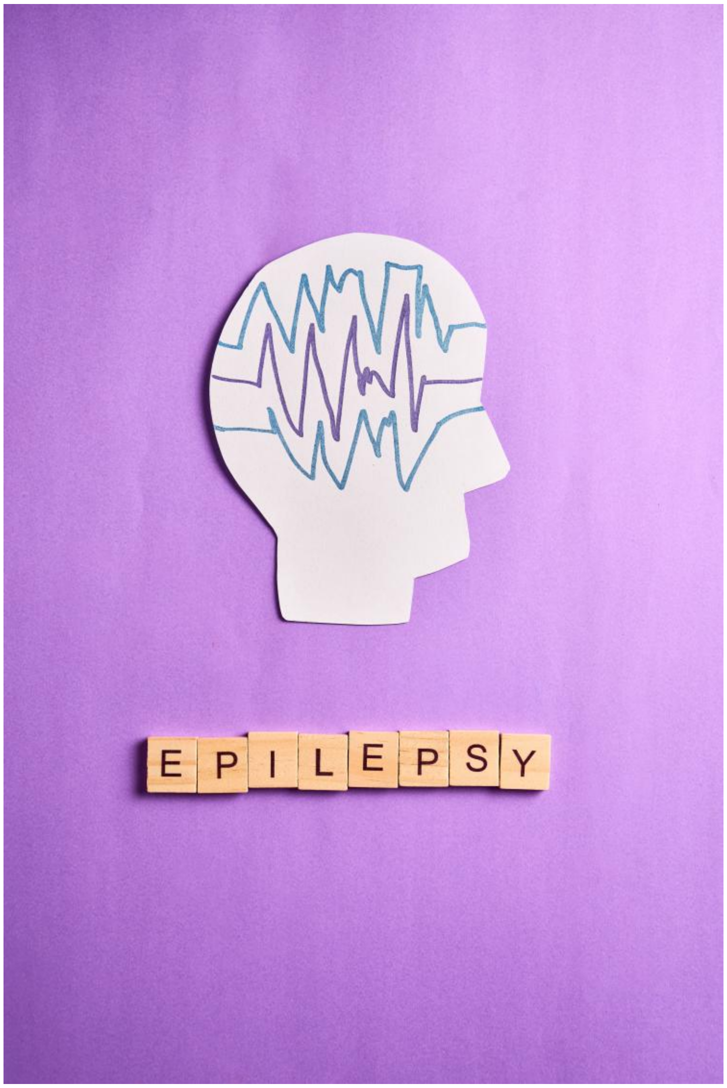
You Are Not Alone: A Guide for a New Epilepsy Diagnosis



EPILEPSY FOUNDATION
MICHIGAN

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We Are Here For You

If you or a loved one has been diagnosed with epilepsy, we want to begin by letting you know that you are not alone. It is natural to feel a whirlwind of emotions -- fear, uncertainty, desire for greater understanding, or even a mixture of them all. Everyone's journey with epilepsy shares some common experiences, yet each person's path is also uniquely their own.

This guide is designed to walk alongside you in these first steps. Our goal is to provide clear information, supportive resources, and a sense of companionship as you begin navigating this new chapter. The Epilepsy Foundation of Michigan is here to offer guidance, comfort, and care.

Epilepsy by the Numbers

Let's begin with some basics. Epilepsy is a condition that causes seizures, which can take many different forms. Some may look like brief moments of staring or unresponsiveness, while others may involve sudden movements or loss of awareness.

Seizures are more common than many people realize:

- 1 in 10 people will have a seizure at some point in their life.
- 1 in 26 people will be diagnosed with epilepsy during their lifetime.
- In Michigan, nearly 109,000 people live with active epilepsy.
- Epilepsy is the fourth most common neurological condition, after migraines, strokes, and Alzheimer's disease.

Knowing these numbers reminds us: You are not alone on this journey, and we work to ensure that no one faces epilepsy alone.

Getting to Know Epilepsy

Not everyone who experiences a seizure will be diagnosed with epilepsy. A diagnosis usually comes after two or more seizures, or after one seizure with a strong likelihood of more to follow.Seizures are categorized by where they begin in the brain. Understanding this helps doctors recommend the best treatment options.

Types of seizures include:

- **Generalized seizures:** Affect both sides of the brain. These may cause loss of consciousness, convulsions (shaking), or stiffness.
    - *Tonic-clonic seizures* (previously called grand mal seizures) involve shaking and loss of awareness.
    - *Absence seizures* (previously called petit mal seizures) are shorter and may look like brief staring spells.
- **Focal seizures:** Begin in one area of the brain and may cause sensations, movements, or changes in awareness. These can include unusual sounds, movements, or even walking or speaking unexpectedly.

- **Other seizure types:**
    - *Myoclonic seizures* involve quick jerks or twitches.
    - *Atonic seizures* cause sudden loss of muscle control.
    - *Tonic seizures* involve sudden stiffness.
    - *Clonic seizures* cause repeated shaking of part of the body.

There is also a type of seizure known as **functional seizures**, or **psychogenic non-epileptic seizures (PNES)**. These are not caused by electrical activity in the brain but may look and feel similar to epileptic seizures.

With more than 30 types of seizures and 60 types of epilepsy, experiences can vary widely. Whatever your seizures look like, know that they are valid and part of your unique journey.

Documenting what happens for you or what others might witness, before, during, and after a seizure can be helpful information for doctors to determine where seizures are occurring in your brain.

What Causes Seizures?

Epilepsy can have many causes, including genetics, brain injuries, infections, developmental conditions, or tumors. For some people, seizures are triggered by factors such as sleep deprivation, stress, certain medications, or flashing lights.

It's important to remember that not everyone has identifiable triggers, and only about 3% of people with epilepsy are sensitive to flashing lights. Keeping a seizure diary can help you and your doctor identify possible patterns or triggers.

How Is Epilepsy Diagnosed?

If you suspect epilepsy, seeking medical care promptly is important. Early diagnosis and treatment can improve quality of life and reduce risks.

Epilepsy affects the neurological system and the first specialist most people see is a neurologist, someone whose training focuses on the neurological system. For some people, this level of care is sufficient to control their seizures. However, if you've tried two or more medications, have medication side-effects, are pregnant or have other complicated issues, then seeking an epileptologist – a neurologist who has additional specialized training caring for patients with epilepsy – may be the right choice for you.

A doctor will review your history, perform a physical and neurological exam, and may order tests such as:

- **Electroencephalogram (EEG):** Records brain waves.
- **Magnetic Resonance Imaging (MRI):** Provides images of the brain.
- **Blood tests:** Rule out other causes.

The specialist—either a neurologist or epileptologist—can bring all of your information together to give you a clear diagnosis and treatment plan.

Navigating the Emotional Journey

Receiving a diagnosis can stir up many emotions. It's common to feel shocked, frightened, frustrated, or even relieved to finally have answers.

Common emotions include:

- Fear of the unknown.
- Anxiety about future seizures.
- Frustration about lifestyle changes.
- Concerns about stigma or misunderstanding.

Each of these responses is natural. Education can help reduce uncertainty, and support can ease the weight of these feelings. The Epilepsy Foundation of Michigan offers resources, conferences, and support groups where you can connect with others who understand. You may also benefit from speaking with a mental health professional.

Building Your Toolkit

Developing strategies to cope with stress and manage daily life can make a meaningful difference. Your toolkit might include:

- Mindfulness or breathing exercises.
- Physical activity, even gentle movement.
- Journaling or creative outlets.
- Support from family, friends, or professionals.

The key is to explore and find what works for you. And remember—it's okay to ask for help. You don't have to navigate this journey on your own.

You Have a Team

You are not alone in managing epilepsy. Your family, friends, healthcare providers, and the Epilepsy Foundation of Michigan form a circle of support. Each plays an important role:

- **Family and friends:** Offer care, encouragement, and practical help.
- **Healthcare professionals:** Provide expertise in treatment and care.
- **The Foundation and support groups:** Connect you with others living with epilepsy, reducing isolation and building community.

You may also find helpful information online through trusted sources such as non-profit organizations, hospitals, universities, and government research. Reliable information empowers you to make informed decisions.

Taking Charge of Your Treatment

Your treatment plan is your pathway forward. It may include:

- **Medication:** Following prescriptions carefully and reporting side effects.
- **Lifestyle adjustments:** Prioritizing sleep, reducing stress, and adopting healthy habits.
- **Complementary approaches:** Exploring therapies like yoga, acupuncture, or specialized diets (with medical guidance).

Work closely with your healthcare team to find the right balance for your needs.

Safety First

Safety is a key part of living with epilepsy. Some helpful steps include:

- Making your home environment safer by padding sharp corners and securing furniture.
- Wearing a medical ID bracelet or carrying emergency information.
- Creating a Seizure Action Plan and sharing it with loved ones.
- Educating others on how to respond: stay calm, move the person to safety, turn them on their side, time the seizure, and stay until it ends.

Seek emergency help if a seizure lasts longer than five minutes, seizures occur back-to-back, or injury or complications arise.

Living Fully with Epilepsy

Epilepsy may shape your story, but it does not define you. You can:

- **Educate others:** Reduce stigma and build understanding.
- **Advocate:** Assert your rights and seek supportive environments.
- **Pursue goals:** Continue to dream, achieve, and celebrate accomplishments.
- **Maintain perspective:** Focus on strengths and nurture resilience.

With the right support and resources, life with epilepsy can still be full of joy, meaning, and purpose.

Checking In and Adjusting Along the Way

Epilepsy is a journey that changes over time. Keep track of seizures, attend regular medical appointments, and adjust your treatment plan as needed. Celebrate milestones, whether large or small, and acknowledge your resilience along the way.

You Are Not Alone

As you move forward, remember this truth: you are not alone. The Epilepsy Foundation of Michigan is here to walk alongside you, offering resources, community, and care. Together, we will help you face challenges, find support, and live life to the fullest.

Contact Us

The Foundation is here to support you through every step of your epilepsy journey. You can reach us through our Here for You Helpline, (800) 377-6226, or visit our website www.epilepsymichigan.org.