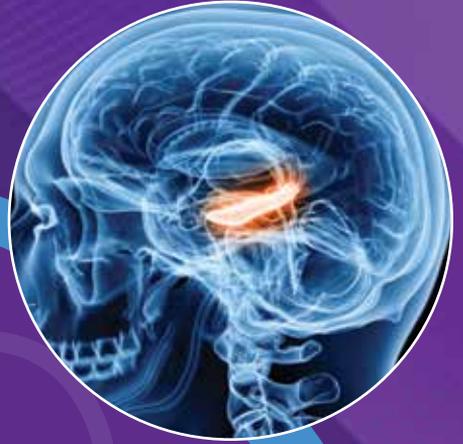




National Institute of
Neurological Disorders
and Stroke



Epilepsy and Seizures



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What are epilepsy and seizures?

Epilepsy is a chronic brain disorder in which groups of nerve cells, or neurons, in the brain sometimes send the wrong signals and cause seizures. Neurons normally generate electrical and chemical signals that act on other neurons, organs, and muscles to produce human thoughts, feelings, and actions.

During a seizure, many neurons send signals at the same time, much faster than normal. This surge of excessive electrical activity may cause involuntary movements, sensations, emotions, and/or behaviors. The disturbance of normal nerve cell activity may cause a loss of awareness. Some people recover immediately after a seizure, while others may take minutes to hours to feel like themselves again. During this time, they may feel tired, sleepy, weak, or confused.

Epilepsy (sometimes referred to as a seizure disorder) can have many different causes and seizure types. Epilepsy varies in severity and impact from person to person and can be accompanied by a range of co-existing conditions. Epilepsy is sometimes called “the epilepsies” because of the diversity of types and causes. Some people may have convulsions (muscles contract repeatedly) and lose consciousness. Others may simply stop what they are doing, have a brief lapse of awareness, and stare into space for a short period. Some people have seizures very infrequently, while other people may experience hundreds of seizures each day.

While any seizure is cause for concern, having a seizure does not by itself mean a person has epilepsy. First seizures, febrile seizures, nonepileptic events, and eclampsia (a life-threatening condition that can occur during pregnancy) are examples of conditions involving seizures that may not be associated with epilepsy. Regardless of the type of seizure, it's important to inform your doctor when you have a seizure.



Who is more likely to have epilepsy and seizures?

Anyone can develop epilepsy. It affects both men and women of all races, ethnic backgrounds, and ages.

Epilepsy has many possible causes, but about half of people living with epilepsy do not know the cause. In some cases, epilepsy is clearly linked to genetic factors, developmental brain abnormalities, infection, traumatic brain injury (TBI), stroke, brain tumors, or other identifiable problems. Anything that disturbs the normal pattern of nerve cell activity—from illness to brain damage to brain development problems—can lead to seizures.

Epilepsy may develop because of problems in the brain's wiring, an imbalance of nerve signaling in the brain (in which some cells are unusually active or stop other brain cells from sending messages), or some combination of these factors. Sometimes, when the brain tries to repair itself after a head injury, stroke, or other problem, it can unintentionally create nerve connection issues that lead to seizures.

The role of genes in epilepsy

Genetic changes may play a key role in the development of certain types of epilepsy. Many types affect multiple members of a family, pointing to an inherited gene or genes. In other cases, gene variations may occur spontaneously and contribute to the development of epilepsy in people with no family history of the disorder (called "de novo" mutations). Overall, researchers estimate that hundreds of genes could play a role.

Several types of epilepsy (called channelopathy-associated epilepsy) have been linked to variations in genes that provide instructions for ion channels, the “gates” that control the flow of ions (charged molecules) in and out of cells and help regulate neuronal signaling. Other genetic changes that may play a role in epilepsy include variations in genes that control how neurons move through the brain during development (neuronal migration) and genes that help break down carbohydrates in the brain.

Other genetic changes may not cause epilepsy but may influence the disorder in other ways. For example, some genes may affect a person’s susceptibility to seizures and responsiveness to anti-seizure medications.

Conditions that can lead to epilepsy

Epilepsy may develop as a result of many types of conditions that disrupt normal brain activity, known as “co-occurring conditions.” Once these conditions are treated, individuals may no longer have seizures. However, whether the seizures stop varies based on the type of disorder, the brain region that is affected, and how much brain damage occurred prior to treatment. Examples of conditions that can lead to epilepsy include:

- Brain tumors
- Head trauma
- Alcoholism or alcohol withdrawal
- Alzheimer’s disease
- Strokes, heart attacks, and other conditions that deprive the brain of oxygen
- Abnormal blood vessel formations (called arteriovenous malformations) or bleeding in the brain
- Brain inflammation or swelling
- Infections such as meningitis, HIV-related infections, and viral encephalitis

Cerebral palsy and other developmental disorders also may be associated with epilepsy. Epilepsy is often seen in people with other brain development disorders—for example, among individuals with autism spectrum disorder or intellectual disabilities.

What can trigger seizures?

Seizure triggers do not cause epilepsy but can provoke seizures in those who are susceptible. For those who are already diagnosed with epilepsy and taking medication, triggers can spark a seizure. Triggers include:

- Stress
- Drinking alcohol, or alcohol withdrawal
- Dehydration or missing meals
- Exposure to toxins or poisons, including lead, carbon monoxide, illicit drugs, and very large doses of prescription medications
- Hormonal changes associated with the menstrual cycle
- Sleep deprivation
- Visual stimulation such as flashing lights or moving patterns

In surveys of people with epilepsy, stress is the most commonly reported seizure trigger.



Types of seizures

Seizures are divided into two broad categories: focal seizures and generalized seizures. There are many different types of seizures within each of these categories.

Focal seizures

Focal seizures come from just one part of the brain. About 60% of people with epilepsy have focal seizures. These seizures are frequently described by the area of the brain in which they originate. For example, many people are diagnosed with focal frontal lobe or medial temporal lobe seizures.

Symptoms of focal seizures

In some focal seizures, the person remains conscious during the seizure but may experience motor, sensory, or psychic feelings (for example, intense déjà vu or memories) or sensations. The person may experience sudden and unexplainable feelings of joy, anger, sadness, or nausea. They also may hear, smell, taste, see, or feel things that are not real and may have movements of just one part of the body—for example, just one hand.

In other focal seizures, the person has a change in consciousness, which can produce a dreamlike experience. The person may display unusual, repetitive behaviors such as blinks, twitches, mouth movements, or even walking in a circle. These repetitive movements are called automatisms. A person may perform more complicated actions, which may seem purposeful, involuntarily. Individuals may also continue activities they started before the seizure began, such as washing dishes in a repetitive, unproductive fashion. These seizures usually last no more than a minute or two.

Some people with focal seizures may experience auras—unusual sensations that warn of an impending seizure. An individual's symptoms, and how they progress, tend to be similar every time. Some people report experiencing a prodrome, a feeling that a seizure is imminent, lasting hours or days.

Following focal seizures, a person may experience symptoms in areas controlled by the area of the brain where their seizure originated. This can help doctors locate the brain region where the seizure started. After a seizure, some people may experience a headache or pain in the muscles that contracted during the seizure.

The symptoms of focal seizures can be easily confused with other disorders. The strange behavior and sensations caused by focal seizures also can be mistaken for symptoms of narcolepsy, fainting, or even mental illness. Several tests and careful monitoring may be needed to make the distinction between epilepsy and these other disorders.

Generalized seizures

Generalized seizures are a result of abnormal neuronal activity that rapidly emerges on both sides of the brain. These seizures may cause loss of consciousness, falls, or massive muscle contractions. Types of generalized seizures and their effects include:

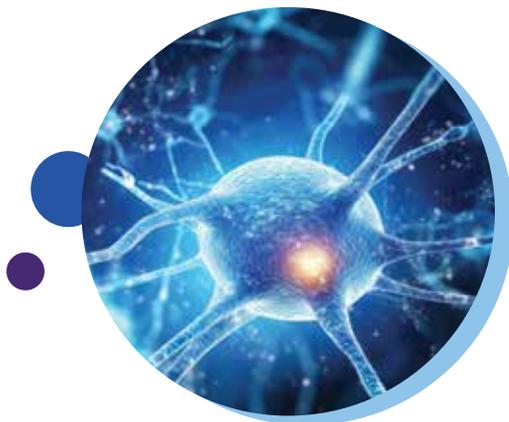
- **Absence seizures** may cause the person to appear to be staring into space, with or without slight twitching of the muscles
- **Tonic seizures** cause a stiffening of muscles of the body, generally in the back, legs, and arms
- **Clonic seizures** cause repeated jerking movements of muscles on both sides of the body

- **Myoclonic seizures** cause jerks or twitches of the upper body, arms, or legs
- **Atonic seizures** cause a loss of normal muscle tone, which can cause the person to fall or drop the head involuntarily
- **Tonic-clonic seizures** cause a combination of symptoms, including stiffening of the body and repeated jerks of the arms and/or legs as well as loss of consciousness
- **Secondary generalized seizures** begin in one part of the brain, then spread to both halves of the brain (basically, a focal seizure followed by a generalized seizure)

Other types of seizures

Not all seizures can be easily defined as either focal or generalized. Some people have both types of seizures but with no clear pattern.

Febrile seizures happen when a child has an illness that causes a high fever. Children who have febrile seizures are typically not prescribed antiseizure medications unless they have a family history of epilepsy, signs of nervous system impairment before the seizure, or have a relatively long or complicated seizure or more than one febrile seizure. The risk of subsequent non-febrile seizures is low unless one of these factors is present.



First seizures can be provoked or unprovoked, meaning that they can occur with or without any obvious triggering factors. Unless the person has suffered brain damage or there is a family history of epilepsy or other neurological abnormalities, most single seizures usually are not followed by additional seizures. Medical disorders which can provoke a seizure include:

- Low or very high blood sugar
- Changes in chemical levels in the blood (sodium, calcium, magnesium)
- [Eclampsia](#) during or after pregnancy
- Impaired function of the kidneys or liver

In some cases where additional epilepsy risk factors are present, drug treatment after the first seizure may help prevent future seizures. Evidence suggests that it may be beneficial to begin antiseizure medication once a person has had a second unprovoked seizure, as the chance of future seizures increases significantly after this occurs. A person with a pre-existing brain problem—for example, a prior stroke or TBI—will have a higher risk of experiencing a second seizure. In general, the decision to start antiseizure medication is based on the healthcare provider’s assessment of many factors that influence how likely it is that another seizure will occur in that person.



Types of epilepsy

Just as there are many different kinds of seizures, there are many different kinds of epilepsy. Hundreds of different epilepsy syndromes—disorders that include seizures as a prominent symptom—have been identified. Some of these syndromes appear to be either hereditary or caused by de novo gene changes. For other syndromes, the cause is unknown. Epilepsy syndromes are frequently described by their symptoms or by where in the brain they originate.

- **Absence epilepsy** is characterized by repeated seizures that cause momentary lapses of consciousness. The seizures almost always begin in childhood or adolescence and tend to run in families, suggesting that they may at least be partially due to genetic factors. Individuals may show purposeless movements during their seizures, such as a jerking arm or rapidly blinking eyes, while others may have no noticeable symptoms except for brief times when they appear to be staring off into space. Immediately after a seizure, the person can resume whatever they were doing. However, these seizures may occur so frequently (in some cases up to 100 or more a day) that the person cannot concentrate in school or other situations.
- **Frontal lobe epilepsy** is a common epilepsy syndrome that features brief focal seizures that may occur in clusters. It can affect the part of the brain that controls movement. Its seizures, which are usually associated with some loss of awareness, can cause muscle weakness or unusual, uncontrolled movement such as twisting, waving the arms or legs, eyes drifting to one side, or grimacing. Seizures usually occur during sleep but may also occur while awake.

- **Temporal lobe epilepsy (TLE)** is the most common epilepsy syndrome in people who get focal seizures. These seizures are often associated with auras of nausea, emotions (such as déjà vu or fear), or unusual smell or taste. The seizure itself is a brief period of impaired consciousness which may appear as a staring spell, dream-like state, or repeated automatisms. TLE often begins in childhood or the teenage years. Research has shown that repeated temporal lobe seizures are often associated with shrinkage and scarring (sclerosis) of the hippocampus. The hippocampus is a brain region that is important for memory and learning.
- **Neocortical epilepsy** is characterized by seizures that originate from the cerebral cortex, or outer layer of the brain. The seizures can be either focal or generalized. Symptoms may include unusual sensations, visual hallucinations, emotional changes, muscle contractions, convulsions, and a variety of other symptoms, depending on where in the brain the seizures originate.

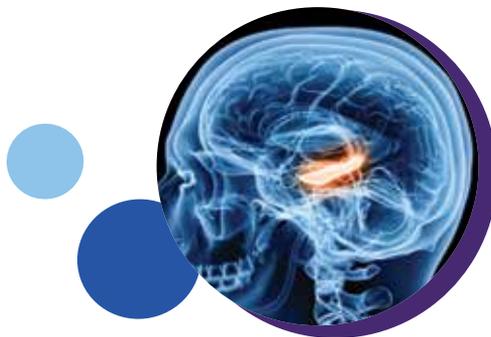
Types of childhood epilepsy

There are many other types of epilepsy that begin in infancy or childhood. Some childhood epilepsy syndromes tend to go into remission or stop entirely during adolescence. Other syndromes, such as juvenile myoclonic epilepsy and Lennox-Gastaut syndrome are usually present for life.



For example:

- **Infantile spasms** are clusters of seizures that usually begin before the age of 6 months. During these seizures, the infant may drop their head, bend at the waist, jerk their arms up toward their head, and/or cry out.
- **Childhood absence epilepsy** usually stops when the child reaches puberty. However, some children will continue to have absence seizures into adulthood and/or go on to develop other seizure types.
- Children with [Lennox-Gastaut syndrome](#) have several different types of seizures, including atonic seizures, which cause sudden falls and are also called drop attacks. Children with this condition usually begin having seizures before age 4. This severe form of epilepsy can be very difficult to treat.
- **Rasmussen's encephalitis** is a progressive form of epilepsy in which half the brain shows chronic inflammation.
- Children with [Dravet syndrome](#) and [Tuberous Sclerosis Complex](#) typically have seizures that start before age 1.
- **Hypothalamic hamartoma** is a rare form of epilepsy that first occurs during childhood and is associated with malformations of the hypothalamus at the base of the brain. People with this disorder have seizures that resemble laughing or crying. Such seizures frequently go unrecognized and are difficult to diagnose.



- **Developmental and Epileptic Encephalopathy (DEE)** refers to a group of severe epilepsies that are characterized both by seizures, which are often drug-resistant, as well as encephalopathy, which is a term used to describe significant developmental delay or even loss of developmental skills.

Nonepileptic seizures

Nonepileptic seizures outwardly resemble epileptic seizures but are not associated with electrical discharge in the brain.

Nonepileptic events may be referred to as psychogenic nonepileptic seizures (PNES). PNES do not respond to antiseizure drugs; instead, they are often treated by cognitive behavioral therapy to decrease stress and improve mindfulness.

A history of traumatic events is among the known risk factors for PNES. People with PNES should be evaluated for underlying psychiatric disorders and treated appropriately. Some people with epilepsy have psychogenic seizures in addition to their epileptic seizures.

Other nonepileptic events may be caused by:

- [Narcolepsy](#)
- [Tourette syndrome](#)
- Cardiac arrhythmia (irregular heartbeat)
- Other medical conditions with symptoms that resemble seizures

Because symptoms of these disorders can look very much like epileptic seizures, they are often mistaken for epilepsy.

How are epilepsy and seizures diagnosed and treated?

Diagnosing epilepsy and seizures

Accurate diagnosis of epilepsy is crucial for finding an effective treatment. Several tests are used to determine whether a person has epilepsy and, if so, what kind of seizures the person has. Generally, epilepsy is diagnosed after a person has had two or more unprovoked seizures separated by at least 24 hours.

Medical history

Taking a detailed medical history, including symptoms and duration of the seizures, is still one of the best methods available to determine what kind of seizures a person has had and to help determine what type of epilepsy the person has. The medical history should include details about any past illnesses or other symptoms a person may have had, as well as any family history of seizures.

Since people who have a seizure often do not remember what happened, accounts from people who have witnessed the seizures are very important. The person who experienced the seizure is asked about whether they felt anything unique (warning experiences) before the seizure started. The observers will be asked to provide a detailed description and timeline for the seizure.

Imaging and monitoring epilepsy

There are several scans and imaging techniques that can help diagnose and monitor a person's epilepsy. These include:

- An **electroencephalogram (EEG)**, a test that measures electrical activity in the brain, can look for abnormalities in the person's brain waves and may help to determine if antiseizure drugs would help. Video monitoring may be used in conjunction with EEG to determine the nature of a person's seizures and to rule out other disorders that may look like epilepsy.
- **SEEG (stereoelectroencephalography)** is the surgical implantation of electrodes into the brain in order to better find where the seizures are located. SEEG can help determine if an individual is a candidate for epilepsy surgery. A magnetoencephalogram (MEG) measures the magnetic signals generated by neurons to help find unusual brain activity. MEG can help surgeons plan any appropriate surgeries to remove focal areas involved in seizures while minimizing interference with normal brain function.
- **CT (computerized tomography)** and **MRI (magnetic resonance imaging)** scans reveal structural abnormalities of the brain such as tumors and cysts, which may cause seizures. A type of MRI called functional MRI (fMRI) can be used to localize normal brain activity and detect abnormalities in brain function.
- **PET (positron emission tomography)** scans take pictures of the brain and show regions of the brain with normal and abnormal chemical activity. PET scans can be used to identify brain regions with lower-than-normal metabolism, which can indicate the focus of the seizure after it has stopped.

- **Single photon emission computed tomography (SPECT)** is sometimes used to find the location of focal seizures in the brain. In a person admitted to the hospital for epilepsy monitoring, the SPECT blood flow tracer is injected within 30 seconds of a seizure. The images of brain blood flow at the time of the seizure are compared with blood flow images taken in between seizures. The seizure onset area shows a high blood flow region on the scan.

Blood tests

Blood tests can screen for metabolic or genetic disorders that may contribute to the seizures. They also may be used to check for underlying health conditions such as infections, lead poisoning, anemia, and diabetes that may be causing or triggering the seizures.



Developmental, neurological, and behavioral tests

Tests to measure motor abilities, behavior, and intellectual ability often are used to determine how epilepsy is affecting an individual. These tests also can provide clues about what kind of epilepsy the person has.

Treating epilepsy and seizures

Once epilepsy is diagnosed, it is important to begin treatment as soon as possible. There are many different ways to successfully control seizures. There are several treatment approaches that can be used, depending on the individual and the type of epilepsy.

Medications to treat seizures in epilepsy

The most common approach to treating epilepsy is to prescribe antiseizure medications. More than 40 different antiseizure medications are available today, all with different benefits and side effects. Most seizures can be controlled with one drug. Combining medications may amplify side effects such as fatigue and dizziness, so doctors usually prescribe just one drug whenever possible. Combinations of drugs, however, are still sometimes necessary for some forms of epilepsy that do not respond to a single drug.

Which drug a person should be prescribed depends on many different factors, including:

- Seizure type
- Lifestyle and age
- Seizure frequency
- Drug side effects
- Medicines for other conditions
- Pregnancy

It may take several months to determine the best drug and dosage. If one treatment is unsuccessful, another may work better.

When starting any new antiseizure medication, a doctor will begin with a low dose and increase the dose as needed depending on how effective the drug is. Sometimes doctors monitor the level of the drug in a person's blood to help determine when the optimal dosage has been reached. It may take time to find a dose that gives the best seizure control while minimizing side effects.

Side effects are often worse when first starting a new medicine and get better over time. Talk with your doctor about any side effects you experience while on medications and make sure they are aware of any other prescription or over-the-counter medications you are taking, including any herbs or supplements.

Some antiseizure medications can affect how and whether other drugs work and can interact in harmful ways with other medications. Some may make hormonal birth control less effective in women. Some medications are harmful to the fetus, so women who plan to get pregnant should consult with their physician to be sure that they are using medications that are safe during pregnancy.

Discontinuing medication should always be done with supervision of a healthcare professional. It is very important to continue taking antiseizure medication for as long as it is prescribed. Discontinuing medication too early is one of the major reasons people who have been seizure-free start having new seizures and can lead to status epilepticus, which is potentially life threatening. Some people with epilepsy may be advised to discontinue their antiseizure drugs after two to three years have passed without a seizure. Others may be advised to wait for four to five years, depending on the cause of the seizures.

While antiseizure medications are effective for many people with epilepsy, some do not respond to or are not able to take medications. Those individuals may be candidates for surgery, dietary changes, or devices to stop their seizures.

Diet and lifestyle changes in epilepsy

Some types of epilepsy may respond to changes in diet. A high-fat, high-protein, very low carbohydrate ketogenic diet is sometimes used to treat medication-resistant epilepsies. The diet induces a state known as ketosis, which means that the body shifts to breaking down fats instead of carbohydrates to survive. A ketogenic diet effectively reduces seizures for some people, especially children, with certain forms of epilepsy.

The ketogenic diet can be difficult to maintain since it requires that a person only eat certain foods and avoid many common foods that contain sugars and carbohydrates. Individuals using this diet to manage their seizures should be monitored to make sure they are getting enough nutrients. One side effect of a ketogenic diet is a buildup of uric acid in the blood, which can lead to kidney stones. A doctor or nutritionist can help people on this diet make sure they are getting the nutrients they need, and in the right amounts.

Sleep disorders are common among people with epilepsy and sleep deprivation is a powerful trigger of seizures. Treating sleep problems can help reduce seizures. People with epilepsy should practice good sleep hygiene: going to bed and getting up at the same time each day, reducing distractions in the bedroom, and avoiding big meals and exercise within a few hours of bedtime.



Surgery for epilepsy

Surgery is typically only considered after a person with epilepsy has unsuccessfully tried at least two medications to prevent seizures, or when doctors have found a brain lesion (an area of abnormal brain tissue) believed to be causing the seizures. When someone is found to be a good candidate, the surgery should be performed as soon as possible.

In considering a person's candidacy for surgery to prevent seizures, doctors will review:

- Seizure type
- Brain region involved
- Effect of the brain region on everyday function and behavior

Surgeons usually avoid operating in areas of the brain that are necessary for speech, movement, sensation, memory and thinking, or other important abilities.

While surgery can significantly reduce or even halt seizures for many people, any kind of surgery involves risk. Surgery for epilepsy does not always successfully reduce seizures and it can result in cognitive or personality changes as well as physical disability, even in people who are excellent candidates for it. Nonetheless, when medications fail, several studies have shown that surgery is much more likely to make someone seizure-free compared to attempts to use other medications.

Anyone thinking about surgery for epilepsy should be assessed at an epilepsy center experienced in surgical techniques and should discuss the surgery's risks and benefits with their healthcare team.

Even when surgery completely ends a person's seizures, it is important to continue taking antiseizure medication for some time, as prescribed by your healthcare provider. It is generally recommended that individuals continue medication for at least two years after a successful operation to avoid recurrence of seizures.

Surgical procedures for treating epilepsy disorders include:

- **Surgery to remove a seizure focus** involves removing the defined area of the brain where seizures originate. This procedure, which doctors may refer to as a lobectomy or lesionectomy, is the most common type of surgery for epilepsy and is appropriate only for focal seizures that originate in just one area of the brain.
- **Multiple subpial transection** may be performed when seizures originate in parts of the brain that cannot be removed. It involves making a series of cuts that are designed to prevent seizures from spreading into other parts of the brain while leaving the person's normal abilities intact.
- **Corpus callosotomy** or severing the network of neural connections between the right and left halves (hemispheres) of the brain, is done primarily in children with severe seizures that start in one half of the brain and spread to the other side. Corpus callosotomy can end drop attacks and other generalized seizures. However, the procedure does not stop seizures in the side of the brain where they originate, and these focal seizures may get worse after surgery.
- **Hemispherectomy and hemispherotomy** involve removing half of the brain's cortex, or outer layer. These procedures are used predominantly in children who have seizures that do not respond to medication because of damage that involves only half the brain, as in Rasmussen's encephalitis.

- **Thermal ablation for epilepsy**, also known as laser interstitial thermal therapy, directs energy to a specific, targeted brain region causing the seizures (the seizure focus). The energy, which is changed to thermal energy, destroys the brain cells causing the seizures. Laser ablation is less invasive than open brain surgery for treating epilepsy.

Devices

Some people may use neurostimulation devices to treat their epilepsy. These devices deliver electrical stimulation to the brain to reduce seizure frequency:

- **Vagus nerve stimulation** involves surgically implanting a device under the skin of the chest. The device, which is attached by wire to the vagus nerve in the lower neck, delivers short bursts of electrical energy to the brain.
- **Responsive stimulation** uses an implanted device that analyzes brain activity patterns to detect a forthcoming seizure. Once detected, the device administers an intervention, such as electrical stimulation or a fast-acting drug to prevent the seizure from occurring.
- **Deep brain stimulation** involves surgically implanting an electrode connected to a pulse generator (similar to a pacemaker) to deliver electrical stimulation to specific areas in the brain to regulate electrical signals in neural circuits.



How can I or my loved one live with epilepsy and seizures?

Many people with epilepsy can do the same things as people without the disorder. People who respond to treatment may go months or years without having a seizure. One-third or more of people with epilepsy, however, may have cognitive or neuropsychiatric symptoms that can negatively impact their quality of life.

People with treatment-resistant epilepsy may have as many as hundreds of seizures a day or they may have one seizure a year with sometimes disabling consequences. Having treatment-resistant epilepsy is associated with an increased risk of cognitive impairment, particularly if the seizures developed in early childhood. These impairments may be related to the underlying conditions associated with the epilepsy rather than to the epilepsy itself.



Special risks associated with epilepsy

Although many people with epilepsy lead full, active lives, there is an increased risk of death or serious disability associated with epilepsy. There may be an increased risk of suicidal thoughts or actions related to some antiseizure medications that are also used to treat mania and bipolar disorder. Two life-threatening conditions associated with epilepsy are status epilepticus and sudden unexpected death in epilepsy (SUDEP).

1. **Status epilepticus** is a potentially life-threatening condition in which a person either has an abnormally prolonged seizure (over five minutes) or does not fully regain consciousness between recurring seizures. Status epilepticus can be convulsive (where signs of a seizure are seen) or nonconvulsive (which cannot be seen and is diagnosed by an abnormal EEG). Nonconvulsive status epilepticus may look like a long episode of confusion, agitation, loss of consciousness, or even coma.

Evidence has shown that five minutes is sufficient to damage neurons and that seizures are unlikely to end on their own, making it necessary to seek medical care immediately.

2. **SUDEP (Sudden Unexplained Death in Epilepsy)** refers to deaths in people with epilepsy that are not from injury, drowning, or other known causes. Most, but not all, cases of SUDEP happen during or right after a seizure.

Current research on SUDEP points to abnormal brain activity that impacts heart and respiratory function. This may be due to variations in a person's genes, particularly genes that cause epilepsy and also affect heart function. SUDEP can occur at any age and people with seizures that are difficult to control tend to have a higher incidence of SUDEP. People with epilepsy may be able to reduce their risk of SUDEP by carefully taking all antiseizure medication as prescribed and making sure they are receiving the best possible care for their epilepsy. Not taking the prescribed dosage of medication or not taking the most appropriate medication may increase the risk of SUDEP, especially in people who are taking more than one medication.



Mental health and stigmatization

In adults with epilepsy, depression and anxiety are the two most frequent mental health diagnoses. These conditions can be treated with counseling or most of the same medications used in people who do not have epilepsy. People with epilepsy should discuss their symptoms with their healthcare professionals so they can receive the appropriate treatments and care.

Children with epilepsy have a higher risk of developing depression and/or attention deficit hyperactivity disorder (ADHD) compared with their peers. Behavioral problems and/or mental health issues may precede the onset of seizures in some children. Counseling and support groups can help families cope with epilepsy in a positive manner.

Driving and recreation

Some states may not issue a driver's license to a person with epilepsy. Individuals with epilepsy may be able to get an exception if they can demonstrate a period of being seizure-free, or if their seizures only happen during sleep.

The risk of seizures may also limit a person's ability to participate in sports, exercise, or other recreational activities, including climbing, sailing, swimming, or working on ladders. There is some evidence that regular exercise may improve seizure control in some people, but this should be done under a doctor's supervision. The benefits of sports participation may outweigh the risks. Coaches and activity leaders can take appropriate safety precautions. Individuals with epilepsy should avoid dehydration, overexertion, and low blood sugar, as these problems can increase the risk of seizures.

Education and employment

By law, people with epilepsy in the U.S. cannot be denied employment or access to any educational, recreational, or other activity because of their epilepsy. However, significant barriers still exist for people with epilepsy in school and work. Antiseizure medications may cause side effects that interfere with concentration and memory.

Children with epilepsy may need extra time to complete schoolwork, and they may need to have instructions or other information repeated for them. Some children with epilepsy will need special educational plans to help address their learning challenges. Teachers should be given instructions on what to do if a child in their classroom has a seizure, and parents should work with the school system to find reasonable ways to accommodate any special needs their child may have.

Pregnancy and parenthood

Epilepsy itself does not interfere with the ability to become pregnant and women who have epilepsy and take appropriate precautions have similar odds of having a healthy pregnancy and a healthy child to women without a chronic medical condition. With the appropriate selection of safe antiseizure medications during pregnancy, use of supplemental folic acid, and ideally, with pre-pregnancy planning, most people with epilepsy can have a healthy pregnancy with good outcomes for themselves and their developing child.

Women with epilepsy should be advised that some antiseizure medications carry an increased risk of birth defects. It is important to work with a team of providers that includes a neurologist and an obstetrician to learn about any special risks associated with epilepsy and antiseizure medications.

Children of parents with epilepsy have about 5% risk of developing the condition at some point, compared to roughly 1% in a child in the general population. However, the risk of developing epilepsy increases if a parent has a hereditary form of the disorder. Parents who are concerned that their epilepsy may be hereditary may wish to consult a genetic counselor to determine their risk of passing on the disorder.



What are the latest updates on epilepsy and seizures?

The National Institute of Neurological Disorders and Stroke (NINDS) conducts and supports research to better understand and diagnose epilepsy, develop new treatments, and ultimately, to prevent epilepsy. NINDS epilepsy research efforts include:

The Epilepsy Therapy Screening Program (previously called the Anticonvulsant Screening Program) was created in 1975 to facilitate the discovery of new antiseizure drugs and has contributed to the development of nearly a dozen approved medications.

NINDS Centers Without Walls (CWoW) for Collaborative Research in the Epilepsies are multicenter, multidisciplinary groups that address research challenges to advance prevention, diagnosis, and/or treatment of the epilepsies and related co-occurring conditions.

NINDS's epilepsy CWoW projects include:

- Epilepsy 4000 (Epi4K) was an international effort to analyze DNA from 4,000 people with epilepsy and their relatives to identify disease-causing genes. Epi4K has now expanded into the worldwide effort called the [Epi25 Collaborative](#) with support from the National Human Genome Research Institute.
- [The Center for SUDEP Research](#) (CSR) brought together a collaboration of researchers with diverse expertise from multiple academic institutions in the United States and England to study and understand SUDEP.

- [The Epilepsy Bioinformatics Study for Antiepileptogenic Therapy \(EpiBioS4Rx\)](#) uses human and animal studies to investigate epilepsy that develops following traumatic brain injury (TBI) with the goal of identifying biomarkers (biological signs of disease) that could be used to predict who is most likely to develop epilepsy following TBI.
- [The Channelopathy-Associated Epilepsy Research Center](#) combines high-throughput technologies and high-content data modeling systems to investigate the functional consequences of genetic variants in channelopathy-associated epilepsy, including Dravet Syndrome.
- [The Epilepsy Multiplatform Variant Prediction \(EpiMVP\)](#) aims to advance knowledge of genetic variants of uncertain significance in non-ion-channel epilepsy genes.

NINDS researchers are conducting clinical studies aimed at finding better ways to safely detect, treat, or prevent epilepsy.

Several projects relevant to epilepsy are funded through the Brain Research through Advancing Innovative Neurotechnologies (BRAIN) Initiative®. These efforts aim to better understand, measure, and monitor how the brain generates neural activity and are working to develop new technologies and devices to measure brain activity, predict seizure onset, and deliver therapeutic stimulation to limit seizure activity.

Other areas of epilepsy research include:

- Advancing gene sequencing tools and technologies to identify genetic mutations that cause various forms of epilepsy.
- Understanding the underlying biology that contributes to epilepsy, including how brain cells communicate with one another and the role that various brain chemicals play in the disease.

- Developing new animal models to learn about the causes of epilepsy, find ways to prevent the disease, and test promising therapies.
- Studying brain tissue obtained from epilepsy surgery or via donation at the time of death to increase knowledge into causes of epilepsy and how they affect the brain.
- Identifying the genes and their function(s) relevant to rare epilepsy syndromes so that targeted treatments can be developed for children and adults with these causes of epilepsy.
- Developing new therapies through preclinical studies utilizing the NINDS translational research programs as well as the Blueprint Neurotherapeutics programs.
- Studying the impact of early in life seizures on cognitive and behavioral outcomes in children with epilepsy.
- Using artificial intelligence (AI) and machine learning (ML) to help to identify the specific area of the brain where the seizures begin.



How can I or my loved one help improve care for people with epilepsy and seizures?

Consider participating in a clinical trial so clinicians and scientists can learn more about epilepsy, seizures, and related disorders. Clinical research with human study participants helps researchers learn more about a disorder and perhaps find better ways to safely detect, treat, or prevent disease.

All types of study participants are needed—those who are healthy or may have an illness or disease—of all different ages, sexes, races, and ethnicities to ensure that study results apply to as many people as possible, and that treatments will be safe and effective for everyone who will use them.

For information about participating in clinical research visit NIH [Clinical Research Trials and You](#). Learn about clinical trials currently looking for people with epilepsy and seizures at [Clinicaltrials.gov](#).

There are additional ways for people with epilepsy and their families to help advance research. Pregnant people who are taking antiseizure drugs can help researchers learn how these drugs affect unborn children by participating in The North [American Antiepileptic Drug \(AED\) Pregnancy Registry](#). Registry participants are given educational materials on pre-conception planning and perinatal care and are asked to provide information about the health of their children, which is kept confidential and only used in an anonymized fashion by researchers.

People with epilepsy can help research efforts by making arrangements to donate brain tissue either at the time of surgery for epilepsy or at the time of death. Researchers can then use the tissue to study epilepsy and other disorders to better understand what causes seizures. For example, the [NIH NeuroBioBank](#) is an effort to coordinate a network of brain banks in the U.S. where brain tissue and data are collected, evaluated, stored, and made available to researchers in a standardized way for the study of neurological, psychiatric, and developmental disorders, including epilepsy. A list of participating NIH NeuroBioBank repositories and additional brain banks are maintained on the [NIH NeuroBioBank website](#). Each brain bank may have different protocols for registering a potential donor. Individuals are strongly encouraged to contact the brain bank directly to learn more.



Where can I find more information about epilepsy and seizures?

Information about epilepsy and seizures may be available from the following organizations and resources:

[National Institute of Neurological Disorders and Stroke](#)

800-352-9424

[American Epilepsy Society](#)

312-883-3800

[BeMedWise Program at NeedyMeds](#)

978-281-6666

[Caregiver Action Network](#)

202-454-3970 or

Caregiver Help Desk: 855-227-3640

[Child Neurology Foundation](#)

888-417-3435

[CURE Epilepsy](#)

312-255-1801 or 844-231-2873

[Dravet Syndrome Foundation](#)

203-392-1950

[Epilepsy Alliance of America](#)

800-642-0500

[Epilepsy Leadership Council](#)

312-883-3800

[Epilepsy Foundation](#)

800-332-1000

Family Caregiver Alliance

415-434-3388 or 800-445-8106

International League Against Epilepsy

+860-586-7547

Lennox-Gastaut Syndrome (LGS) Foundation

718-374-3800

National Organization for Rare Disorders (NORD)

800-999-6673

Partners Against Mortality in Epilepsy (PAME)

The Charlie Foundation for Ketogenic Therapies

310-393-2347

The North American Antiepileptic Drug (AED) Pregnancy Registry

888-233-2334

Tuberous Sclerosis Complex Alliance

800-225-6872 or 301-562-9890

SLC6A1 Connect

303-907-8038

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