

Exploring Epilepsy:



INFORMATION / KNOWLEDGE / EMPOWERMENT

MODULE 1: EPILEPSY 101



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What Is Epilepsy?

Learning about epilepsy and how it affects you can help you manage your epilepsy.¹

Epilepsy is a brain disorder that involves seizures.² Seizures are strong bursts of electrical activity in the brain.^{3,4}

A seizure is an event, and epilepsy is the disease.⁵ Just because a person has seizures does not mean that a person has epilepsy.¹

There are 3 definitions of epilepsy²

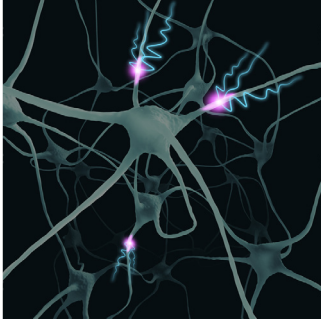
- Person has at least 2 seizures more than 1 full day apart.
No known cause of the seizures.
- Person has epilepsy syndrome with a known cause of the seizures.
- Person has 1 seizure.
No known cause of the seizures.
Person is at high risk of seizures because of other health conditions.

Epilepsy is a chronic medical condition, meaning that it may last for the rest of your life.¹

Epilepsy is not contagious, and it is not a mental disorder.¹

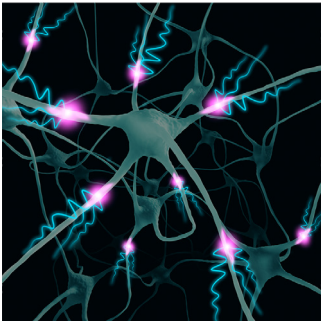
What Are Seizures?

Seizures are strong bursts of electrical activity in the neurons (nerve cells) of the brain.^{3,4}



During normal brain activity,

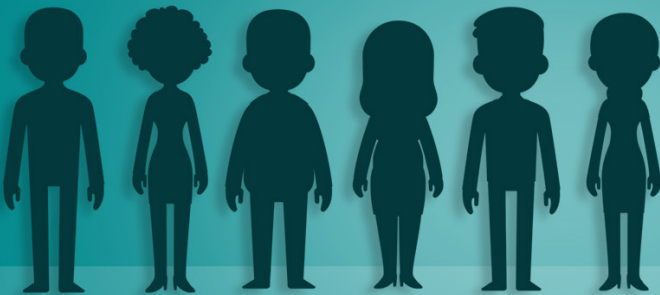
nerve cells fire as different parts of the brain become activated. Different nerve cells alternate their firing patterns as they send their messages throughout the brain.



During a seizure, large groups of nerve cells fire at the same time. A seizure is like an electrical storm in your brain.

What Causes Seizures?

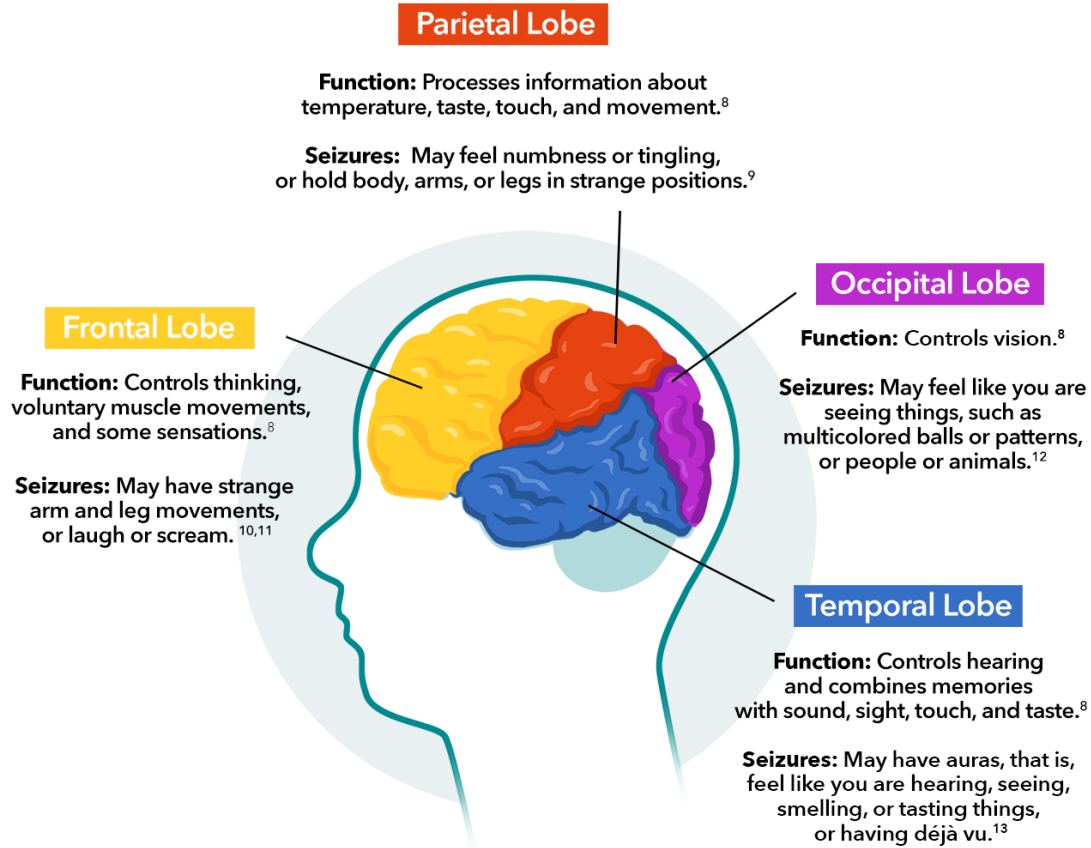
For 6 out of 10 people with epilepsy, the cause of their seizures is unknown.⁶



For 4 out of 10 people with epilepsy, their seizures are caused by a brain injury, an infection, or a genetic disorder.⁶

What Happens During a Seizure?

Each functional region (color-coded) of the brain has a different job. What happens to you during a seizure depends on where the seizure happens in the brain.⁷



Are There Different Types of Seizures?

There are 2 main types of seizures: focal seizures and generalized seizures.¹⁴



Focal Seizures

Focal (partial) seizures start in a group of neurons in a specific part of the brain.¹



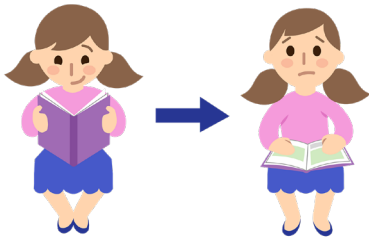
Generalized Seizures

Generalized seizures start in a network of neurons spread across the brain.¹

Generalized seizures have many subtypes.¹⁴

Absence Seizure

A seizure that causes a sudden loss of consciousness (awareness), usually for about 10 to 20 seconds. The person may just stare into space.¹⁵



Atonic Seizure

A seizure that causes a sudden loss of muscle tone, usually for less than 15 seconds. The person may drop things or fall. Atonic seizures are also called drop attacks or drop seizures.¹⁶



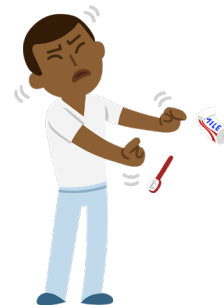
Clonic Seizure

A seizure that causes muscles to go back and forth between contracting and relaxing, usually for a few seconds to 1 minute. The person may make jerky movements with their arms or legs.¹⁷



Myoclonic Seizure

A seizure that causes brief, shock-like jerks that last 1 or 2 seconds. The person usually has muscle jerks on both sides of the body at the same time.¹⁸



Tonic Seizure

A seizure that causes muscles on both sides of the body to contract strongly and become intensely stiff, usually for less than 20 seconds. The person may fall if standing when the seizure starts.¹⁹



Tonic-clonic Seizure

A seizure that has 2 parts. First, during the tonic part, the muscles of the body contract strongly and may cause the person to fall. Then, during the clonic part, arms and legs jerk in a repeated pattern. A tonic-clonic seizure may last from 1 to 3 minutes.²⁰




Tonic part



Clonic part

Who Has Epilepsy?

Epilepsy affects children, men, and women of all races, ethnic backgrounds, and ages.¹
Here are a few facts about who has epilepsy.



Epilepsy affects men and women.¹



Epilepsy affects people from all races and ethnic backgrounds.¹



65 million people around the world have epilepsy.²¹



Epilepsy is the fourth most common neurologic disorder in the US.²²

Each year, 150,000 people in the US are diagnosed with epilepsy.²¹



Up to 3 million people in the US have epilepsy.²¹
There are about 325 million people in the US.²³
That means 1 of every 100 people has epilepsy.



Epilepsy affects people of all ages.¹

People are most likely to be diagnosed with epilepsy as a child or as an older adult.¹

In the US, the total number of people who have epilepsy increases with age.¹

How Is Epilepsy Diagnosed?

It can be hard for a doctor to diagnose someone with epilepsy. The doctor might not ever see you having a seizure.²⁴

The information you give to your doctor about your seizures is very important. This information will help the doctor decide if you have epilepsy or not. Family members, friends, or anyone else who has seen you have a seizure might have helpful information, too.²⁴

Your doctor will talk to you about your seizures and examine you. The doctor might run some tests to try to find out the cause of the seizures.²⁵



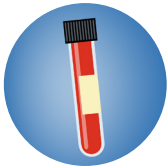
Family History and Medical History

A family history helps the doctor understand if there is any family tendency to have seizures. The medical history helps the doctor understand if any medical conditions you've had in the past might be causing your seizures.²⁵



Physical and Neurologic Exam

The physical and neurologic exams help the doctor figure out if any other medical conditions might be causing the seizures.²⁵



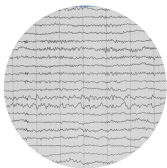
Blood Tests

Blood tests give the doctor information about what's happening in your body.²⁵



Computerized Tomography (CT)

A CT scan uses radiation to see if there are changes in the brain, such as bleeding, that might be causing the seizures. CT scans are also called CAT scans.²⁵



Electroencephelogram (EEG)

An EEG records electrical activity in the brain. EEGs can help the doctor understand what's happening in the brain.²⁵

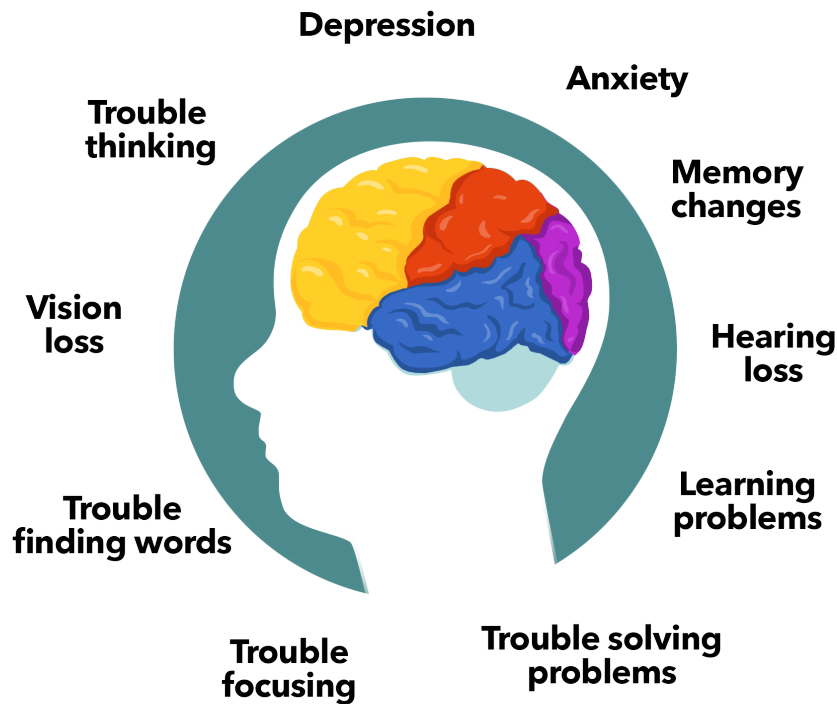


Magnetic Resonance Imaging (MRI)

An MRI uses magnetic fields to see if there are structural changes in the brain, such as tumors, that might be causing the seizures.²⁵

What Other Medical Conditions May Coexist With Your Epilepsy?

You may have medical conditions affecting your brain that are caused by the seizures or related to your epilepsy.¹



There are other medical conditions that some people may have. Talk to your epilepsy doctor about how these other medical conditions may or may not affect your epilepsy.¹

Does Epilepsy Affect People Differently?

Epilepsy affects people in different ways at different times of their lives.¹

- Children, teenagers, adults, and older adults may all face different problems in managing their epilepsy¹
- Times of change, such as moving from youth to adulthood, starting a new medication, or having a change in how often seizures happen, might be hard to manage¹

Children or Teenagers

Children and teenagers with epilepsy may worry about:¹

- Having seizures at school
- Having seizures in front of friends
- Having learning problems
- Being safe at school
- Participating in sports or other after-school activities
- How epilepsy affects their future



Adults

Adults with epilepsy may worry about:¹

- Driving
- Working
- Sleeping
- Having a seizure in public
- Dying during a seizure
- How stress affects seizures
- Whether their children will have epilepsy



Women

Women with epilepsy may worry about:¹

- How monthly hormonal changes may affect seizures
- How menopause may affect seizures
- How seizures affect sexual function
- How seizures affect pregnancy
 - How medications may affect pregnancy
 - How pregnancy might affect seizure control



Men

Men with epilepsy may worry about:¹

- Memory problems
- Confidence
- Plans for the future
- How seizures affect sexual function



Older Adults

Older adults with epilepsy may worry about:¹

- Driving
- Working
- Falling
- Taking epilepsy medications with other medications
- Living alone



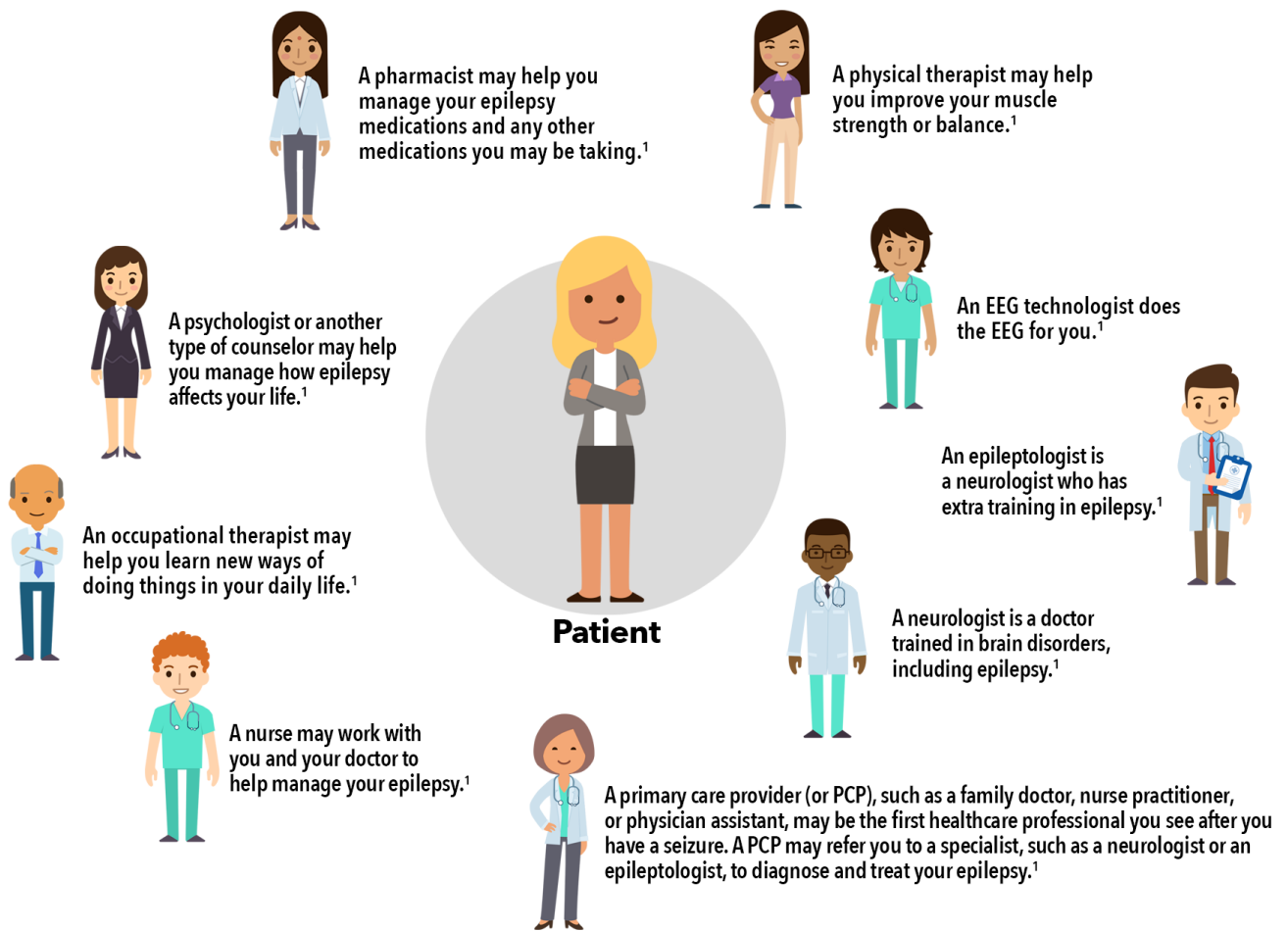
Is Managing Your Epilepsy a Team Approach?

For most people, epilepsy is a chronic medical condition.¹ One part of epilepsy management is control of seizures. Another part is managing how epilepsy affects other parts of your life.¹

Management of your epilepsy will probably require a team approach.

- **You are the most important member of your healthcare team**
- Your family members and other caregivers are also important members of your epilepsy team
- There are many healthcare professionals who may be members of your healthcare team¹

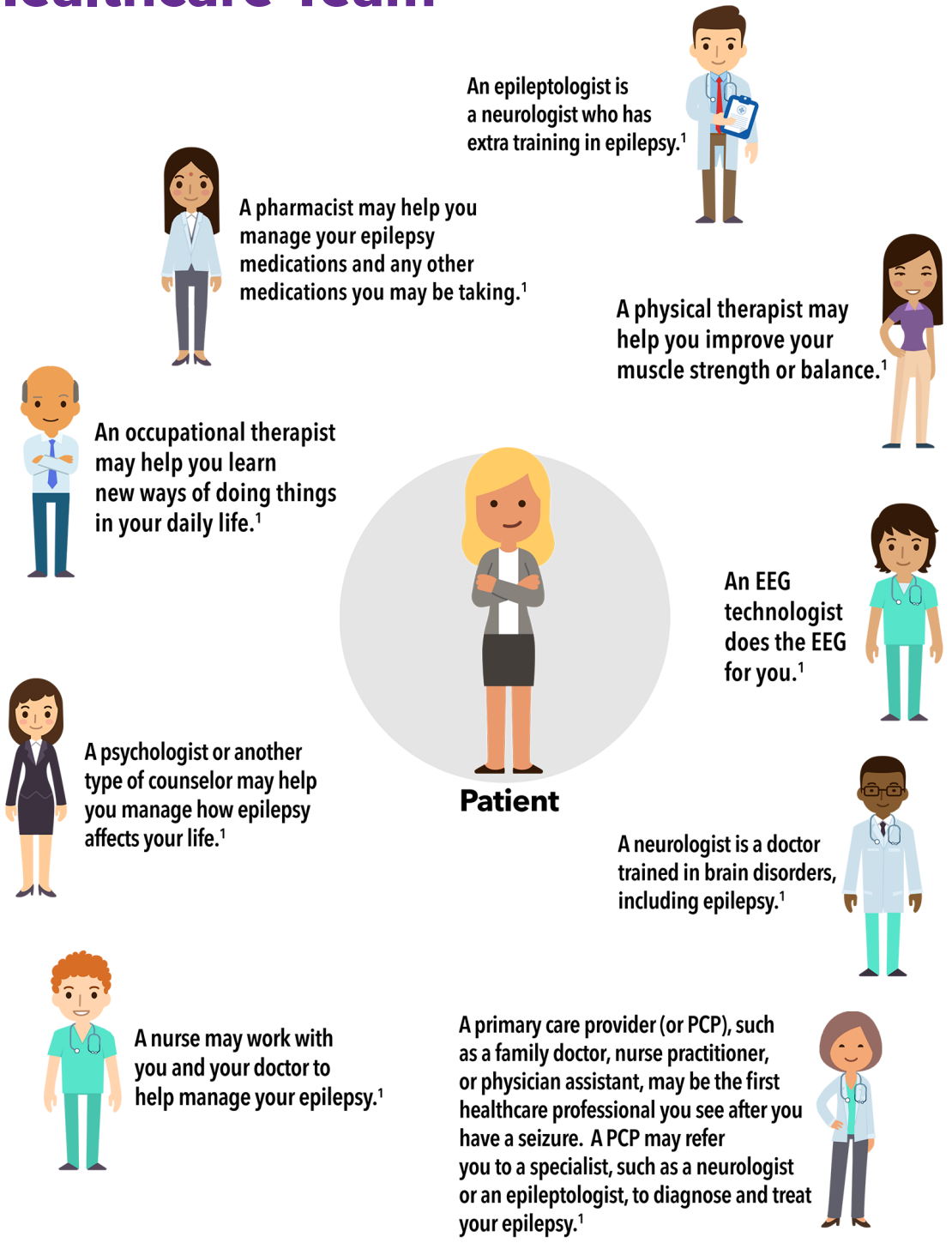
Possible Members of Your Healthcare Team



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Possible Members of Your Healthcare Team



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How to Make the Most of Your Doctor's Visit

Before your next appointment with the doctor who treats your epilepsy, make a list of all the questions you have. Some of your questions may have been answered today, but you may think of more questions after you go home. Having a list of questions to ask your doctor will help you get the most out of the short amount of time you might have with the doctor.



Remember, you are the most important member of your healthcare team. You need to know why your epilepsy is being managed the way your doctor is managing it. Here are some questions you might want to ask your epilepsy doctor.

- Do we know what is causing my epilepsy?
- What type of seizures do I have?
- Are there organizations out there for people with epilepsy?
- Are there things I need to do differently at home/work?
- Do I need someone watching me all the time?
- How do we know what medication is right for me?
- How will we decide if it is time to change my medications?
- Can we talk about my treatment goals?
- What determines if I need an EEG, MRI, or CT scan?
- Can I have children?
- What should I do after I have a seizure?
- What changes in my epilepsy should I make you aware of?
- How may epilepsy affect my social life or intimate relationships?

For women with epilepsy

- If I get pregnant, will the medication(s) I take to treat my seizures affect my baby?
- How will hormonal changes each month affect my epilepsy?
- How will menopause affect my epilepsy?



When you go to your epilepsy doctor, take this list of questions and a pen and paper so you can take notes during the visit. You might want to take a family member or friend with you so you'll have help remembering everything the doctor said.

Frequently Asked Questions and Answers

What kind of seizures do I have?

You may already know the answer to this question. If not, you can discuss this with your doctor.



Will I have seizures for the rest of my life?

For some people with epilepsy, it is a childhood disorder that goes into remission (the seizures go away). For other people with epilepsy, it is a lifelong condition.¹



Will I have to take medications for the rest of my life?

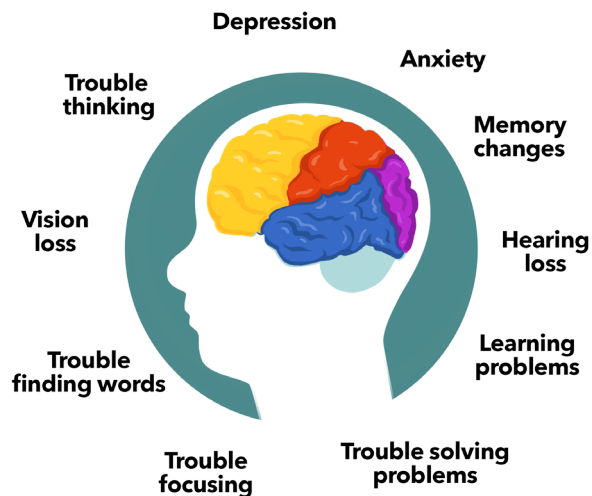
This will depend on how your seizures change during your life and how well the medications you are taking control your seizures.² We will talk more about your specific medications during subsequent visits.

Can the type of seizures I have change?

The type of seizures, how often you have seizures, and how severe the seizures are may change over time.¹

Do seizures cause brain damage?

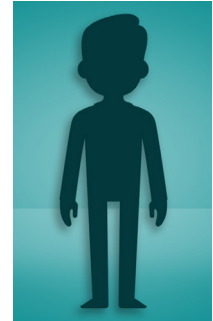
Some people with epilepsy may have changes in their brain caused by seizures that lead to problems. For example, some people may have trouble thinking, focusing, or solving problems. Some people have memory changes or have learning problems because of their epilepsy.¹



Frequently Asked Questions and Answers

Can seizures damage other parts of my body?

Some people with epilepsy may have accidents or injuries because of seizures. For example, if you fall during a seizure, it's possible you could break a bone. We'll talk more about safety concerns for people with epilepsy in Module 3. It's also possible that seizures can lead to some hearing or vision loss in some people.¹



Can I die from a seizure?



It's possible to die from a seizure. There is something called sudden unexpected death in epilepsy (SUDEP) that is the most common cause of epilepsy-related deaths.¹ SUDEP is more common in people with generalized tonic-clonic seizures.³ We'll cover SUDEP in more detail in Module 3.

People with epilepsy have a greater chance of experiencing accidents and injuries. Therefore, an accident or injury resulting from a seizure could be severe enough to cause death.¹ There are things you can do to potentially eliminate this risk. We'll talk about safety concerns for people with epilepsy in a separate visit.

Will my kids have epilepsy?

Probably not, but it's possible. Most children will not inherit epilepsy from a parent. For example, if a mother has epilepsy and the father does not, the risk of their child having epilepsy is less than 5 in 100. In other words, if there were 100 couples where the mother has epilepsy and the father does not, less than 5 out of 100 of their babies would inherit epilepsy.⁴



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Healthcare Lingo

Absence seizure

Causes a sudden, short period of “blinking out,” usually for 10 to 20 seconds. The person may just stare into space.¹

Atonic seizure

Causes a sudden loss of muscle tone, usually for less than 15 seconds. The person may drop things or fall. Atonic seizures are also called drop attacks or drop seizures.²

Clonic seizure

Causes muscles to go back and forth between contracting and relaxing, usually for a few seconds to 1 minute. The person may make jerky movements with their arms or legs.³

Comorbid disorders

Medical conditions that might accompany epilepsy. Some of these conditions affect your brain and are caused by seizures or related to your epilepsy. Other types of comorbid conditions are not related to seizures or your epilepsy.⁴



CT scan

A CT scan uses radiation to see if there are changes in the brain, such as bleeding, that might be causing the seizures. CT scans are also called CAT scans. CT stands for computerized tomography.⁵

Diagnosis

The identification of a medical condition, such as epilepsy, by a doctor, nurse practitioner, or physician’s assistant.⁵

EEG test

An EEG (electroencephalogram) records electrical activity in the brain. EEGs can help the doctor understand what’s happening in the brain.⁵

EEG, CT, MRI technologists

The healthcare professionals who perform these tests.⁴

Epilepsy

Epilepsy is a brain disorder that involves seizures.⁶

Epileptologist

A neurologist who has extra training in epilepsy.⁴

Focal seizures

Focal (partial) seizures start in a group of neurons in a specific part of the brain.⁴

Frontal lobe

The part of your brain at the front of your head (above your eyes) that controls thinking, voluntary muscle movements, and some sensations.⁷⁻⁹

Generalized seizures

Generalized seizures start in a network of neurons spread across the brain.⁴

MRI scan

MRI (magnetic resonance imaging) uses magnetic fields to see if there are structural changes in the brain, such as tumors, that might be causing the seizures.⁵

Myoclonic seizure

A seizure that causes brief, shock-like jerks that last 1 or 2 seconds. The person usually has muscle jerks on both sides of the body at the same time.¹⁰

Neurologist

A doctor trained in brain disorders, including epilepsy.⁴

Healthcare Lingo (cont)

Neuron

A nerve cell. Nerve cells communicate with each other in the brain and can send messages to other parts of the body.¹¹

Nurse

A healthcare professional who may work with you and your doctor to help manage your epilepsy.⁴

Occipital lobe

The part of your brain at the back of your head that controls vision.^{7,12}

Occupational therapist

A healthcare professional who may help you learn new ways of doing things in your daily life.⁴

Parietal lobe

The part of your brain behind your frontal lobe (in the middle of the head) that processes information about temperature, taste, touch, and movement.^{7,13}

Pharmacist

A healthcare professional who may help you manage your epilepsy medications and any other medications you may be taking.⁴

Physical therapist

A healthcare professional who may help you improve your muscle strength or balance.⁴

Primary care provider

A family doctor, nurse practitioner, or physician assistant who may be the first healthcare professional you see after you have a seizure. A PCP may refer you to a specialist, such as a neurologist or an epileptologist, to diagnose and treat your epilepsy.⁴

Psychologist

A mental health counselor who may help you manage how epilepsy affects your life.⁴

Seizure

Seizures are strong bursts of electrical activity in the brain.^{11,14}

Temporal lobe

The part of your brain on the side of your head (over your ears) that controls hearing. This part of your brain also combines memories with sound, sight, touch, and taste.^{7,15}

Tonic seizure

A seizure that causes muscles on both sides of the body to contract strongly and become intensely stiff, usually for less than 20 seconds. The person may fall if standing when the seizure starts.¹⁶

Tonic-clonic seizure

A seizure that has 2 parts. First, during the tonic part, the muscles of the body contract strongly and may cause the person to fall. Then, during the clonic part, arms and legs jerk in a repeated pattern. A tonic-clonic seizure may last from 1 to 3 minutes.¹⁷



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USP-DSEP1118-0051- Module 1
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