

Epilepsy Diagnosis and Treatment: A Guide for New Patients and Advocates



Figure 1: Purple Brain for Epilepsy

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Introduction

For an experience many people can't remember, the aftermath of your first seizure can be hard to forget. The fear and confusion of not knowing what happened or what comes next leaves many people feeling lost and isolated. You rely on doctors and other medical professionals to guide you, but in doing so, you lose control of your life and often your independence. Seizures already take away control, of your body and mind, so you should not also have to give away control of your treatment.

This guide was written to give new seizure patients control back. Starting on the journey of knowing and understanding your condition begins with the diagnosis. This guide walks you through everything you may experience in an epileptic's medical journey, from the people you will meet, to the tests you will take, to the treatments you will try, to how your everyday life will change. Diagnosis may take a few days to years depending on your situation, but since epilepsy is often a lifelong condition, learning about it early means you will feel empowered for years to come.

Advocates Included

Friends and family can learn from this guide as well. These purple boxes indicate tips and tricks for those who want to get more involved in a loved one's epilepsy journey. Advocates are an important part of a medical team to make sure the patient's voice and needs are heard, so read along and get involved!

What is Epilepsy?

Epilepsy is having at least two unprovoked seizures occurring more than 24 hours apart or being diagnosed with a specific epilepsy syndrome. If you have had only one seizure, you may not have epilepsy. If doctors find a reason behind your seizures, such as low blood sugar or a high fever, you may not have epilepsy. At the start though, epileptics and those who just have a seizure, do not have different medical experiences. **Seizures**, or **electrical**

misfiring of the brain, are treated with caution, so you will be treated the same whether you end up with an epilepsy diagnosis or another condition.

Empowering with Transparency

Depending on the circumstance of your first seizure, you may start your seizure or epilepsy journey in multiple ways. If your first seizure was dramatic, you may have been taken to a hospital. However, if you or your family have noticed episodes of unresponsive staring, twitching, or other strange symptoms, you might not know what to think until a doctor brings up seizures.

You could leave your medical decisions up to the professionals, who will let you know about the diagnosing process on a need-to-know basis. While this works for some, the fear and uncertainty that come with each new seizure mean you may not want to wait for the step-by-step approach.

Doctors rarely give you the whole picture since they do not want to worry you with worst case scenarios. However, if you know that is only one of many possibilities, it can be good to know where the road leads. You will not be disappointed if you get diagnosed and treated quicker after all. This guide focuses on the broad, general picture so you know where your journey may take you. The specifics on different disorders, medications, and seizure types are omitted so that you can find more in-depth, specific sources that apply to your personal circumstances.

This guide introduces:

- Different healthcare providers you may meet
- Strategies for describing seizures to your doctors
- Electroencephalograms, the most common seizure test
- Basic seizure classification
- Strategies for living with seizures
- Basic information on taking seizure medications
- Seizure-like diagnoses
- Other resources for continued learning

There is not a universal, direct path to diagnosing seizures and epilepsy, so feel free to go to the sections that will answer your most pressing questions first. From there you can decide where to go next in this guide, or to other resources for your further research into epilepsy.

Diagnosis and Treatment Flow Overview

The following is a visual representation of how epilepsy is diagnosed and treated with each layer continuing only if no seizures are caught on an **Electroencephalogram (EEG)**—the most common diagnostic test for seizures—and episodes continue despite treatment. The different types of doctors can order tests and treatment within their same level or the ones they are connected to in the next. Refer back to this image, as each element is expanded upon more later in this guide.

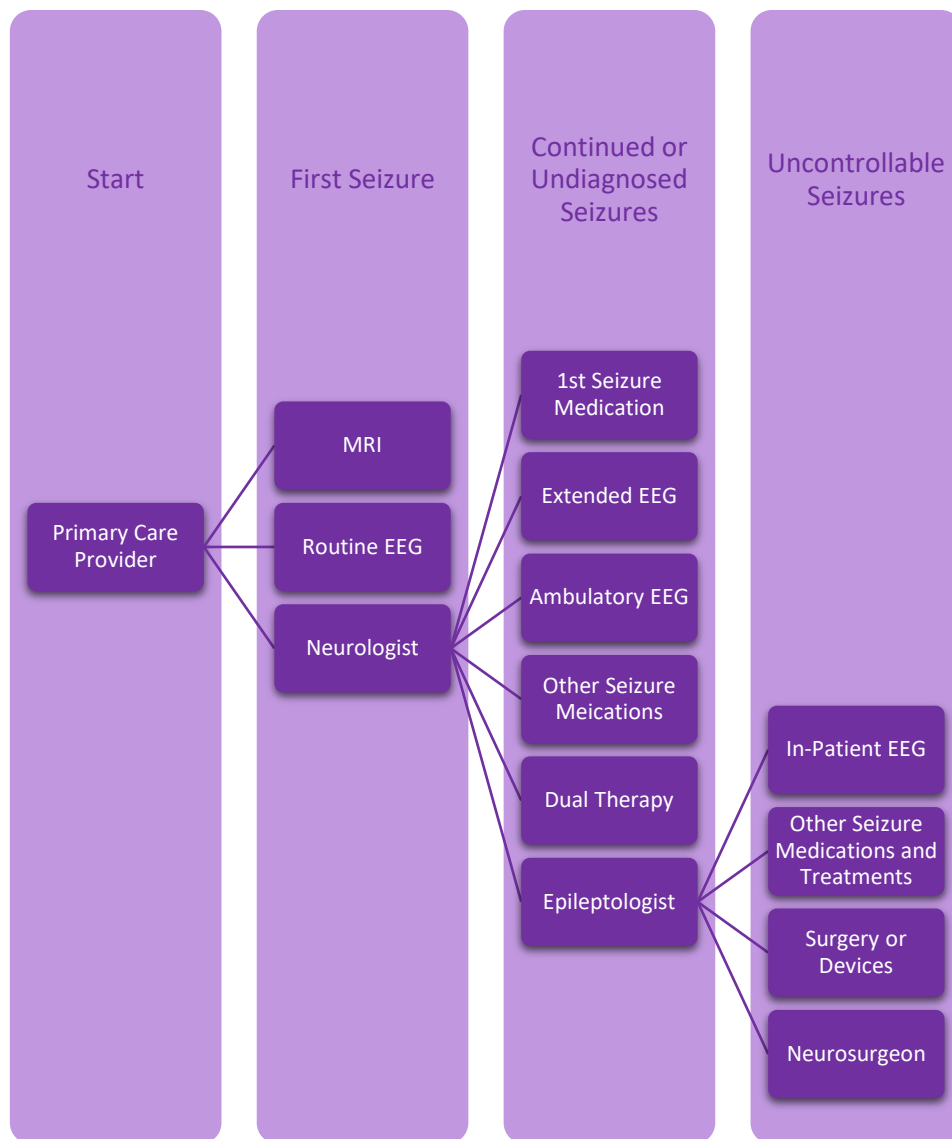


Figure 2: Epilepsy Diagnosis and Treatment Flow

Meeting your Healthcare Providers

There are many different types of medical professionals who will work with you on diagnosing your seizures. These people will make up and help you build your epilepsy care team. They may bring in others, such as dieticians or psychologists to help with your treatment, or simply treat your seizures themselves. Depending on how simple or complex your case is, you might meet one or all the following providers:

Primary Care Provider

It is always best to meet with your internist or family care doctor first when you have a health issue. It may seem like an extraneous step, but depending on your insurance, it may be necessary to see your primary care provider first to have insurance cover a specialist. Your PCP can order basic tests like a routine EEG or brain MRI while you are waiting to see a neurologist. Also, by talking to them first, they can direct you to specialists they know they can communicate and work with to provide you the best care.

Neurologist

Your primary care provider will most likely refer you to this specialty. Neurologists treat and diagnose conditions of the brain, spine, and nervous system. Along with seizures, they also treat strokes, neuropathy, headaches, and more.

Some neurologists have more familiarity with epilepsy than others. Some neurologist's offices may have a wait list to be seen, while others may be able to get you in within a week or two. Neurologists generally handle epilepsies controllable with one or two medications. If your seizures are difficult to control, your neurologist may refer you to an epileptologist.

Neurology and EEG Technician

This is a specially trained technician that specializes in EEGs and other neurologic tests. If you have many EEGs, you will probably meet many different technicians. They spend a considerable amount of time with you, setting up and running the EEG. As they often work closely with your neurologist or epileptologist, communicating with them can help keep your doctor informed.

Epileptologist

As a sub-specialist of neurology, epileptologists specifically deal with seizures and epileptic disorders. They often work with or in an epilepsy clinic, which can take months to get an appointment with after a referral. Epileptologists treat and manage seizures that are difficult to control and evade diagnosis. They have more specific knowledge about the different types of seizures and have tools and treatments for those types.

Epilepsy Nurse

These are specialized nurses who often work in epilepsy clinics. They will treat you if you are admitted for an in-patient EEG or for epilepsy surgery. Like all nurses, they are an important part of your healthcare team.

Neurosurgeon

If you consider surgery for treating your seizures, you will be referred to a surgeon who specialized in brain surgery. The surgeon will have to know where your seizures originate in the brain before they can suggest appropriate surgery, which can require extensive testing. Not every epileptic is eligible for surgery, but it is an option for some with uncontrollable seizures.

Describing Episodes

The most helpful thing you can bring to a doctor treating you for seizures is a description of your seizure or seizure-like episodes. You may not remember your own seizures, so it is important to collect this information from friends or family members who witnessed the seizure before your doctor's appointment.

Witnesses and Evidence

Family, friends, or bystanders can help you collect information if you cannot describe your seizures yourself. Witnesses can:

- Come with you to your appointment and answer questions directly.
- Write a detailed description you can bring with you to your appointment.
- Take a video of you during your episode that you can show your doctor.

***Advocate tip:** Taking a video of a loved one having a seizure may seem uncaring in the moment, but it will be helpful after the fact. If they are in a safe position or another person can provide adequate aid, try to remember to take a step back and record it so that they will have a detailed record that they can show to their doctor.*

Seizure Stages

To help you outline your description and for your personal understanding of your episodes, you can try to use the medical designations for different parts of seizures. Fitting what you are seeing and experiencing to this outline can help you to better understand what is happening to your body.

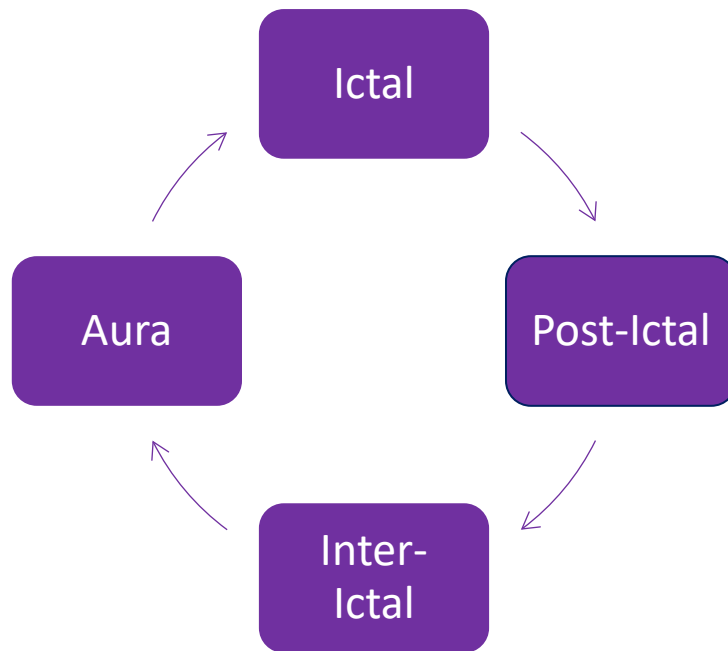


Figure 3: Seizure Stages

Aura

While not all seizure patients have one, you may have a warning that you are about to have a seizure. These sensations cannot be detected by a witness, but you may react predictably each time. **Auras** can manifest as a feeling of déjà vu, a bad smell, or simply an off feeling. If you do have an aura, let those around you know and try to get to a safe position. The specifics of the aura can help locate the source of the seizures, so note your sensations for your doctor.

Ictal

The **ictal phase** is the actual seizure 'event.' Seizures are varied, so they result in many different reactions. Typically, people recognize seizures with involuntary movements and loss of consciousness, but seizures can also cause less well-known symptoms like uncontrollable laughing or not being able to speak at all. Note any and all symptoms so a doctor can decipher whether the activity is seizure activity or another kind of neurologic condition.

It is also important to note the length of the episodes. Most seizures are shorter than 3 minutes. If a seizure is **over 5 minutes**, it is dangerous to your health. If your episodes are longer, **call 911 or go to a hospital.**

If you easily return to normal after long episodes, you may be experiencing something other than a seizure, but leave that up to doctors to decide. Reporting the duration of your episodes aids your doctor in reaching a correct diagnosis.

Post-Ictal

The ***Post-ictal phase*** is the aftermath of a seizure. You may be combative, confused, or exhausted. You may not remember your actions in this phase afterwards as your brain recovers from the seizure. Sometimes, witnesses believe this is part of the ictal phase. If they do not know for sure, make sure they note when your activity and demeanor changes.

Inter-Ictal

Often ***Inter-ictal events*** are “sub-clinical,” or without observable symptoms, but you may feel something like an aura without a full-fledged ictal event. These are small bursts of electrical energy that happen in-between seizures.

They can increase in frequency leading up to seizures or simply happen at random in between seizures. You may not have any at all, especially with the help of seizure medication. If you have no symptoms, you won't be able to report these yourself, but if you do have strange, reoccurring feelings in-between your episodes, let your doctor know.

Getting EEGs

Electroencephalograms, or **EEGs**, are the main test for diagnosing seizures. Brain MRIs are also commonly used but are only helpful if the seizures stem from structural issues in the brain. Since many seizures have no known cause, they cannot be identified and categorized by MRIs alone. An EEG is especially suited to identifying seizures.

Electroencephalograms record the electrical activity of the brain. They are commonly confused with EKGs, the more well-known test recording the electrical beat of the heart. An EEG, though, not only tests a different part of the body but is also more involved. There are often 20–30 or more electrodes attached to the scalp. Their signals are then translated electronically into 18 or more channels, comparing the electrical charge in different sections of the brain. Simply put, there are 18 or more lines squiggling across a screen, which doctors interpret as normal or abnormal brain signals.

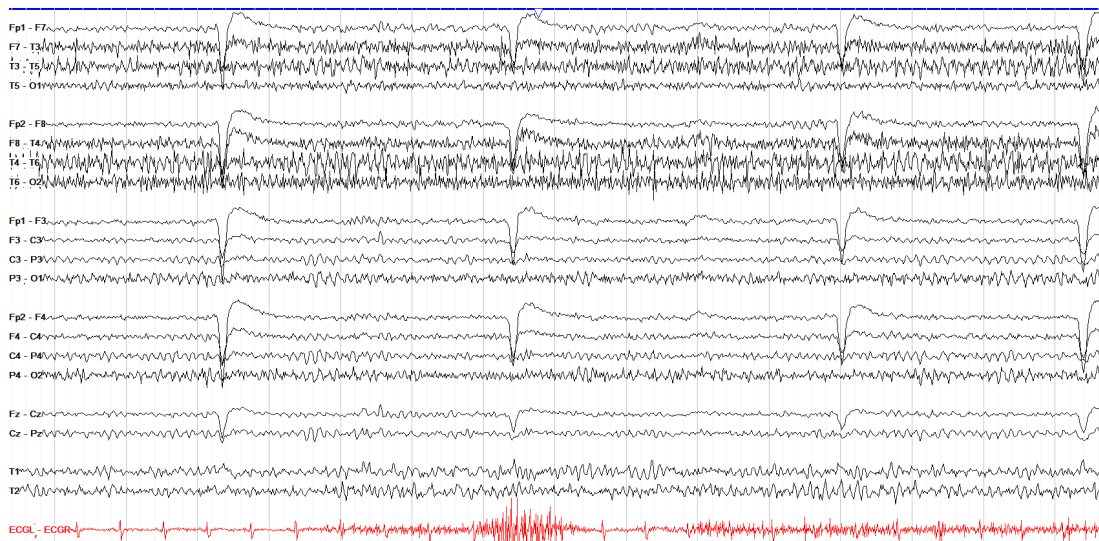


Figure 4: Normal Awake EEG

Note. By David Valentine, MD, 2020, from LearningEEG.com

Seizures are a sudden burst of electrical activity in the brain, which show as different abnormal patterns on the EEG.

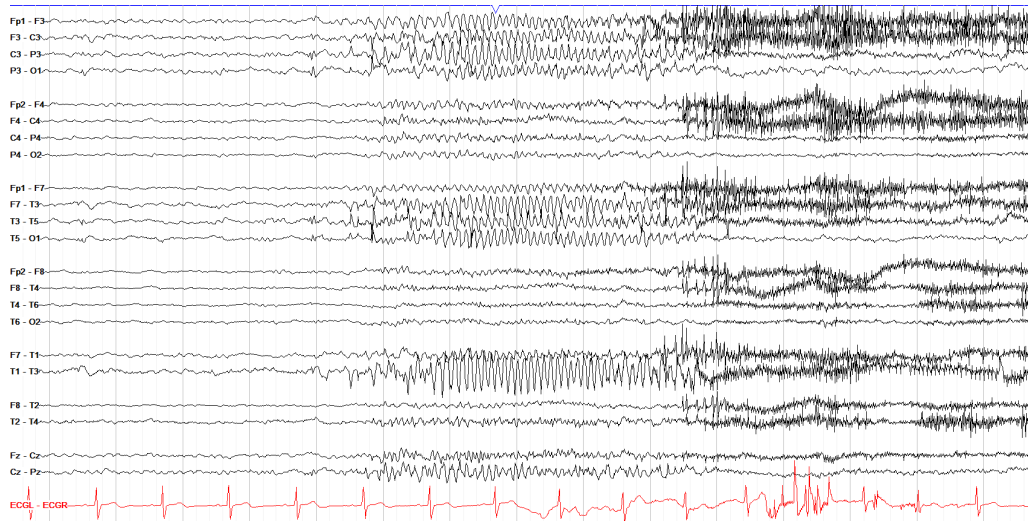


Figure 5: Partial Seizure on EEG

Note. By David Valentine, MD, 2020, from LearningEEG.com

EEGs are used almost exclusively for identifying seizures because there is no other way to accurately visualize seizure activity. Typical MRIs or CTs only show pictures of the brain which will not pick up those electrical bursts.

When seizures are suspected, an EEG will be the first test ordered by your doctor.

Why so many EEGs?

Odds are if you have epilepsy or suspected epilepsy, you will never get away with a single EEG. Even if you are diagnosed on your first EEG, doctors often order EEGs routinely to monitor your condition.

Many patients are not lucky enough to get diagnosed and treated with a single routine EEG. Most epileptics have normal EEGs in their lifetime.

When a doctor tells you your EEG came back 'normal' and then orders another one, it can be frustrating. You may be terrified of having another episode. You may be struggling with having them interrupt your daily life. However, that is the nature of an EEG, a test of activity. So, if the abnormal activity is not happening when the test is running, it will not be caught.

If you are struggling to understand, it may help to imagine this scenario:

Pretend you are trying to determine if a stranger is a jogger. You can't talk to this stranger, but it's important that you determine this information.

They are wearing gym clothes and sweating, so you could assume the person was jogging. However, they could also have been cycling, lifting weights, or exercising in other ways.

So, you try to ask other people who know the stranger what they witnessed the stranger doing. Then you could be more certain. A few people describe something similar to jogging or that sounds like jogging, but their descriptions are vague enough it could be running or walking. People have different definitions for jogging after all. Again, you could just assume the person is a jogger, but you will never be certain until you see them jog yourself.



Figure 6: Walking, Jogging, or Running?

Note. From Darebee retrieved March 9, 2023

In this analogy, jogging is seizure activity and the stranger is your brain. Your doctor cannot talk to your brain. While seeing someone run is quite easy, they cannot see your brain function either. An MRI shows a picture but not the activity. An EEG allows your doctor to observe your brain activity but only when EEG is recording. In the analogy, you could think of an EEG as special glasses that allow you to observe the stranger.

If you ever wonder why your doctor orders so many EEGs, it is because you cannot and do not want to be constantly wearing an EEG. Unfortunately, the easiest way to ensure answers

is to have a seizure while attached to an EEG, and nobody wants you to go through another seizure.

Types of EEGs

During your diagnosis and treatment process, you may have different types of EEGs, often increasing in length, changing the environment, or adding activities, which may increase your likelihood of seizures. Different facilities and doctors will run their EEGs differently, but in general, some preparations will be the same for all EEGs:

- Come with clean, dry hair with no products in it, like hair spray or hair gel.
- Be prepared to remove hair ornaments, earrings, wigs, hats, braids, or other decorations that may block your scalp.
- Plan what to do with your hair after the EEG as it will probably still contain gel, paste, cream or glue until washed. Consider:
 - Going straight home to wash it.
 - Bring a hat or scarf to cover it.
 - Bring a comb, a brush, or accessories to restyle it.

***Advocate tip:** Nobody enjoys getting medical tests, and EEGs can be particularly annoying because most feel self-conscious being in public with messy hair so you need to wash it. It can help to plan something to counteract the unpleasantness. This might mean bringing a hat or comb and going out to dinner, shopping, or another fun activity. Then everyone remembers the good time rather than the stress, annoyance, and discomfort from the EEG.*

Routine

The basic EEG which is often the “gateway” to other EEGs. Insurance companies require a routine EEG within a year before approving more extensive EEG tests.

Duration: 20–25 minutes while being monitored by a technician. Setup can add an additional 20–40 minutes (for all EEG types).

Setting: Office or home

Electrodes are attached with easy to remove adhesives, like paste and gel.

Additions

Hyperventilation: a technician will instruct you to breathe heavily for 3 minutes. This is used to simulate exercise or exertion. You may feel light-headed, have a dry mouth, or feel dizzy, as a normal reaction.

Photic Stimulation: a bright flashing light will cycle through different frequencies. You will be instructed to keep your eyes closed while the light is flashing, but you will still see it through your eyelids. You may see different colors in the flashing or feel uneasy. Both are normal reactions.

Clicker: you may be given a device to repeat a pattern of clicks performed by the technician sometime during the test. This activity tests your cognition during that specific instance, so try to repeat the pattern as soon as you hear it.

Long

Extended EEGs are the same as routine EEGs, but increase the duration. Increasing the time increases the probability of catching epileptic forms if they are present.

Duration: 45 minutes to 2 hours or more, depending on the facility.

Setting: Office or home

Electrodes are attached with use easy to remove adhesives, like paste and gel.

Additions

Sleep-deprivation: You may be instructed to stay up for 24 hours before an extended EEG. This will cause additional stress to your brain and encourage you to fall asleep during the recording. Some seizures only happen when you are asleep, so do not drink caffeine, or take anything that may keep you awake during the test.

Ambulatory

Ambulatory EEGs again increase the length. Patients wear the EEGs at home in their daily lives. They are not actively monitored but are asked to record their activities.

Duration: 24–72 hours

Setting: Home but often office for setup and maintenance.

Electrodes are often attached with a hard to clean glue or cement.

Additions

Button: You will be provided with a button that will mark the record automatically for when the EEG is reviewed. You will be instructed to press this button if you feel any of your typical symptoms or have an episode. You should also make sure those around you know about this button, so they can press the button if you cannot.

Advocate Tip: *You or the patient may be apprehensive about pressing the button because many people assume their symptoms will be obvious on the EEG if they occur. However, this may not be true, especially if the episodes are not seizures, so pressing the button when the patient has their typical symptoms can be vital for diagnosing episodes.*

In-Patient Epilepsy Clinic and Units

For the difficult to capture or control seizures, you may be scheduled to be admitted to an Epilepsy Unit. In this setting, doctors can adjust medications safely as someone will always be there to help if you have a seizure.

Duration: 3–5 (sometimes up to 7) days while being monitored 24 hours a day.

Setting: Hospital

Electrodes are attached with a harder to clean glue or cement.

Additions

Like with ambulatory EEGs, you will be provided a button you or visitors can press if you are having symptoms. In this setting, this will cause an alarm to sound so that nurses can check on you. Technicians may also sound the alarm if they see seizure activity on your EEG.

Special In-Patient Additions

Ictal-Spect

This is a procedure that is added to an in-patient EEG, in preparation for epilepsy surgery. Surgery is usually only considered for epilepsy if seizures cannot be controlled with medications. While connected to the EEG, you will be taken off seizure meds, and you will sit with a trained epilepsy nurse. The nurse will be trying to inject you with a special dye within a minute of your seizure starting. Then you will quickly be sent to have a brain scan to try and locate the origin of the seizures.

Depth Electrodes

If doctors have reason to believe that your seizures are originating or focused deep inside the brain and not on the surface, they may have to admit you to have electrodes placed deeper in the brain. Other EEGs consist of only surface electrodes that are non-invasive. Depth electrodes are inserted surgically and only used in specific cases after extensive tests and alternative treatments.

Identifying Seizure Types

Seizures present differently depending on where they start in the brain and how they evolve. Doctors classify seizures based on these different presentations, and these classifications will influence how your seizures are treated. There are also specific seizure syndromes, which are even more specific classifications and often include an etymology, or cause of the seizures. If you are diagnosed with a specific syndrome, it will help to do research on that specific type of epilepsy. However, if you are just starting out, you can start with the basics of seizure classification.

Onset of Seizures

The onset of the electrical activity in the brain is one way seizures are classified (Bullinger, 2019). Sometimes this can be determined through clinical observation, but it is more often determined through EEG tracings. The classifications for onset include the following:

- **Generalized:** seizures observed starting all over the brain at once. They always cause impaired awareness as their whole brain is affected.
- **Focal or Partial:** seizures observed starting in one section of the brain. It often spreads to other parts of the brain, but does not spread to the entire brain. You could maintain awareness but some may still lose consciousness, depending on the part of the brain affected (Bullinger, 2019).
- **Secondary-Generalized:** seizures observed originating in one section of the brain, but then evolve to affect the whole brain. You may be aware at the beginning but as the seizure spreads, you lose awareness.
- **Unknown:** If seizures have not been observed with EEGs and have no clinical signs to confirm the origin, they may be classified as unknown until more information is gathered.

Motor and Non-Motor Seizures

The next level of classification is whether and what types of movements happen during the seizures (Bullinger, 2019). These classifications include the following:

- **Non-Motor:** any type of seizure that does not cause movement. It can affect language, consciousness, heartbeat, behavior, and more.
- **Simple Motor:** seizures with unnatural, simple, and repetitive movements.
- **Complex Motor:** seizures with movements that imitate natural movements. They are complex and can involve many parts of the body (Randolph, 2017).

Common Types of Seizures

Your doctors may also describe your seizures in unfamiliar terms. These words refer to types of movements or symptoms of the seizure. They can be combined, such as “Tonic-Clonic,” to be even more specific. Some of the most common terms are listed below:

Seizure Name	Description	Classification
<i>Grand Mal or Tonic-Clonic</i>	Legs and arms extended, followed by rapid flexing of the limbs	Generalized Motor Seizure
<i>Petit Mal or Absence</i>	Stares and is unresponsive for a short time.	Generalized Non-Motor Seizure
<i>Myoclonic</i>	A single jerk caused by muscles contracting	Generalized or Focal Simple Motor Seizure
<i>Versive</i>	Eyes and head turning up and to one side	Focal Simple Motor Seizure (may evolve into generalized seizure)
<i>Clonic</i>	Rhythmic jerking	Focal or Generalized Simple Motor Seizure
<i>Tonic</i>	Sudden stiffening or tensing	Focal or Generalized Simple Motor Seizure
<i>Atonic</i>	Sudden loss of muscle tone, often resulting in falls if standing	Focal or Generalize Seizures
<i>Gelastic</i>	Sudden often inappropriate laughter	Focal Complex Motor Seizure

Table 1: Common Seizure types (Randolph, 2017)

Living with Seizures

Seizure First Aid

Witnessing a seizure can be terrifying. Many people panic and do not know how to respond. While not universal, you can prepare people by teaching them the 3 **S**s of seizure safety:

- **Stay:** Someone should stay with the person and time the seizure. If the seizure is longer than 5 minutes, the seizure repeats, or a person is having difficulty breathing, call 911. Do not leave until they are awake and alert again.
- **Safe:** Make sure that the person is away from anything that may harm them. You can place something soft under their head to protect it.
- **Side:** Try to turn the person onto their side to keep their airway clear. Additionally, loosen anything around the neck that may strangle them (*Seizure First Aid, 2020*).

Also, let people know the 2 things they should not do:

- 1] **Do not** restrain the person.
- 2] **Do not** put any objects in their mouth (*Seizure First Aid, 2020*)

Sometimes when you have a seizure, you will be with family or friends who will know how to respond to your specific seizure type. Sometimes it will be the general public, who may have knowledge of seizures or not. You cannot control strangers.

To make the world safer for everyone with seizures, teach the in-between people in your life, such as acquaintances, co-workers, and neighbors, about seizure first aid. If you let them know you have seizures, they may have questions about what to do. Giving those people the three Ss can help you or others in the future.

While it is not your responsibility to teach people seizure first aid, every new person that knows how to respond to seizures could help you one day. Raising awareness makes the world a better place for all epileptics.

Seizure Plans

While seizure first aid works for anyone having a seizure, you should also create a personalized plan for you. This includes emergency contacts, when to take rescue medication, seizure types, and care for after your seizures. For a personal seizure plan template, go to: <https://www.epilepsy.com/preparedness-safety/action-plans>

Once you have a plan, share it, and keep it in common places, such as:

- Give one to a school nurse
- Give one to roommates
- Keep one in your workplace
- Keep one in your home in an easy to access location
- Keep one on your person in a wallet or purse

Review and update your plan regularly, ideally with your healthcare provider (Sirven et al., Oct. 2013).

Tracking Seizures and Managing Triggers

Keeping track of your seizures, when and where they happen, may illuminate a pattern that can help you identify behaviors or stimuli which “triggers” your seizures. By identifying and avoiding your triggers, you may be able to decrease the frequency of your seizures.

Some triggers like lack of sleep, alcohol, drugs, stress, and flashing lights are within your control. Others, like menstrual cycle, are not in your control, but you can work with your doctor to alter your treatment after a trigger is identified (Schachter, n.d.).

Driving with Seizures

For seizures with loss of consciousness, laws may dictate that your healthcare provider report your seizures. In the United States, each state has different laws about whether epileptics can drive, but in general, you must be seizure-free for a certain time to drive unrestricted. You may not be able to drive for 3 months to over a year after having a single seizure. Your doctor may also be required to fill out a form clearing you to drive after having a seizure. If there is any question about whether you can or should drive, refer to your local laws and talk to your healthcare professional to keep yourself and others safe.

Starting Seizure Medications

Medications are often prescribed before or during the testing in the diagnosing process. There are many different types of anti-seizure medications. Some work better for different types of seizures, and some are more effective for certain individuals than others. Most people with epilepsy remain on anti-seizure medications for their lifetime as most seizures cannot be cured. However, medications do reduce or prevent the seizures from occurring. When prescribed anti-seizure medications:

- Take them regularly, at the same time each day. Taking a dose late or skipping it may increase your risk of seizures.
- **Never stop or change your medication on your own.** Doing so puts you at risk for more severe seizures.
- Keep track of side effects and their severity. Some of the most common side effects include dizziness, fatigue, nausea, vertigo, and brain fog.
- Report the side effects to your doctor. This can help them decide whether to try a new medication or adjust your dosage, while keeping you in the therapeutic range for the drug.

Therapeutic range tests the amount of the medication in your blood. Too low and you may have break-through seizures or other effects. Too high and you may have severe effects and damage from the drug.

Finding the right medication and dosage may take a while. In the end, about 7 out of 10 people with epilepsy will control their seizures (“Medical Therapy in Epilepsy”, 2019). Once found, you could stay on the effective medication for years without issue, or something may change causing you to have to find a new medication. You should continue to maintain consistent check-ups with your prescribing doctor, even if you are seizure-free, so they are up-to-date on your condition if a medication change is necessary.

Dual or more therapies

If you continue to have seizures, your doctor may increase your dose, but at some point, you will reach the maximum dosage. At that point, your doctor may put you on an additional medication, which is a practice called **Dual therapy**. While 47% of epileptics become seizure free with one medication, adding a second medication makes an additional 13% of epileptic seizure-free (“Medical Therapy in Epilepsy”, 2019).

If two medications do not work, you can try a third or fourth additional medication. However, the odds of becoming seizure-free decrease. In the end, 36% of epileptics have uncontrollable seizures even with medications (“Medical Therapy in Epilepsy”, 2019).

Uncontrollable seizures, in addition to decreasing quality of life, can cause symptoms of brain damage including memory and cognitive issues. Not everyone with uncontrollable seizures experiences mental decline, but all seizures increase the risk and frequency of physical and cognitive injury.

Rescue Medications

Whether you have controlled seizures or not, regularly taken medications will not help you if you have a break-through seizure. On top of preventative anti-seizure medications, your doctor may also prescribe a rescue medication.

Rescue medication is a medication that you will take to try and stop a seizure as it occurs. For epileptics with auras, these medications can stop the seizures before they start. Rescue medications are another important tool that can help you handle your seizures.

Other Treatments

Medication, while the most common, is not the only approach to managing seizures. If you are still struggling with your seizures after trying many medications, you can investigate these other approaches to see if they may work for you.

Dietary Therapies

The most common diet used for seizure control is the **Ketogenic diet**. It is high in fat, and low in protein and carbohydrates. It is commonly used in children for seizure control, but may help adults with epilepsy have fewer seizures or become

seizure-free, along with medication. Some people are able to take less anti-seizure medications with the help of diets.

The other less common dietary therapies used include: Medium-chain triglyceride diet (MCT), Modified Atkin's diet (MAD), and Low Glycemic Index Treatment (LGIT) ("Dietary Therapies to Treat Seizures and Epilepsy", 2018).

Talk your doctor before starting any of these diets as they can help you work with a nutritionist to adjust them specifically to you.

Surgery and devices

More invasive treatments include performing brain surgery or implanting neuromodulation devices. The two main types of surgical approaches for epilepsy are removal (lesionectomy, the removal of a lesion or mass, or lobectomy, the removal of whole parts of the brain) and disconnection surgeries ("Surgery for Epilepsy", 2018). If your doctor believes you are eligible for surgery, you will have to have comprehensive tests at an epilepsy center to confirm. Having surgery does not guarantee you will become seizure-free and comes with risks. So, surgery should be carefully considered. However, for some, reducing or getting rid of their seizures outweighs the risks.

Neuromodulation devices send small electrical currents to the nervous systems to stop seizures. There are many different devices, but the most common use Vagus Nerve Stimulation, Responsive Neurostimulation, or deep brain stimulation (Shafer & Dean, 2018). Neuromodulation may be an option for people with uncontrollable seizure for whom surgery is not an option or is undesirable.

Alternative Therapies

These are therapies encouraged in alternative medicine and may be used in addition to traditional methods. They do not have strong scientific research or backing, but some people find them helpful. These can include:

- Supplements, like vitamins, herbs, or probiotics
- Meditation, relaxation techniques, or yoga
- Acupuncture, chiropractic and osteopathic manipulation, massage therapy ("Alternative Therapies", 2018)

Alternative and Additional Diagnoses

At the beginning of the diagnosis process, your doctor may consider options for diagnoses that present similar to seizures. They may also consider additional diagnoses if multiple medications, treatments, and tests get your episodes under control. The following are the two of the most common alternative diagnoses, but there are others.

Convulsive Syncope

Syncope, colloquially called “passing out” or fainting, can be either neurological or cardiac in origin and often can be confused with seizures. It can be hard to tell the difference between syncope and seizures through simple observation.

It gets even harder to tell the difference when passing out comes with twitching or shaking while unconscious. Both seizures and syncope can also come with peeing yourself or eyes rolling back.

If you have episodes like this, it is always good to explore cardiac issues that may explain symptoms along with a neurological evaluation.

Psychogenic Seizures

Once called “pseudo-seizures”, **Psychogenic seizures** have been wrongly defined in the past and even by some today as fake seizures. As the name implies, these seizures are not epileptic, or coming from misfiring in the brain, but are psychological in origin. As a response to repressed or unprocessed trauma, some people develop shaking and confusion, or even lose consciousness, in reoccurring episodes that can look like seizures.

You can have these episodes on an EEG and it will show normal brain activity. Psychogenic seizures continue no matter what anti-seizure medications are tried.

Psychological diagnoses can be hard to accept as it can feel like being called a liar. However, you should be receptive to trying treatment for psychogenic seizures, if your doctor presents it to you. Just remember:

- If therapy or psychiatric medications help to control your episodes, you are not faking seizures. Your seizures just need to be treated in a different way.
- Some people with epileptic seizures also have psychogenic seizures. So, you may have both. Learning how these episodes are different and receiving treatment for both can be beneficial.

While receiving a diagnosis for psychogenic seizure can be hard, a good neurologist or epileptologist will work with you to find the right treatment for you. No one will judge or belittle you for a legitimate diagnosis, even if it was not the one you were expecting.

Learning More

As you proceed on your epilepsy journey, you will have further questions on ideas only briefly covered here. Any good patient or advocate is always trying to find new and useful information to help them navigate the medical field and promote their wishes and desires. Here are some recommendations for where to look next for more information on epilepsy:

Epilepsy Foundation

Epilepsy Foundation is a national non-profit with many local chapters that focus on educating people about seizures and epilepsy as well as striving to find therapies and treatments to stop seizures and cure epilepsy all together. Their website is <https://www.epilepsy.com/>

Empowering Epilepsy

An organization founded by people with epilepsy. This group focuses on connecting epileptics and their families to support groups and epilepsy specialists. Their support groups meet via Zoom. They have events targeted for different groups and life stages, such as kids, teens, seniors, and parents. Their website is <https://www.empoweringepilepsy.org/>

International League Against Epilepsy

A global organization for professionals and scientists that are working towards advancements in epilepsy treatment. They have content in many languages. They also focus on professionals, so material is much more advanced and technical. However, if you are looking for the latest advancements and discussions in the field, you will find the most recent research and articles here. Their website is <https://www.ilae.org/>

Epilepsy Awareness month

November is National Epilepsy Awareness Month. It is represented by the color purple, which is why this guide uses purple text. While you may be educating yourself and living with the condition year-round, you can use this special time to spread the word about epilepsy and share your experience to others. Epilepsy organizations use this month to fight for legislation that protects and aids this little understood disability. November is a great time to connect with other epileptics and come together to fight for an important cause!

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