HAVENWAY

Starter Guide

Understanding and Navigating Epilepsy

Clear guidance for navigating Epilepsy with confidence

Practical tools, grounding strategies, and compassionate support
for individuals and families living with Epilepsy

A FREE EDUCATIONAL RESOURCE FROM HAVENWAY

For educational purposes only. This guide is not medical advice and is not a substitute
for care from a qualified healthcare provider.

Contents

1. Welcome to Havenway 3
2. What Is Epilepsy? 3
3. Understanding Seizures 4
4. Talking With Others About Epilepsy 4
5. Recognizing Possible Triggers 5
6. Tracking Seizures and Possible Triggers 6
7. Managing Stress 6
8. Routine, Journaling, Movement, and Rest 7
9. Working With Your Doctor 7
10. Managing Fear and Emotional Concerns 8
11. Lifestyle and Nutrition 9
12. Seizure First Aid 10
    When to Call 911 11
13. Your Next Step: Havenway Quest 12
14. Sources and Further Reading 13

Welcome to Havenway

You have taken a meaningful step simply by being here. Whether you are newly diagnosed, have lived with Epilepsy for years, or are supporting someone you love, this guide was created with you in mind.

Havenway was founded on the belief that navigating Epilepsy should not feel like something you do alone. Clear information and good support can make daily life feel more manageable, including on the hard days.

> **A note before you begin.** This guide is for educational purposes only and does not provide medical advice, diagnosis, or treatment. Every person's experience with Epilepsy is different. Please talk with your healthcare provider about anything specific to your situation.

What you will find in this guide

- Plain explanations of what Epilepsy is and how it can affect daily life
- Practical language for talking with others about Epilepsy
- Ways to notice and keep track of possible triggers
- Ideas for managing stress and caring for your well-being
- Suggestions for working with your medical team
- Support for the worries and feelings that can come with Epilepsy
- General health habits and nutrition considerations
- Seizure first aid basics for the people around you

What Is Epilepsy?

Epilepsy is a brain condition in which groups of nerve cells sometimes send abnormal signals and cause seizures [1]. Having Epilepsy means having an ongoing tendency to have epileptic seizures [2].

Doctors usually diagnose Epilepsy after more than one unprovoked seizure. In some situations, a diagnosis can be made after a single seizure [2]. Your healthcare team can explain how this applies to you.

Epilepsy affects people of all ages and backgrounds. Most people with Epilepsy live a full life [6], and many find that good information and support make daily life easier.

A few things Epilepsy is not

- Epilepsy is not contagious.
- Epilepsy is not caused by something a person did wrong.
- Epilepsy is a neurological condition, not a mental illness. Epilepsy can lead to feelings of sadness, loneliness, or depression [6], and support for mental health is available.

Understanding Seizures

Seizures are the main symptom of Epilepsy, and they look different from person to person. Some seizures cause a person to act confused or stare into space. Others cause a person to lose awareness, fall down, and shake [5]. A seizure can also involve a strange sensation, a sudden jerk of a limb, or a short period of confusion.

Doctors use the International League Against Epilepsy (ILAE) classification to describe seizures. It has four main classes [3]:

- **Focal seizures** begin in a network limited to one side of the brain. Doctors also note whether consciousness is preserved or impaired, based on awareness and responsiveness [3]. Some focal seizures spread to both sides of the brain [3][9].
- **Generalized seizures** involve both sides of the brain. They can look very different from one another. Some involve shaking or jerking, while others involve brief staring spells, a sudden loss of muscle tone, or small twitches [3][5].
- **Unknown seizures** are those where there is some information about the seizure, but not enough to tell whether it was focal or generalized [3].
- **Unclassified seizures** are used when there is not enough information to describe the seizure, even though a clinician is confident it is an epileptic seizure. The label can change as more information becomes available [3].

This is a simplified overview, not a complete list. Your healthcare team can tell you which terms describe your seizures.

Talking With Others About Epilepsy

There is no single right way to share that you have Epilepsy. You decide what to share, with whom, and when. Clear, simple language can help the conversation feel more comfortable.

At Work

Whether to tell an employer is a personal choice. In the United States, the Americans with Disabilities Act (ADA) covers many employers. Under EEOC guidance, an applicant generally does not have to volunteer that they have Epilepsy unless they will need an accommodation for the application process [4]. If you later ask for an accommodation, you may need to provide enough information about the need for it so your employer can consider your request. Employers generally must keep medical information confidential, with limited exceptions [4].

Rules can differ by employer, by role, and by country, and some jobs or driving requirements may have their own rules. Check what applies to you.

If you decide to ask for support, you might say:

- "I have a medical condition that sometimes causes seizures. I would appreciate it if you could learn basic seizure first aid, and I am happy to share what helps."
- "I may need occasional flexibility in my schedule for medical appointments. How can we best manage that?"
- "During certain tasks, short, regular breaks help me manage fatigue. Is there a way to build that into my workflow?"

At School (for parents and students)

Teachers and school staff can support a student better when they know what to expect and how to respond. Consider talking with school staff and the student's healthcare team about a seizure action plan and who at school should have it. CDC guidance says a student's plan should include known triggers, what to expect during a seizure, seizure first aid steps, and instructions for rescue medicines [10]. Sharing information does not guarantee how others will respond, but clear, specific information can help everyone feel better prepared.

With Family and Friends

The people closest to you may want to help but not know how. Simple, specific information, such as what a seizure looks like for you, what helps, and when to call for help, can make it easier for them to respond. Some people may still feel worried, and that is okay.

> **Remember:** You do not owe anyone your full medical history. Share what helps you feel safe and supported.

Recognizing Possible Triggers

A seizure trigger is something that may make a seizure more likely in a person who already has Epilepsy. Triggers do not cause Epilepsy [1]. Some people can identify their triggers, and triggers differ from person to person [6][13]. Others may not find a clear pattern [13].

Commonly reported triggers include [6][13]:

- Lack of sleep
- Missing medicine
- Stress
- Using alcohol, illegal drugs, or prescription drugs in ways other than prescribed
- Flashing lights or certain sounds (these affect some people, not everyone with Epilepsy)
- Hormonal changes with a period or pregnancy

Some people also notice patterns with illness, with or without fever. Others notice patterns with dehydration or long stretches without eating [1][13]. These are individual experiences, not triggers for everyone.

> **Remember:** Triggers vary from person to person. Please talk with your healthcare team before changing your routine or medicine because of a suspected trigger.

Tracking Seizures and Possible Triggers

A seizure diary can help you and your care team look for patterns over time. You can keep it in a notebook, a notes app, or a seizure-tracking app. Where practical, you might note:

- The date, time, and how long the seizure lasted
- What happened before, during, and after, and how long recovery took
- Sleep, stress, illness, and anything else that was different that day
- Whether you took your medicine on time
- Anything you suspect may have played a role

Bring your diary to appointments. It gives your care team useful observations between visits.

Keep in mind that something happening before a seizure does not prove it caused the seizure, and a clear trigger may never be found. If tracking starts to feel stressful, ask your care team what is most useful to record.

Helpful questions after a seizure: How did I sleep? Did I take my medicine on time? Was I unwell or under unusual stress? Was anything else different today?

Managing Stress

Stress is commonly reported as a seizure trigger [6][14]. The exact reason is unclear, and stress can affect people in different ways at different times [14]. There is no definite evidence that reducing stress helps seizures, so it cannot be promised as prevention [14]. Even so, finding ways to relax and cope can support your well-being. Living with Epilepsy can also be stressful in itself, and that is not a personal failing.

The ideas below are options, not requirements. Choose what feels doable and comfortable for you.

Relaxing Breathing

Slow, gentle breathing is a calming technique many people use for stress, whether or not they have recently had a seizure [7]. Keep it natural: let your breath flow only as deep as is comfortable, without forcing it [7]. There is no need for fixed counts or holding your breath, and you can stop at any time if it feels uncomfortable. If you would like guidance that fits you, ask your healthcare team.

Routine, Journaling, Movement, and Rest

Routines

Many people find that predictable routines, such as regular sleep and wake times, help them feel steady. Routines can also make it easier to remember medicine.

Journaling

Some people find that writing about their day or their worries helps them sort through their feelings. A few minutes is enough, and it is entirely optional.

Gentle Movement

Walking and stretching are gentle ways to be active. Exercise may reduce the risk of seizures for some people, and exercising safely can benefit physical and mental well-being [6]. Ask your healthcare team which activities are safest for you, especially contact sports or activities where an injury would be more likely if a seizure happened. Wear protective gear, such as a helmet for biking [6].

Swimming and Water Safety

Swimming and other water sports can be risky for people with Epilepsy, and swimming alone should be avoided [6]. If you or your child would like to swim, ask your healthcare team what is safe for your situation. Swim only with someone who knows about the Epilepsy and is a good enough swimmer to help if a seizure occurs [8]. A seizure that happens in water is an emergency. Call 911 [5].

Rest and Sleep

Rest is not laziness. Lack of sleep is a commonly reported trigger [6], so protecting your sleep is a reasonable priority. Aim for regular sleep and wake times when you can, and talk with your healthcare team if sleep is a struggle.

Working With Your Doctor

A neurologist or epileptologist is a key partner in your care. The questions you bring and the notes you share can make appointments more useful. Many people feel rushed at appointments or unsure what to ask, so a little preparation can help.

Questions worth asking

- What type of Epilepsy do I have, and what does that mean for me specifically?
- What are the goals of my current treatment plan, and how will we know if it is working?
- What should I do if I miss a dose of my medicine?
- Are there lifestyle adjustments that could support my treatment plan?
- What are the possible side effects of my medicine, and what should I watch for?

- When should I consider a second opinion or a specialist referral?
- What does seizure control look like for someone in my situation?

Tracking changes between appointments

Between visits, jot down any changes: new or different seizures, possible medicine side effects, mood changes, thinking or memory changes, or sleep problems. These notes give your doctor useful observations between visits. If a change worries you, contact your care team rather than waiting.

Managing Fear and Emotional Concerns

Many people with Epilepsy feel worried at times: about the next seizure, how others will react, independence, relationships, or the future. You may experience some of these feelings, all of them, or none. Acknowledging a feeling is not weakness. It can be a starting point for working with it.

Emotional Health and Epilepsy

Epilepsy can lead to feelings of loneliness, sadness, depression, and isolation from others [6]. Depression can have more than one contributor, including neurological, medicine-related, and social factors, so it is not only a reaction to the unpredictability of seizures [15]. If low mood, worry, or other changes are persistent or troubling, please talk with a qualified healthcare or mental health professional.

Free support is available. The Epilepsy Foundation's 24/7 helpline can connect you with specialists in Epilepsy and mental health: 1-800-332-1000 (English) or 1-866-748-8008 (Spanish). If you are thinking about suicide, or are worried about someone, call or text 988 [6].

Some people also feel grief, for example about a life that has changed, freedoms they have had to rethink, or the certainty they felt before a diagnosis. If that fits you, it deserves space and kindness.

Focusing on What You Can Influence

You cannot control whether a seizure happens, but you can influence many things around it: how prepared you and the people around you are, your sleep habits, taking your medicine as prescribed, and who you reach out to for support. Having a seizure is not a sign that you failed or did something wrong.

Building Support

Connection can help many people feel less alone, whether that is one trusted person who knows your plan, a local support group, or an online community. Community can offer connection, but it does not guarantee less fear and it does not replace mental health care. Consider building your support network before you need it.

Lifestyle and Nutrition

There is no single diet or lifestyle plan that fits every person with Epilepsy. General healthy habits, such as regular sleep, regular meals, drinking fluids, and staying active, support overall health. Please discuss significant changes with your healthcare provider before making them.

Fluids. Drinking fluids regularly through the day is a good general health habit. Some people notice that illness or dehydration affects them [13], but this is individual. Alcohol and other substances can be triggers for some people [6], so ask your healthcare team what is right for you.

Sleep. A calm wind-down routine, such as dimmer lights, a cooler room, and less screen time, helps some people sleep. See Rest and Sleep above.

Regular meals. Regular meals with a mix of protein, healthy fats, and complex carbohydrates are part of healthy eating for anyone. Ordinary changes from one meal to the next are not known to cause seizures in everyone with Epilepsy. Significant medical problems with blood sugar are a different matter, so ask your healthcare team if you have concerns, especially if you also have diabetes.

Dietary therapies. You may have heard of the ketogenic diet and similar dietary therapies. These are treatments prescribed and monitored by a specialized care team for certain people [1]. They are not general eating advice and are not something to start on your own.

Gradual changes. Sudden, large changes to diet, sleep, or routine can be hard to sustain. Gradual changes, made with your healthcare team's input, are usually easier.

Supplements. Ask your healthcare professional whether testing or supplements are appropriate for you [16]. Supplements are not a general treatment for Epilepsy and should not replace prescribed medicine [16].

Seizure First Aid

> **In an emergency:** go straight to **When to Call 911** on page 11.

Most seizures last just a few minutes and do not usually need emergency medical attention [5]. Knowing a few steps can help you keep someone safe. Share this page with the people around you.

If someone is having a seizure [5]

- Stay calm and keep others calm.
- Stay with the person.
- Remove anything nearby that could cause an injury.
- Check for a medical bracelet or necklace with information about medical conditions, medicines, and emergency contacts.
- If the person is lying down, gently turn them onto their side, with their mouth pointing toward the ground, to keep the airway clear.
- Time the seizure.
- When it ends, help them sit in a safe place to recover. Once they are alert, comfort them and explain what happened.

If the person is falling, shaking, or jerking [5]

- Ease them to the ground if they appear to be falling.
- Turn them gently onto one side, with their mouth pointing to the ground.
- Clear the space around them.
- Put something soft and flat under their head, such as a jacket.
- Take off their eyeglasses.
- Loosen anything around the neck that could block breathing.
- Time the seizure.

What not to do [5]

- Do not hold the person down or stop their movements. This could injure you or them.
- Do not put anything in their mouth. This can hurt their teeth or jaw. A person cannot swallow their tongue during a seizure [8].
- Do not give mouth-to-mouth breaths during the seizure. People usually start breathing again on their own afterward.
- Do not offer food or water until they are fully alert.

WHEN TO CALL 911

Call 911 if one or more of these happens [5]:

- The seizure lasts longer than 5 minutes.
- Another seizure starts soon after the first.
- The person has trouble breathing or waking up after the seizure.
- The person is injured during the seizure.
- The seizure happens in water.
- The person has never had a seizure before.
- The person has diabetes and loses consciousness.
- The person is pregnant.

If the person has an individual seizure action plan that calls for earlier action, follow it.

After the Seizure

People may feel tired or confused after a seizure [1][11]. When the seizure is over, help the person sit in a safe place to recover. Once they are alert, comfort them and explain what happened. Offer to call a friend or loved one to help them get home safely [5]. Call 911 if the person has trouble breathing or waking up after the seizure [5].

If the person has a seizure action plan, follow it. The plan is made with the person's healthcare team and their family, which may include a caregiver such as a parent or guardian who may need to use it. If the plan includes a prescribed rescue medicine, anyone who may need to give it should be trained to use it and follow the healthcare provider's instructions. The plan will say when to give it [12]. If there is no plan yet, ask the healthcare team about creating one.

Your Next Step: Havenway Quest

You do not have to navigate this alone. If this guide has been helpful, it is only the beginning of what Havenway offers.

Havenway Quest is an eight-week program of live small-group coaching. It is led by Courtney, Havenway's founder, who brings a psychology background, a holistic health certification, and a lifetime of lived experience with Epilepsy.

Quest members receive:

- **Havenway Compass**, a reflective workbook that supports emotional needs while navigating life with Epilepsy, for both people with Epilepsy and their caregivers.
- **Havenway Bridges**, communication guides on talking with others about Epilepsy and the needs that go with it. The guides cover school and work, setting boundaries, your medical team, and personal and romantic relationships.
- **Havenway Connections**, a virtual community included with Quest. Members get two months of access.

After those two months, members may choose to continue in the community through an optional paid monthly membership.

Havenway Quest is educational coaching. It does not replace care from your healthcare team.

> **Learn more:** Join the free Living Confidently With Epilepsy webinar: havenway.net/living-confidently-with-epilepsy

Visit www.Havenway.net and follow Havenway for updates.

Sources and Further Reading

Source information was reviewed in November 2026. Laws, guidance, and recommendations can change, so please check with your healthcare team and the organizations below for the most current information.

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