact, epilepsy is so common that **1 in 26 people in the United States** will develop epilepsy in their lifetime.

An estimated 5% of people with epilepsy experience seizure clusters, including children. Learn more about these seizure episodes on page 8.

**LET OTHERS WITH EPILEPSY LIGHT YOUR PATH FORWARD**

This book is a collection of insights from people living with or caring for someone with epilepsy. They’ve shared their own personal experiences, tips, and words of wisdom in hopes that it will make your journey a bit smoother. Of course, everyone’s experience with epilepsy is different, so make sure you talk to your healthcare provider before trying anything new. This e-book is not intended to replace or provide any medical advice.
You may have noticed that certain situations or stimuli can trigger your seizures, like being under stress or not getting enough sleep. Knowing what brings on a seizure can help you avoid or better manage these situations.

### Common Seizure Triggers

- Stress
- Lack of sleep
- Illness
- Alcohol or recreational drugs
- Flashing or flickering lights
- Missing a dose of antiseizure medication
- Menstruation or hormonal changes
- Certain prescription, over-the-counter, and herbal medications
- Nutritional deficiencies such as low blood sugar

### Did You Know?

Flashing lights between the frequencies of 5 to 30 flashes per second are most likely to trigger seizures. To be safe, a group of international experts recommends that people with a sensitivity to light (called photosensitivity) should not be exposed to more than 3 flashes per second.
Tackle Your Triggers

Take a look at some of the lifestyle choices people with epilepsy are making to help manage their triggers and improve their overall well-being.

Did you know?

In a survey of 48 people with epilepsy, 71% said increased stress is most likely to trigger their seizures, followed by irregular sleep and periods of high emotion.

How do you manage your stress?

→ Music
→ Massage
→ Healthy foods
→ Exercise
→ Sleep
→ Time management
→ Aromatherapy
→ Acupuncture
→ Meditation
→ Counseling and therapy

DID YOU KNOW?

In a survey of 48 people with epilepsy, 71% said increased stress is most likely to trigger their seizures, followed by irregular sleep and periods of high emotion.
SLEEP STRATEGIES FOR BETTER Z’S

Not getting enough sleep, or having poor quality sleep, can make you more likely to experience a seizure.

HERE ARE SOME WAYS YOU CAN STOP COUNTING SHEEP AND DRIFT INTO DEEPER, MORE RESTFUL SLEEP

→ Limit bright light in evenings, especially from televisions, tablets, and smartphones
→ Keep the bedroom cool
→ Practice a relaxing bedtime routine
→ Sleep on a comfortable mattress and pillow
→ Keep electronics out of the bedroom
→ Avoid caffeine 4 to 6 hours before bedtime
→ Keep a consistent sleep schedule
→ Relax and read before bed
→ Sound machine
→ Avoid screen time before bed
→ Listen to guided meditation
→ Keep the room completely dark

WHAT’S YOUR GO-TO FOR GETTING BETTER SLEEP?

DID YOU KNOW?

In a poll by the National Sleep Foundation, 95% of people use some type of electronic device within an hour before bed every week. Scientists are finding that light from electronics can disrupt sleep by sending alerting signals to your brain. Consider keeping electronics out of your bedroom and shutting them off for at least 1 hour before bed to help get a restful night of sleep.
Epilepsy medications are an important part of your treatment plan. From daily medications to rescue treatments, here’s what you need to know.

**TREATMENT ISN’T “ONE SIZE FITS ALL”**

Some daily antiseizure treatments work better for certain types of seizures than others. Partner with your healthcare provider to find the medication, or combination of medications, that works best for you. This can take some trial and error, so be patient as you work with your healthcare provider to find the right fit.

**DAILY MEDICINE VS RESCUE TREATMENTS: DECIPHERING THE DIFFERENCE**

Antiseizure medications are taken every day to help prevent seizures from happening. Even with daily medication, seizures can still occur, and sometimes they don’t stop on their own. When this happens, on-hand rescue treatments should be used to treat the seizure activity.

Rescue treatments do not take the place of daily antiseizure medications or emergency medical care. If a true medical emergency happens, get urgent help right away.

**MEDICATION MATTERS**

Did you know?

It takes an average of 56 minutes to reach the hospital in an emergency, making rescue medications an important tool for prompt treatment.
A large majority of breakthrough seizures resolve on their own and do not require intervention.

CONSISTENCY IS KEY WITH DAILY ANTISEIZURE MEDICATIONS

However, even if you never miss a dose, a “breakthrough seizure” can still happen. This refers to a seizure you experience unexpectedly when you’ve been seizure-free for a period of time.

WHEN DOES A BREAKTHROUGH SEIZURE REQUIRE TREATMENT?

→ When it keeps going without stopping on its own
→ When it repeats within the day or is followed by more seizures that same day

DID YOU KNOW?

In a survey of 48 people with epilepsy, 48% said missing a dose of their medication triggers their seizures.
DO YOU HAVE SEIZURE CLUSTERS?

Not everyone is familiar with the term “seizure clusters,” but you may experience them if you have 2 or more seizures in a 24-hour period that occur outside of your usual seizure pattern.

Seizure clusters may affect each person differently in terms of the type of seizure that happens, number of seizures, severity, or length of the seizure.

SEIZURE CLUSTERS CALL FOR EMERGENCY TREATMENT

Left untreated, seizure clusters can significantly impact your health, leading to injuries or hospitalization. They can also lead to longer or more dangerous seizure activity.

Not only can seizure clusters affect your health, they can be extremely disruptive to your daily life.

YOUR HEALTHCARE PROVIDER MAY USE DIFFERENT TERMS TO DESCRIBE SEIZURE CLUSTERS

→ Acute repetitive seizures
→ Recurrent seizures
→ Multiple seizures
→ Seizure episodes
→ Crescendo seizures
→ Seizure flurries
→ Cyclical seizures
→ Serial seizures

DID YOU KNOW?

When it comes to rescue medications, you have options. Ask your healthcare provider which treatment may be right for you or your loved one.
We spend a lot of time in our homes—from eating and sleeping to bathing and entertaining. Your home should be the last place you have to worry about getting hurt by a seizure. Take a look at these suggestions for creating a safe environment.

### Bedroom
- Keep floors clear of objects and piles of clothing
- Place pillows around the bed
- Install bed railings
- Consider sleeping in a low-lying bed

### Living Room
- Steer clear of glass tables
- Pad sharp corners of furniture and counters
- Choose carpet over hardwood or tile
- Use a fireplace screen at all times

### Bathroom
- Opt for showers over baths
- Use nonskid strips in the tub or shower
- Use tub rails or grab bars
- Consider a shower or tub seat with a safety strap

**MAKE YOUR HOME A HAVEN**
Having epilepsy doesn’t mean you can’t have a successful career or handle a demanding job. Sometimes, the hardest part of working with epilepsy is fear—that people will look at you differently or judge you in some way. Having epilepsy is nothing to be ashamed of, but when and how you tell your colleagues is up to you.

When it comes to telling coworkers, it’s normal to be nervous

Some people surveyed were concerned about telling their coworkers in fear of being:

→ Judged
→ Alienated
→ Fired
→ Misunderstood
→ Passed up for a promotion

Most people surveyed received a positive response when telling coworkers about their epilepsy:

“My coworkers are more understanding now—especially when I have to miss work.”

“They showed concern for me but don’t judge me or look down on me in any way.”

“I feel safer because I know they’re looking out for me if something happens.”

“They didn’t overreact and were actually thankful I told them.”

Did you know?

The Americans with Disabilities Act (ADA) protects people from disability-based discrimination. Learn more about your rights and the responsibilities of employers.
If you’re a care partner to a child with epilepsy, you know how important it is to keep your little one safe—especially when they’re out of sight.

Read on for some tips on encouraging independence while ensuring their safety.
STAYING SAFE DURING PLAY DATES

Having your child socialize outside of your home doesn’t have to be an anxiety-inducing event. Connect with the adult in charge, making sure they know what to do in case of emergency—seizure first aid is a good start. Make sure they also have your child’s rescue medication, know how to use it, and know when to call for help.

WHAT ABOUT SPORTS?

Children can participate in most sports activities as long as their coaches know what to do if they have a seizure during practice and follow any safety precautions.

WHAT ABOUT TEENS?

In most cases, teenagers can hang out with their friends without a parent present as long as someone in the group knows seizure first aid.

WHAT ABOUT SLEEPOVERS?

If you’re comfortable with a sleepover, make sure that your child doesn’t stay up too late if their seizures are associated with sleep. Sharing the same bed is also discouraged since it can lead to disrupted sleep.

CARE PARTNER CORNER

There are overnight camps designed just for kids with epilepsy. With trained counselors and medical staff on site, kids can swim, climb, and do other activities that might otherwise be considered dangerous. It’s also a great way for kids to meet other children with epilepsy. To find a camp near you, contact your local epilepsy foundation.²
# Staying Safe at School

Two of the biggest things you can do to help manage your child’s epilepsy at school is to **communicate** and **educate**.

## Communicate So They Can Accommodate

Talk to your child’s teacher, school nurse, and other personnel who will be in contact with your child. Make sure you review your child’s seizure action plan with them (see more information on page 17). This will help them know what to do in case of an emergency.

Communicate often to stay on top of your child’s well-being and academic performance at school. Ask the teacher to let you know if your child seems unusually tired, is having trouble concentrating, or is struggling with schoolwork.

## Help Educate Teachers—And Kids

You child’s teacher may not be familiar with epilepsy, so make sure to discuss your child’s condition at the start of every year. As part of that discussion, create a plan to ensure any substitute teachers are also aware of your child’s condition and seizure action plan.

Ask the teacher to talk to the class about epilepsy in a way that’s age-appropriate and comfortable for your child. This can help prevent teasing or dispel any myths that kids may have about seizures.

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## Care Partner Corner

Have you filled out a seizure action plan?

Being prepared is crucial to managing your child’s epilepsy. A seizure action plan can help you organize your child’s seizure information so it’s available when needed. Learn more about working with your healthcare provider to build your own plan at [Epilepsy.com](http://Epilepsy.com).³
DOES YOUR CHILD NEED EXTRA SUPPORT?

Although most kids with epilepsy test in the average IQ range, they are more likely to experience learning difficulties. If your child is having trouble learning, ask the school about available support. Many kids with epilepsy and learning difficulties can qualify for additional educational services.

SCHOOL CHECKLIST

→ Provide the school with a seizure action plan filled out with your child’s healthcare provider. Create one at Epilepsy.com.4

→ Give the school nurse any medication your child needs to take during school hours, including any prescribed rescue medication in case of emergency. Educate the nurse on how to use your child’s rescue medication.

→ Check to see if the school will allow your child to keep their rescue medication in their backpack in addition to the school office.

→ Check expiration dates regularly for medicines kept at school and ensure they’re stored according to the medicine’s prescribing information.

→ Make sure to update your child’s seizure action plan every year to reflect any changes needed as they grow.

CARE PARTNER CORNER

Seizures can be a foreign concept for children who don’t have epilepsy, and they may ask your child questions about their condition. Giving your child a good understanding of epilepsy can help them feel more confident responding to questions.
Living with epilepsy can feel lonesome at times. In fact, 67% of people surveyed said they sometimes or often feel the need to be isolated from friends, family, or social activities because of their epilepsy.

**NEED SOME WAYS TO STAY POSITIVE WHEN TIMES FEEL TOUGH? TAKE A LOOK.**

→ **Stay connected** with other people living with epilepsy
→ **Communicate openly** with friends, family, coworkers, and teachers
→ **Stay active** with daily exercise you enjoy
→ **Talk to your healthcare provider** if you are feeling depressed or anxious. Depression and anxiety are estimated to affect approximately 1 in 3 people with epilepsy at some point in their lives.
THRIVE WITH 5

STAY PREPARED FOR THE UNPREDICTABLE BY FOLLOWING THESE 5 GUIDELINES:

1. Take your daily medication.

2. Have a rescue medication on hand.

3. Create a seizure action plan with your healthcare provider and share with family, friends, coworkers, and school personnel.

4. Keep a health journal to track triggers and seizure frequency.
   We like the Seizure Tracker™ app. ⁵

5. Partner closely with your healthcare provider.

CARE PARTNER CORNER

Seizure-tracking technology is making it easier than ever to monitor your or your loved one’s seizure patterns. From smart watches to mattresses to cameras and motion detectors, these alert devices can be useful in letting you know when a seizure is occurring. Learn more at Epilepsy.com. ⁶
BE PREPARED WITH A SEIZURE ACTION PLAN

A well-thought-out plan has all the information someone may need to care for you or a loved one during a seizure. Take a look at this action plan from The Epilepsy Foundation. A school-specific action plan is also available. Download the form you need from Epilepsy.com and work with your healthcare provider to fill it out.

SEE MORE ABOUT HELPING YOUR CHILD STAY SAFE AT SCHOOL ON PAGE 13.

SEIZURE ACTION PLAN (SAP)

Name: ___________________________________________ Birth Date: __________________________
Address: _________________________________________ Phone: __________________________
Emergency Contact/Relationship __________________________ Phone: __________________________

Seizure Information

<table>
<thead>
<tr>
<th>Seizure Type</th>
<th>How Long It Lasts</th>
<th>How Often</th>
<th>What Happens</th>
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How to respond to a seizure (check all that apply)

☐ Notify emergency contact at __________________________
☐ Give rescue therapy according to SAP
☐ Call 911 for transport to __________________________
☐ Notify emergency contact
☐ Other ____________________________________________

First aid for any seizure

☐ STAY calm, keep calm, begin timing seizure
☐ Keep me SAFE – remove harmful objects, don’t restrain, protect head
☐ SIDE – turn on side if not awake, keep airway clear, don’t put objects in mouth
☐ STAY until recovered from seizure
☐ Swipe magnet for VNS
☐ Write down what happens __________________________
☐ Other __________________________________________

When to call 911

☐ Seizure with loss of consciousness longer than 5 minutes, not responding to rescue med if available
☐ Repeated seizures longer than 10 minutes, no recovery between them, not responding to rescue med if available
☐ Difficulty breathing after seizure
☐ Serious injury occurs or suspected, seizure in water

When to call your provider first

☐ Change in seizure type, number or pattern
☐ Person does not return to usual behavior (i.e., confused for a long period)
☐ First time seizure that stops on its’ own
☐ Other medical problems or pregnancy need to be checked

Make sure to update if dosing changes.

Reiterate this information in person with care partners, school personnel, and coworkers.

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SEE MORE ABOUT HELPING YOUR CHILD STAY SAFE AT SCHOOL ON PAGE 13.

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SEE MORE ABOUT HELPING YOUR CHILD STAY SAFE AT SCHOOL ON PAGE 13.
Seizure Action Plan continued

Care after seizure
What type of help is needed? (describe) _______________________________________________________________
When is person able to resume usual activity? ___________________________________________________________

Special instructions
First Responders: ___________________________________________________________________________________
Emergency Department: _____________________________________________________________________________

Daily seizure medicine

<table>
<thead>
<tr>
<th>Medicine Name</th>
<th>Total Daily Amount</th>
<th>Amount of Tab/Liquid</th>
<th>How Taken (time of each dose and how much)</th>
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Other information
Triggers: ________________________________________________________________________________________
Important Medical History: __________________________________________________________________________
Allergies: ________________________________________________________________________________________
Epilepsy Surgery (type, date, side effects): ________________________________
Device:  □ VNS  □ RNS  □ DBS  Date Implanted ________________________________
Diet Therapy:  □ Ketogenic  □ Low Glycemic  □ Modified Atkins □ Other (describe) __________
Special Instructions: _____________________________________________________________________________

Health care contacts
Epilepsy Provider: ___________________________________________ Phone: ________________________________
Primary Care: _____________________________________________ Phone: ________________________________
Preferred Hospital: ________________________________________ Phone: ________________________________
Pharmacy: ________________________________________________ Phone: ________________________________

My signature ____________________________________________ Date ________________________________
Provider signature ________________________________________ Date ________________________________

Learn more about triggers and dietary therapies at Epilepsy.com.

Review your action plan with your healthcare provider.
JUST DIAGNOSED?

Keep these questions on hand for your next appointment.

QUESTIONS TO ASK YOUR HEALTHCARE PROVIDER

→ What kind(s) of seizures do I have?
→ What could be triggering my seizures?
→ Is it possible that I will have a seizure that will not stop or that will repeat?
→ What are my treatment options?
→ Should I or my care partner carry an on-hand rescue medication?
→ Can you review and sign off on my seizure action plan?
→ What are the possible side effects of seizure medicine?
→ Do I need to have any tests done?
→ Are there certain activities I need to be careful doing—or should not do at all?

CARE PARTNER CORNER

Your loved one’s healthcare provider is a great resource in your own journey as a care partner. Asking questions like “How can I better support my loved one?” or “How can I make sure I’m prepared for their seizures?” can empower you in your role as a care partner.
People with epilepsy share their personal words of wisdom for living each day with confidence.

**WORDS OF WISDOM FROM THEM—TO YOU**

"Take it one day at a time!"

"Take your medication exactly as prescribed."

"Don’t be scared. It gets easier to deal with over time."

"Figure out your triggers as soon as you can."

"Don’t give up, it can be managed!"

**WHAT IS YOUR ADVICE FOR LIVING WITH EPILEPSY?**

**CARE PARTNER CORNER**

Top tips for supporting a loved one with epilepsy—directly from care partners like you.

- Use all the resources available to you
- Join a support group
- Research, research, research!
- Be patient, understanding, and supportive
- Keep working to find the right medication regimen
You can swallow your tongue during a seizure. It’s physically impossible to swallow your tongue, but you can bite it during a seizure.

People who have seizures can’t handle high-pressure, demanding jobs.

There are only a handful of jobs—such as piloting airplanes—where epilepsy is prohibitive. Otherwise, people with epilepsy are successful in a wide array of professions, from business and government to sports and medicine.

What’s the most ridiculous thing someone has asked you about epilepsy?

“Do you get smarter with seizures?”

“I told them: "Yes, a lot smarter!"
READY TO DELVE INTO MORE INFORMATION ABOUT EPILEPSY?

Continue reading with these resources.

Epilepsy Foundation of America®
List of local epilepsy foundations by state
Epilepsy.com

Centers for Disease Control and Prevention (CDC)
CDC.gov/epilepsy

American Epilepsy Society® (AES)
AESnet.org

American Academy of Pediatrics® (AAP)
AAP.org

Citizens United for Research in Epilepsy
CureEpilepsy.org

Online resources
1. Epilepsy.com/living-epilepsy/legal-help/your-legal-rights
2. Epilepsy.com/affiliates
4. Epilepsy.com/living-epilepsy/toolbox/seizure-forms
5. Seizuretracker.com/Seizure_Tracker_Mobile.php

6. Epilepsy.com/learn/early-death-and-sudep/sudep/role-seizure-alerts
7. Epilepsy.com/learn/treating-seizures-and-epilepsy/dietary-therapies