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# Chapter 1

# Making Sense of Epilepsy

**E**pilepsy is a condition that affects the brain — the most intricate organ we have — and no two people experience epilepsy in the same way. Causes, symptoms, treatments, and outcomes can vary widely, which can make the condition feel unpredictable and overwhelming.

This chapter offers a roadmap to help you make sense of it all for yourself or people you care for. You find out about what seizures are, what epilepsy is, and how it can begin at any age. The chapter also tells you what treatment options look like and why so many people who receive a diagnosis of epilepsy go on to lead full, active lives. Most importantly, you discover that you're not alone.

## Seeing the Many Sides of Epilepsy

Saying “I have epilepsy” doesn't tell your listener much because epilepsy is so different from one person to the next. Some people have seizures so mild that they can carry on a conversation during a seizure, and no one even notices. Others have seizures so intense that they fall to the ground and convulse. And there are hundreds of variations in between those extremes.

The official definition of *epilepsy* is a medical condition in which the brain has a tendency to experience unprovoked, repeated seizures. But what does that really mean?

Here's a breakdown of the definition:

- » **Medical condition:** A disease, illness, or disorder that affects the functioning of the brain or other parts of the body and that requires medical care
- » **Tendency:** Something that's likely to happen again
- » **Unprovoked:** Not caused by something transient and identifiable, such as a high fever or head injury
- » **Repeated:** Involves more than one seizure — not a single event
- » **Seizure:** A sudden burst of abnormal electrical activity in the brain that disrupts normal brain function

## Unpacking what seizures are

Seizures happen when neurons in your brain fire in a sudden, storm-like burst. That uncontrolled activity interrupts normal brain function. Doctors group seizures into two main types:

- » **Generalized:** These seizures involve both sides of the brain from the beginning of the seizure. By *sides*, we mean both halves of the brain — the left and right *hemispheres*. (We give you the big picture of brain anatomy in Chapter 5.) Because generalized seizures affect so much of the brain, people are typically unaware of what's happening and don't have control over their bodies during the seizure. They may suddenly drop to the floor and shake, and most people don't remember the seizure afterward. Six subtypes of generalized seizures exist.
- » **Focal:** These seizures start in one small area of the brain called the *seizure focus*. What you feel or do depends on where that spot is. The three kinds of focal seizures cause different experiences for the person who has them.
  - In some, you are fully aware of what's going on around you, but you have a weird sensation that is not "real," such as smelling burnt rubber even when nothing is burning.
  - Another type of focal seizure can make you confused, less aware of what's going on, and unable to respond to people.
  - In the third kind, seizures can spread to other brain areas and become generalized seizures.

In addition to seizure types, epilepsy syndromes also exist, and we explain more about seizure types and syndromes in Chapter 7. Understanding the type of seizure or syndrome you're dealing with is your doctor's first step in figuring out the correct medical treatment. The "Understanding Treatment Possibilities" section later in this chapter explains more.

## Discovering who gets epilepsy and why



REMEMBER

Around 50 million people around the world have epilepsy. Anyone can get it — the cashier at the grocery store, a newborn, or an Olympic athlete. Even doctors get epilepsy. While epilepsy can begin at any time, children under two years of age or adults over 65 years of age are the most likely to be newly diagnosed. In many lower-income countries, people are more likely to develop epilepsy from preventable causes, such as malaria, head injuries, or birth complications.

People are born with epilepsy or acquire it for many reasons:

- » **Genetic:** Close to 1,000 genes may be connected to epilepsy. Some mutations directly cause seizures, while others just increase your risk. Epilepsy can often run in families.
- » **Structural:** Areas of the brain that developed unusually, scar tissue, or abnormal blood vessels can cause epilepsy.
- » **Acquired:** Anything that damages the brain can cause epilepsy, including complications during birth, traumatic brain injuries, brain infections (such as meningitis), tumors, or strokes.

## Attitudes toward epilepsy

For much of history, seizures were misunderstood as signs of demonic possession or madness. Unfortunately, myths and misconceptions about what epilepsy is have been around ever since people have had epilepsy. Which is forever.

But today, more people feel comfortable talking openly about their seizures, and public understanding that epilepsy is just another medical condition is growing. Unfortunately, about half of people living with epilepsy still feel judged, excluded, or treated unfairly. That stigma can sometimes take as much of a toll on a person's mental and physical health as the seizures themselves. See Chapter 4 for more information about the myths and stigmas surrounding epilepsy.

# Getting a Diagnosis

Many people understand the feeling of avoidance — when they don't want to listen to the voice in their heads telling them that something's wrong. But when it comes to epilepsy, ignoring that voice and waiting to take action can make the situation worse in the long run.



REMEMBER

The sooner you trust your instincts and get the symptoms you notice checked out, the sooner you can either stop worrying or take steps to get the care you need. Here's what's involved:

- » **Start with your primary doctor:** Tell them what's going on and ask for a referral to a neurologist who could help you figure out what's happening.
- » **Get ready for your first visit:** Gather your medical records, write down details about any suspected seizures, and keep track of any other unusual symptoms, even if they seem hard to explain.
- » **Prepare to share:** At your first visit, the neurologist asks about your family history, reviews your medical history and records, examines you, and talks through suspected seizures and triggers.

To confirm a diagnosis, your doctor may order follow-up tests such as an EEG or a brain scan. We explain what to expect from follow-up testing in Chapter 8.

# Understanding Treatment Possibilities

A century ago, treatment options for epilepsy were limited to a drug or two that had serious side effects and didn't work particularly well. Today, you have dozens of medications to choose from, as well as surgical procedures, devices that act like pacemakers for the brain, and therapeutic diets. In Part 3, we walk you through these treatment options in detail.

## Medication: The first line of defense



REMEMBER

As you find out in Chapter 10, for most people who have epilepsy, treatment with medication is the best place to start. That's because around seven out of ten people can get complete seizure control from medication alone.

Here are a few facts about antiseizure medications:

- » **How they work:** Antiseizure medications help by calming the brain's electrical activity in different ways. They make neurons less likely to fire out of control.
- » **How doctors choose:** No one-size-fits-all “pill” exists, so doctors take various factors into account when choosing your medication. They first consider what type of seizure you have, then factor in your age, any other medical conditions, and medications you're already taking. They also consider possible side effects and how well you're likely to tolerate them.
- » **What side effects they have:** Like any medication, antiseizure medications can cause side effects, such as feeling tired, dizzy, or slow. Pay attention to how you feel and let your doctor know. Some side effects can be serious, so always tell your doctor if you experience anything out of the ordinary.
- » **What form medications take:** Most antiseizure medications come in tablets, capsules, or liquids in a variety of strengths. You take some medications once a day, but you take others more frequently.



TIP

Finding the right medication can take time. Doctors often use a trial-and-error approach to figure out what works best. You may need to try more than one medication or use a combination of medications before getting seizures under control. So if the first attempt doesn't work, don't give up hope.

## Brain surgery

For about one-third of people with epilepsy, medication alone doesn't fully control their seizures. For them, surgery may be a life-changing option. While the idea of brain surgery that removes the brain area causing seizures can be daunting, for carefully selected candidates, it can dramatically reduce or even eliminate seizures.

Having surgery involves a major decision. Reaching the point where you know clearly that surgery is the right option takes time and careful evaluation. As we describe further in Chapter 11, here's how that process unfolds:

- » **Evaluating whether you're a candidate for surgery:** The first step in your evaluation involves a stay in the hospital, which often lasts several days but sometimes as long as a couple of weeks. During this hospital stay, medical professionals monitor you around the clock with video cameras and EEGs so they can match up what your seizures look like with what's going on inside your brain.

Doctors may also order imaging tests such as MRIs, and you may go through neuropsychological testing to find out how your brain is functioning. And even more tests are possible. This presurgical workup takes longer than the surgery itself. Many patients need invasive monitoring with electrodes placed inside the brain to pinpoint where the seizures are coming from before the medical team can decide whether to move forward with surgery.

» **Having and recovering from surgery:** After surgery, patients typically recover in the hospital for one to seven days and gradually return to normal activities soon after they go home. Patients follow up with their neurologist and surgeon to make sure they're healing well and to monitor how well the seizures are being controlled.

## Controlling brain waves

A less invasive surgical alternative — one that doesn't require removing brain tissue — is to smooth out brain activity. This type of treatment is called *neuromodulation*. Surgeons implant a device under the skin or in the skull that sends pulses of electrical signals into the brain. You can think of the device as a pacemaker for your brain.

Neuromodulation doesn't cure epilepsy, but it can make seizures much more manageable. Current examples of this treatment include vagus nerve stimulation (VNS), responsive neurostimulation (RNS), and deep-brain stimulation (DBS).

## Dietary therapy

It may sound too good to be true, but for some people, changing what they eat really does help control seizures. Unfortunately, the diets are usually not simple or easy to follow. If they were, dietary therapy would sometimes be the first treatment doctors try.



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The most well-known dietary therapy is the *ketogenic diet*, which involves drastically limiting carbohydrates so that your body enters a state called ketosis. This change in metabolism makes the brain less likely to have seizures. (You can find all the details of dietary therapy in Chapter 12.) To give you a sense of how rigid the diet is, most Americans eat around half a pound of carbs per day. On the classic ketogenic diet, you're limited to roughly half an ounce. The rest of your calories come from fat and protein.

Three restrictive versions of the diet are available. A modified version of the Atkins diet lets you eat slightly more carbs. The Low Glycemic Index Treatment allows more carbs, but only the carbs that don't raise blood sugar levels as much or as quickly.



REMEMBER

Tracking your meals and monitoring your overall health can be just as involved as managing epilepsy with antiseizure medications. Perhaps even more so. But for some people, these are powerful tools for seizure control. In rare cases, people's seizures go away completely.

## Living Well with Epilepsy

Preventing seizures is only part of the picture of dealing with epilepsy every day. Your doctor should keep in mind that they are treating a whole person, not just the seizures. For you, it's about finding balance — acknowledging that you have a brain condition that requires some adjustments while also remembering that you are much more than your diagnosis. You deserve a full and meaningful life, no matter what shape your epilepsy takes.

### Learning

Learning challenges associated with epilepsy are much more common in people who are diagnosed when they're young compared to people who don't start having seizures until they're adults. That happens for three main reasons:

- » A developing brain is more vulnerable to being disrupted by seizures than a fully developed one.
- » In many children, the underlying cause of their epilepsy, such as genetic conditions or brain malformations, can also affect their ability to learn.
- » Frequent daytime seizures or medication changes can also hamper the classroom learning experience.

As a result, many skills that children need for learning can suffer from the impact of epilepsy. These skills involve speech and language, memory, information-processing speed, social skills, and *executive function* (mental processes that support learning and everyday problem-solving skills). To find out more about what executive function is and why it's so foundational for learning, see Chapter 15.



TIP

If your child has epilepsy, keep an eye on how they learn and communicate and whether they may be struggling. Most developed countries have laws in place to make sure that all children have equal access to learning, which includes providing educational support when needed. For more on how that process works and the types of support available, see Chapter 16.

## Reducing the risk of having seizures

Seizures often occur for no apparent reason. But many seizures happen because of known triggers — situations or conditions that make a seizure more likely. In some cases, triggers can almost guarantee that you have one.



WARNING

Skipping doses of antiseizure medication or stopping it suddenly can trigger seizures, sometimes prolonged ones, or *status epilepticus*, which is a medical emergency. Stopping the ketogenic diet abruptly can trigger rebound seizures in some people. Being sick, under stress, or sleep-deprived can raise the risk, too.

On the flip side, healthy lifestyle choices can help reduce seizure risk. That means eating a nutritious, balanced diet, exercising regularly (which is good for your brain), and minimizing the use of alcohol and drugs that are illegal or not used as prescribed.

## Moderating the potential for danger

Everyday activities come with some risk, and although you can't avoid risk altogether, living with epilepsy means that certain situations — such as swimming — require extra caution. Major life changes, such as moving out of your childhood home, can also disrupt routines that help keep you safe.



TIP

Whether you've had epilepsy since childhood or were diagnosed as an adult, be proactive and ensure that the people you spend time with know how to help if you have a seizure. Sharing a seizure action plan — a document that includes what to do during a seizure, when to call for help, and any specific needs — can help keep you safe and give everyone confidence on how to respond. For more on creating a seizure action plan, see Chapter 17.

## Knowing That You're Not Alone

Even though epilepsy is common, you may still feel alone in dealing with it. You may not have met anyone else with epilepsy, or at least not someone who speaks openly about it. That silence can make the condition feel invisible. But the truth is, you're far from alone.

Connecting with a support group — whether online or in person — can make a world of difference in how you manage your condition. These supportive communities offer practical tips, encouragement, and the comfort of shared experiences. As you listen to others, learn from them, and share your own story, you

may find that helping someone else helps you, too. For more ideas about how to help others, turn to Chapter 21.



TIP

You can get started finding support with national organizations like the Epilepsy Foundation of America ([www.epilepsy.com](http://www.epilepsy.com)) or Epilepsy Action in the U.K. ([www.epilepsy.org.uk](http://www.epilepsy.org.uk)). They offer both in-person and virtual support groups, as well as calendars of local events and activities. Your doctor or local epilepsy organizations can also point you to groups that may meet your needs. If you want to jump right into finding support and discovering the many ways it can help you, check out Chapter 20.

You can find dozens of active groups on Facebook — some run by foundations, while others are run by people living with epilepsy or their caregivers. You find groups focused on specific types of epilepsy, unique needs (such as educational support), or various communities (such as caregivers, teens, or pregnant women with epilepsy). Many of these groups are private, so you need to request to join them.

Find the type of support and level of engagement that works for you. Reaching out can save you time, improve your emotional well-being, and connect you with practical advice — such as recommendations for doctors, news about clinical trials, or tips on navigating school support for your child.



REMEMBER

Support doesn't have to come only from people living in the world of epilepsy. Family, friends, coworkers, and neighbors can all be part of your support system, too.

