HAVENWAY

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

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This revised guide follows the original Havenway structure while adding a clear contents page, page numbering on every page, and an updated invitation to join the Havenway cohort.

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The final page includes an updated call to action directing readers to learn more and join through www.havenway.com.

Welcome to Havenway

> *You have taken a meaningful step simply by being here. Whether you are newly diagnosed, have been living 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. With the right tools, the right knowledge, and the right support, you can move through life with clarity and confidence, even on the hard days.*

A note before you begin

> **NOTE** This guide is intended for educational purposes only and does not constitute medical advice, diagnosis, or treatment. Every person's experience with epilepsy is unique. Please consult your healthcare provider for guidance specific to your situation.

What you will find in this guide

- Clear, compassionate explanations of what epilepsy is and how it affects daily life
- Practical language for telling others about your condition
- Tools for identifying and managing your personal triggers
- Grounding strategies to reduce stress and support your nervous system
- Guidance for working with your medical team more effectively
- Emotional support for navigating fear, uncertainty, and everyday life
- Lifestyle and nutrition considerations to support your overall wellbeing
- Seizure emergency basics every person around you should know

What Is Epilepsy?

Epilepsy is a neurological condition characterized by recurring, unprovoked seizures. It occurs when there is a disruption in the normal electrical activity of the brain, causing temporary changes in movement, sensation, behavior, or awareness.

It is one of the most common neurological disorders in the world, affecting people of all ages, backgrounds, and walks of life. Having epilepsy does not define your intelligence, your character, or your potential.

Understanding Seizures

Seizures are the primary symptom of epilepsy, but they look different from person to person. Not all seizures involve convulsions or loss of consciousness. Some people experience a brief staring spell, a sudden jerk of a limb, a strange sensation, or a period of confusion lasting only seconds.

- Focal seizures: These begin in one area of the brain. A person may remain aware or may experience altered awareness during the seizure.
- Generalized seizures: These involve both sides of the brain from the start and often result in loss of consciousness or the more recognizable convulsive movements.

What Epilepsy Is Not

- Epilepsy is not contagious.
- Epilepsy is not a mental illness.
- Epilepsy is not caused by something you did wrong.
- Having epilepsy does not mean your condition will never improve.

Many people with epilepsy live full, rich, independent lives. With the right treatment and support, seizure freedom is a realistic goal for a significant number of individuals.

How to Discuss Epilepsy with Others

One of the most challenging aspects of living with epilepsy is not always the condition itself — it is the conversations around it. Knowing what to say, and how to say it, can reduce anxiety, build understanding, and strengthen your relationships.

There is no single right way to disclose your epilepsy. You get to decide what to share, with whom, and when. The goal of this section is to give you language that feels natural, clear, and empowering.

At Work

Disclosing epilepsy in the workplace is a personal decision. You are not obligated to share your diagnosis, though in some situations it may support your safety or help you access accommodations.

If you need specific accommodations, you might say:

- "I have a medical condition that sometimes causes seizures. I'd appreciate it if you could familiarize yourself with basic seizure first aid, which I can provide."
- "I may need occasional flexibility with my schedule for medical appointments. How can we best manage that?"
- "During certain tasks, I find it helpful to take short, regular breaks to manage fatigue. Is there a way to incorporate that into my workflow."

At School (for parents or students)

Teachers and school staff benefit from knowing what to look for and how to respond. Being direct and clear protects your child and creates a more supportive environment.

With Family and Friends

The people closest to you want to help, but they may not know how. Giving them simple, specific guidance removes their fear and helps them feel useful.

> **TIP** 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 anything that makes a seizure more likely to occur. Triggers do not cause epilepsy, but they can lower the threshold at which a seizure happens. Understanding your personal triggers is one of the most empowering things you can do for yourself.

Common Triggers to Be Aware Of

- Sleep deprivation or disrupted sleep schedule
- High levels of stress or anxiety
- Dehydration or not eating regularly
- Missed or inconsistent medication
- Alcohol or recreational substances
- Hormonal fluctuations (particularly for women)
- Illness, fever, or physical exhaustion
- Photosensitive triggers such as flashing lights (for those with photosensitive epilepsy)
- Overheating or extreme temperature changes

Tracking Your Triggers

A seizure diary is one of the most useful tools available to you. By recording when seizures occur and the circumstances surrounding them — your sleep, stress level, what you ate, your activities — patterns often emerge over time.

You can track this in a notebook, a notes app on your phone, or a dedicated seizure-tracking app. Bring this information to your medical appointments. It is genuinely valuable data for your care team.

> **TIP** Questions to ask yourself after a seizure: How did I sleep last night? Have I been drinking enough water? Was I under unusual stress? Did I take my medication on time?

Stress Reduction Techniques

Stress is one of the most commonly reported seizure triggers. This is not a personal failing — it is a physiological reality. When your nervous system is under chronic strain, your brain's threshold for unusual electrical activity decreases.

The practices below are not about eliminating stress entirely. They are about giving your nervous system regular opportunities to reset. Consistency matters far more than perfection.

Breathing Exercises

Slow, intentional breathing activates the parasympathetic nervous system — the body's natural "rest and recover" mode. Try the 4-7-8 technique: inhale for four counts, hold for seven, exhale slowly for eight. Even three cycles can shift your state.

Routine Building

The brain and nervous system are soothed by predictability. Waking and sleeping at consistent times, eating at regular intervals, and building gentle rituals into your day creates a sense of stability that extends inward.

Journaling

Writing is a way of processing emotions before they accumulate as tension. You do not need to write extensively — even five minutes of free writing each morning or evening can serve as an emotional release valve.

Gentle Movement

Walking, stretching, yoga, and swimming are all forms of movement that support the nervous system without overstimulating it. Always discuss activity recommendations with your neurologist, especially around contact sports or water safety.

Rest as Medicine

Rest is not laziness. For people with epilepsy, protecting sleep and allowing the body genuine downtime is a form of self-care that directly supports brain health. Prioritize it without guilt.

Communicating with Your Doctor

Your neurologist or epileptologist is your most important partner in managing epilepsy. The quality of that relationship — and the information you bring to it — can meaningfully affect your care.

Many people feel rushed during appointments, uncertain what to ask, or reluctant to speak up if something does not feel right. This section is here to help you walk in prepared.

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 medication?
- Are there lifestyle adjustments that could support my treatment plan?
- What are the potential side effects of my medication, and what should I watch for?
- When should I consider seeking a second opinion or specialist referral?
- What does seizure freedom look like for someone in my situation?

Tracking Symptoms Between Appointments

Between visits, keep a record of any changes: new or different seizure activity, medication side effects, mood shifts, cognitive changes, or sleep disruptions. This log becomes the foundation of a productive appointment.

If possible, share your seizure diary entries with your doctor. The patterns you notice between visits are data your doctor cannot access any other way.

Managing Fear & Emotional Concerns

It would be unusual not to feel afraid when navigating epilepsy. Fear of the next seizure, fear of what others will think, fear about independence, relationships, and the future — these are all entirely natural responses to an uncertain situation.

Acknowledging fear is not weakness. It is the starting point for moving through it.

Normalizing the Emotional Experience

Anxiety and depression are significantly more common in people with epilepsy than in the general population — not because of personal weakness, but because of the very real emotional weight of living with an unpredictable condition. If you are struggling emotionally, you are not alone, and support is available.

Grief is also a natural part of the epilepsy experience. You may grieve a version of your life that feels changed, freedoms you have had to reconsider, or simply the certainty you had before your diagnosis. This grief deserves space and compassion.

Focusing on What You Can Control

One of the most grounding practices for epilepsy-related anxiety is consistently returning attention to what is within your influence: your sleep, your medication adherence, your stress practices, your nutrition, and the support you reach out for.

> **TIP** You cannot control whether a seizure will happen. You can control how prepared and supported you are if one does.

Building a Support System

Isolation amplifies fear. Connection and community reduce it. Whether that is one trusted person who knows your plan, a local support group, or an online community, having people in your corner changes the experience of living with epilepsy.

> **TIP** Do not wait until you are in crisis to build your support network. Begin now, in the calm spaces between difficult moments.

Lifestyle & Nutrition Considerations

There is no single diet or lifestyle prescription that applies to every person with epilepsy. However, there are consistent patterns in the evidence and in lived experience that suggest how we eat, sleep, move, and structure our days does matter.

The recommendations below are general and educational. Always discuss significant dietary or lifestyle changes with your healthcare provider before making them.

Hydration

Dehydration can affect brain function and is linked to increased seizure risk in some individuals. Aim for consistent fluid intake throughout the day rather than drinking large amounts at once. Limit alcohol, which disrupts both hydration and sleep.

Sleep Consistency

Sleep deprivation is among the most widely reported seizure triggers. Aim for a consistent bedtime and wake time, even on weekends. Create a wind-down routine that signals to your nervous system that rest is coming: dim lights, quiet, cool temperatures, and reduced screen exposure.

Balanced Nutrition

Regular meals that include adequate protein, healthy fats, and complex carbohydrates help stabilize blood sugar, which in turn supports more stable brain function. Skipping meals or dramatic swings in blood sugar can be destabilizing for some people with epilepsy.

You may have heard of the ketogenic diet as a treatment for certain epilepsy types. This is a medically supervised approach, not a general recommendation, and should only be considered under the guidance of your epilepsy care team.

Avoiding Extremes

Extreme dietary changes, intense fasting, overexertion, or dramatic shifts in daily routine can stress the body in ways that may affect seizure threshold. Gradual, sustainable changes are almost always preferable to dramatic overhauls.

Adding Minerals back into the diet

Minerals can be lost due to the way we absorb our medications. This is true with epilepsy medications as well. It’s important to add minerals back into the diet to reduce seizure activity in part because of mineral loss. One practical option is a mineral supplement with many different mineral types in one pill or drink.

Seizure Emergency Basics

Every person in your life — family members, close friends, coworkers, teachers — benefits from knowing how to respond calmly and effectively if they witness a seizure. Share this page freely.

What to Do During a Seizure

- Stay calm. Your calm presence is genuinely helpful.
- Time the seizure. Note when it starts.
- Keep the person safe. Clear away any hard or sharp objects nearby.
- Gently turn them onto their side if possible, to keep their airway clear.
- Place something soft under their head.
- Stay with them until they are fully alert.

What Not to Do

- Do not restrain the person or hold them down.
- Do not put anything in their mouth. This is a myth — a person cannot swallow their tongue during a seizure.
- Do not give them food or water until they are fully conscious and oriented.
- Do not leave them alone.

After the Seizure

A period of confusion, fatigue, or disorientation after a seizure is completely normal. This is called the post-ictal phase. Speak calmly, reassure the person, and let them rest. Avoid overwhelming them with questions or stimulation right away.

If the person has a seizure action plan, follow it. If they do not, this is a good reminder to create one with their medical team.

You Do Not Have to Navigate This Alone

If this guide has been helpful, it is only the beginning of what Havenway offers. We created this resource because we believe education, community, and compassionate support can genuinely change the experience of living with epilepsy — for individuals and for families.

Join the Havenway Cohort

- In-depth educational modules covering seizure types, treatment options, and lifestyle strategies
- Live group sessions with a psychology-informed coach who understands epilepsy from the inside out
- Community access with others who genuinely understand your experience
- Practical tools, frameworks, and resources to help you build a life you feel confident in

Join the cohort today to learn more, explore upcoming enrollment details, and stay connected with Havenway resources and support.

www.havenway.com

Follow Havenway and stay connected for upcoming programs, cohort information, and supportive educational resources.