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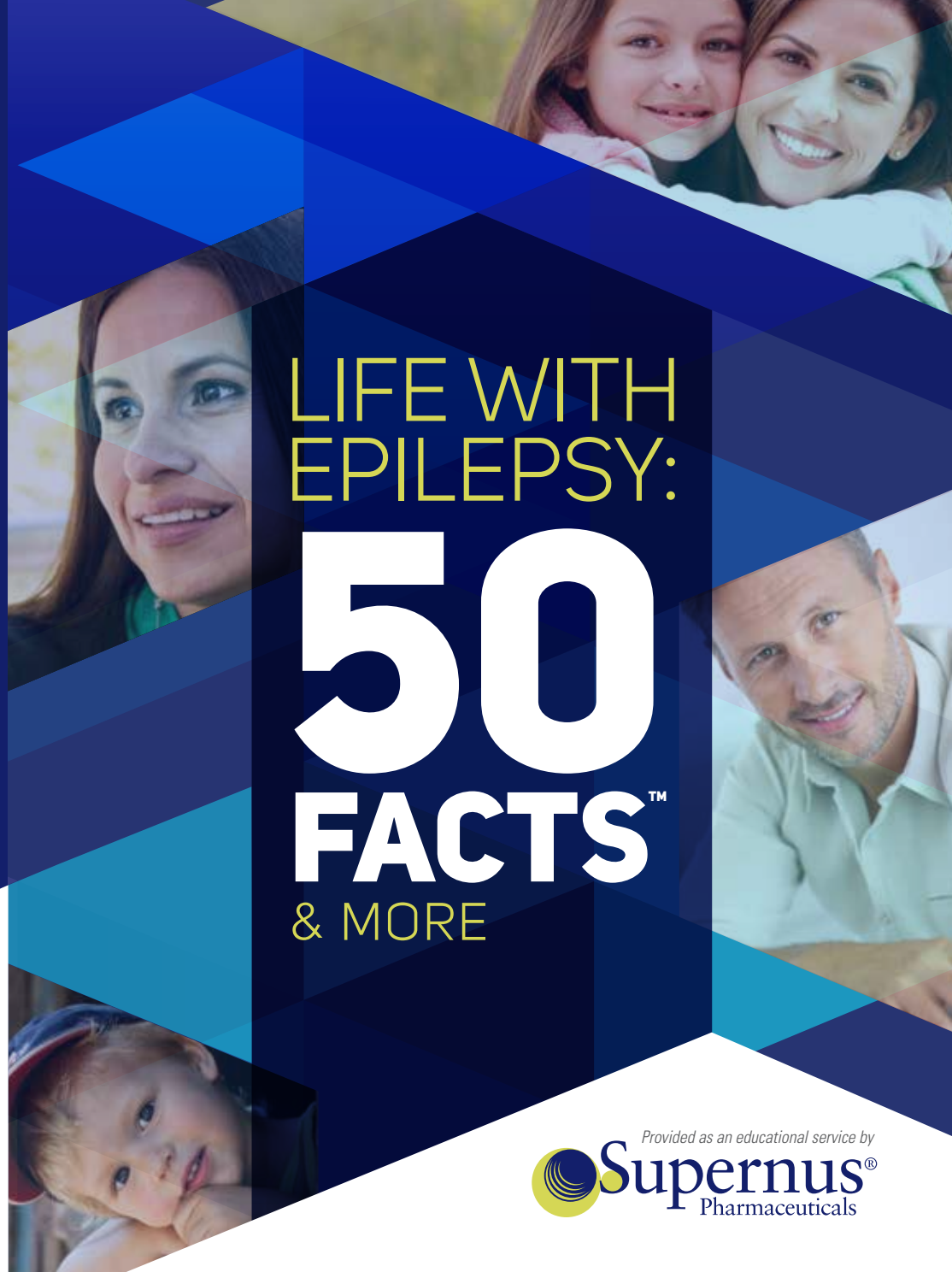
LIFE WITH EPILEPSY: 50 FACTS™ & MORE

Supernus® Pharmaceuticals



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& MORE

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CONTENTS

This
Epilepsy Patient Resource
Belongs To:

_____

_____

Preface

Epilepsy is the fourth most common brain condition and affects people of all ages. Commonly known as a seizure disorder, epilepsy is diagnosed after you have had two or more seizures that weren't caused by another medical condition. Because many seizures are unpredictable, and may happen after long periods of being seizure-free, people with epilepsy should work closely with their healthcare team to develop and maintain a treatment plan that best meets their needs.

1 in 26 people in the United States will develop epilepsy at some point in their lifetime.

FACT 1

The first step in managing your epilepsy is to be prepared. Throughout this book, you'll find facts and information to help you understand how seizures happen and why you may need medicine, as well as tips to help you feel more in control of your life with epilepsy.

Learning the best ways to manage your epilepsy is an ongoing process. Beyond explaining the diagnosis and care of epilepsy, this book is meant to serve as an educational resource for people with epilepsy and their families and caregivers, and can be referenced time and again.

SECTION

1

MY FIRST SEIZURE

neurons
prefrontal cortex
motor cortex
sensory cortex
visual cortex
speech centers
hearing centers
cerebellum
brain stem
action potentials
ions
ion channel
neurotransmitters
synapse
post-synaptic receptors
idiopathic epilepsy
absence seizure
generalized seizure
syncope

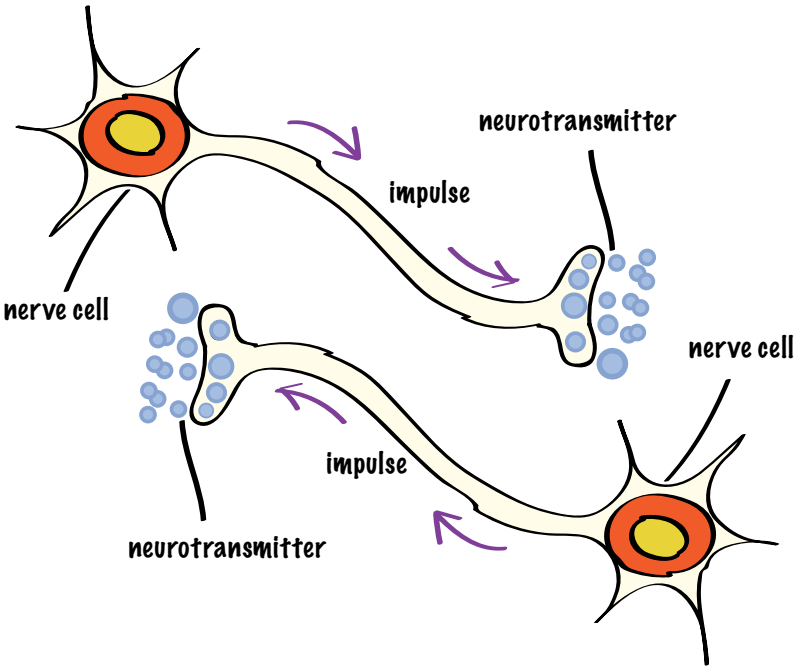
What happened? What now?

Having a seizure can be a scary experience, particularly when it is your first seizure. You were probably concerned about what to do when the doctor first diagnosed your epilepsy. It helps to face these fears by understanding how and why seizures happen, the things you can do to lower your likelihood of having another seizure, and how to live more comfortably with your epilepsy. Let's start by looking at some facts about how the brain works, and what happens during an epileptic seizure.

FACT 2

People who have had 2 or more seizures for no known reason that are separated by at least 24 hours may need to be evaluated for epilepsy.

To understand how and why seizures occur, you should understand a little bit about how the brain works. You already know that the brain controls body functions such as walking, talking, and thinking. To accomplish these tasks, special centers in your brain send signals throughout a network of nerve cells (**neurons**). To send and receive these signals, neurons rely on two forms of information transmission—electrical and chemical.



Nerve cells send information along their lengths as electric impulses, and from cell to cell using special chemicals called neurotransmitters. When a second nerve cell is exposed to neurotransmitters, a second electrical impulse is created that moves along its length, and so on.

Neurons, the primary cell for communication in the brain, transmit information by conducting electrical impulses.

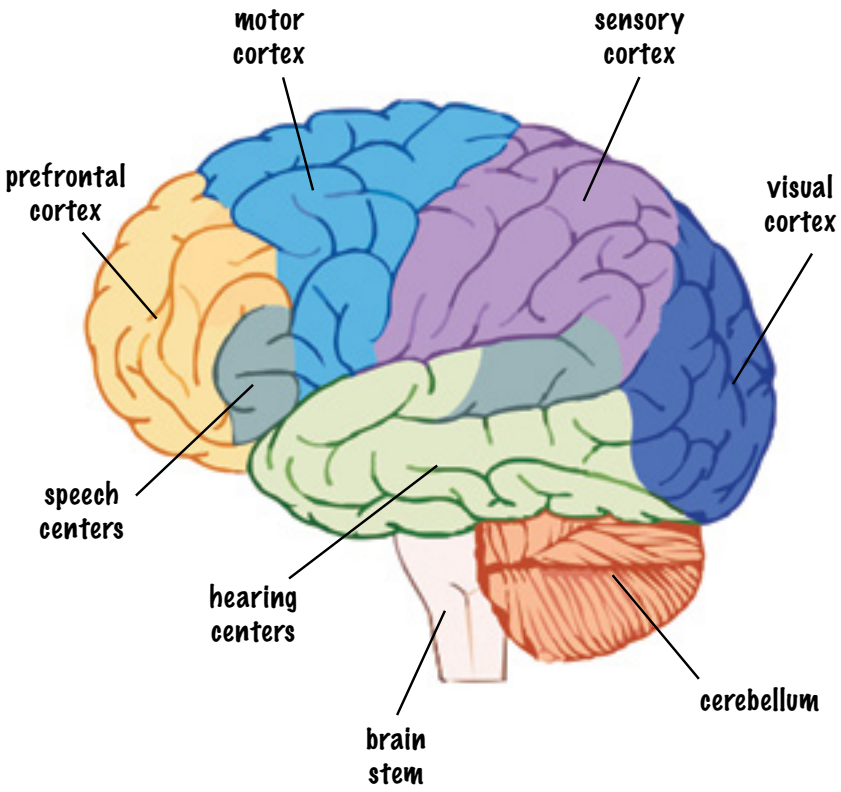
FACT 3

Specific centers in your brain are responsible for controlling voluntary processes (like telling your hand to pick up a pencil, or solving a math equation "in your head"). Other brain centers control involuntary processes (like digesting food, controlling your breathing and heart rate), but they all rely on the same signaling actions. Depending on the type of epilepsy you have, one or more of these brain centers may function differently during a seizure, and cause different effects or symptoms:

- **Prefrontal cortex:** involved with processes that impact behavior and personality
- **Motor cortex:** involved with control and coordination of muscle movement (like telling your hand to pick up a pencil)
- **Sensory cortex:** involved with your understanding of sensations from skin, muscle joints, and organs
- **Visual cortex:** involved with converting information from the eyes into images we understand
- **Speech centers:** involved with interpreting spoken and written language, and with speech
- **Hearing centers:** involved with interpreting sound so that we can understand words and melodies
- **Cerebellum:** involved with coordination of skeletal muscle function
- **Brain stem:** connects the brain and the spinal cord

Neurons located in different areas of the brain are dedicated to controlling specific functions.

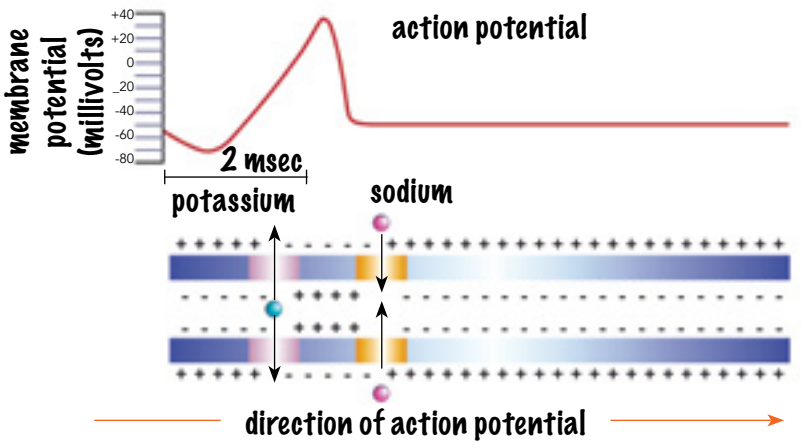
FACT 4



FACT 5

The movement of ions from one neuron to the next creates electrical activity in the brain.

To send information from one end of a neuron to the other, tiny electric impulses (known as **action potentials**) sweep along the length of the neuron like a wave travels across the ocean. These electric impulses are produced when specific **ions** (types of chemicals like sodium, potassium, and calcium) move quickly in or out of the nerve cell. Each ion type moves in and out of cells through a specific **ion channel**, a hole in the outer wall of the cell. These channels can also be controlled by certain seizure medicines used to treat some forms of epilepsy.

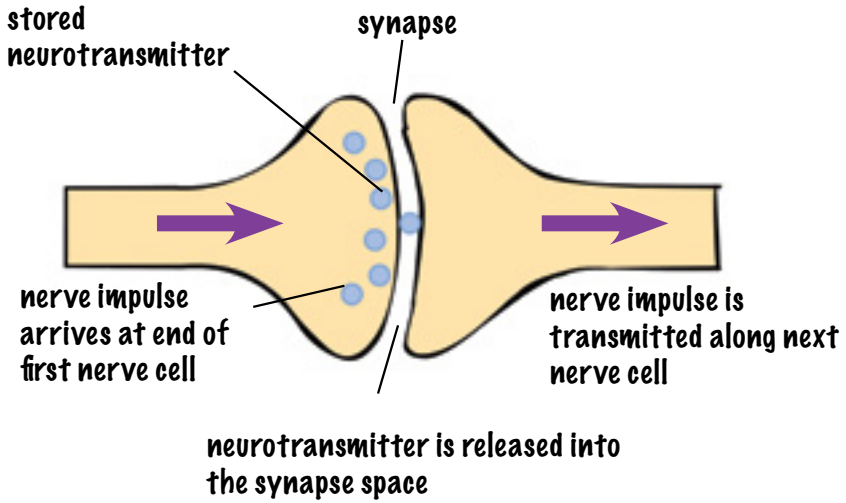


This figure shows the movement of sodium and potassium ions into and out of a nerve cell during an action potential.

YOU CAN LEARN MORE ABOUT:

On page 50 you can learn more about antiepileptic medicines that control the activity of specific ion channels.

When an action potential reaches the end of a nerve cell, it triggers the release of a "chemical messenger" called a neurotransmitter into the space between the cells called a **synapse**. This is how information is sent from one cell to the next. You may recognize the names of some neurotransmitters already (dopamine, serotonin, norepinephrine) but others (GABA, acetylcholine, NMDA) may be less familiar to you. Different parts of the brain rely on different types of neurotransmitters to communicate between nerve cells.



This figure illustrates the transmission of a signal from one nerve cell to another across the synapse. As the action potential reaches the end of one nerve cell, it triggers the release of neurotransmitters. When these neurotransmitters find their receptors on the next nerve cell, a new action potential begins, and then moves along the length of the second nerve.

YOU CAN LEARN MORE ABOUT:

On page 51 you can learn more about antiepileptic medicines that control the activity between specific neurotransmitters and their receptors.

Once released from the nerve cell, these neurotransmitters find and activate special receptors located on the next nerve in the network. These are called **post-synaptic receptors**. Under normal conditions, neurotransmitters interact with specific receptors to either stimulate (excite) or block (inhibit) the electrical signals of the next nerve cell in the chain. When a neurotransmitter overexcites or overblocks the next cell, the normal activity of the chain is disrupted. Sometimes this can cause seizures. Some medicines used to treat epilepsy can control the interaction between neurotransmitters and their receptors.

FACT 6

Epilepsy medicines work by controlling electrical or chemical activity in the brain.

Based on the type of epilepsy you have and the symptoms associated with your seizures, your doctor may recommend medicines that change the activity of ion channels or the interactions between neurotransmitters and their receptors.

DID YOU KNOW?

Because different parts of the brain rely on different neurotransmitters to communicate between nerve cells, medicines that alter the activity of one type of neurotransmitter may not affect activity in other parts of the brain.

Some irregular electrical activity in the brain is caused by inherited gene mutations that interfere with normal nerve cell function. Doctors call this **idiopathic epilepsy**. Irregular electrical activity in the brain also can happen after a head injury, stroke, or brain diseases such as Alzheimer's disease. These injuries can 1) change the way that nerves connect with one another; 2) change the number or intensity of electrical impulses a nerve can generate; or 3) change the way that post-synaptic receptors respond to a neurotransmitter, or any combination of these factors.

However, for many people, the exact cause of the irregular electrical activity in their brain is not known.

FACT 7

There are different causes for irregular electrical activity in the brain.

Depending on where the irregular electrical activity begins in the brain, people with epilepsy may have a variety of symptoms, from a brief loss of attention to the world around them (**absence seizure**), to a range of muscle activity changes that can include momentary muscle tightening or stiffness with the inability to move, and rapid and uncontrolled muscle movement (**generalized seizure**) that can be life-threatening. Loss of consciousness occurs during many episodes of epilepsy.

YOU CAN LEARN MORE ABOUT:

On pages 32–33 you can find a chart of the most common types of epilepsy and symptoms associated with each.

FACT 8

For more than half of people with epilepsy, the exact cause is not known.

FACT 9

It is important to know the difference between seizures and syncope.

Seizures or syncope?

The change in brain activity during a seizure can cause some people to lose consciousness. However, loss of consciousness can also occur when the change in brain activity is caused by a temporary drop in blood flow, a condition known as **syncope**. Syncope is often mistaken for an epileptic seizure because both conditions can happen quickly, without warning, and result in loss of consciousness.

Syncope is more common than epileptic seizures, is treated differently than epilepsy, and has to be ruled out before a diagnosis of epilepsy can be made. About a third of the general population has had an episode of syncope, whereas approximately 8% of the general population may have a seizure once in their lifetime. Because it occurs so frequently, syncope is the medical disorder that is most commonly mistaken for epilepsy.

Seizures are treated with medicines that affect the electrical signals in the brain. Syncope is treated with medicines that address the different causes of not getting enough blood to the brain.

Fever in children or mental stress in adults can trigger seizures in people who don't have epilepsy.

FACT 10

Seizures not caused by epilepsy

Non-epileptic seizures may seem like epileptic seizures. Many of the symptoms are the same, such as convulsions, shaking, and temporary loss of consciousness or attention.

Unlike seizures of epilepsy, non-epileptic seizures are triggered by causes that can be prevented or changed, such as fever in children or mental stress in adults. Traumatic experiences, such as physical or mental harm and abuse, can trigger non-epileptic seizures because of the stress they create. Non-epileptic seizures often are treated with psychiatric counseling, rather than medicine.

Things to talk about with my healthcare provider:

SECTION

2

SYMPTOMS and DIAGNOSTIC TESTING

electroencephalogram (EEG)
computerized axial tomography (CAT) scan
magnetic resonance imaging (MRI) scan
positron emission tomography (PET) scan
magnetic resonance spectroscopy (MRS) scan
polysomnography
partial seizures • secondarily generalized seizure
aura • simple partial seizures
complex partial seizure • generalized seizure
grand mal seizures • convulsions
tonic–clonic seizures • tonic • clonic
myoclonic jerks • atonic seizures
absence seizure • petit mal seizures
Lennox-Gastaut syndrome • febrile seizures

What did I learn from my EEG, imaging, and sleep studies?

FACT 11

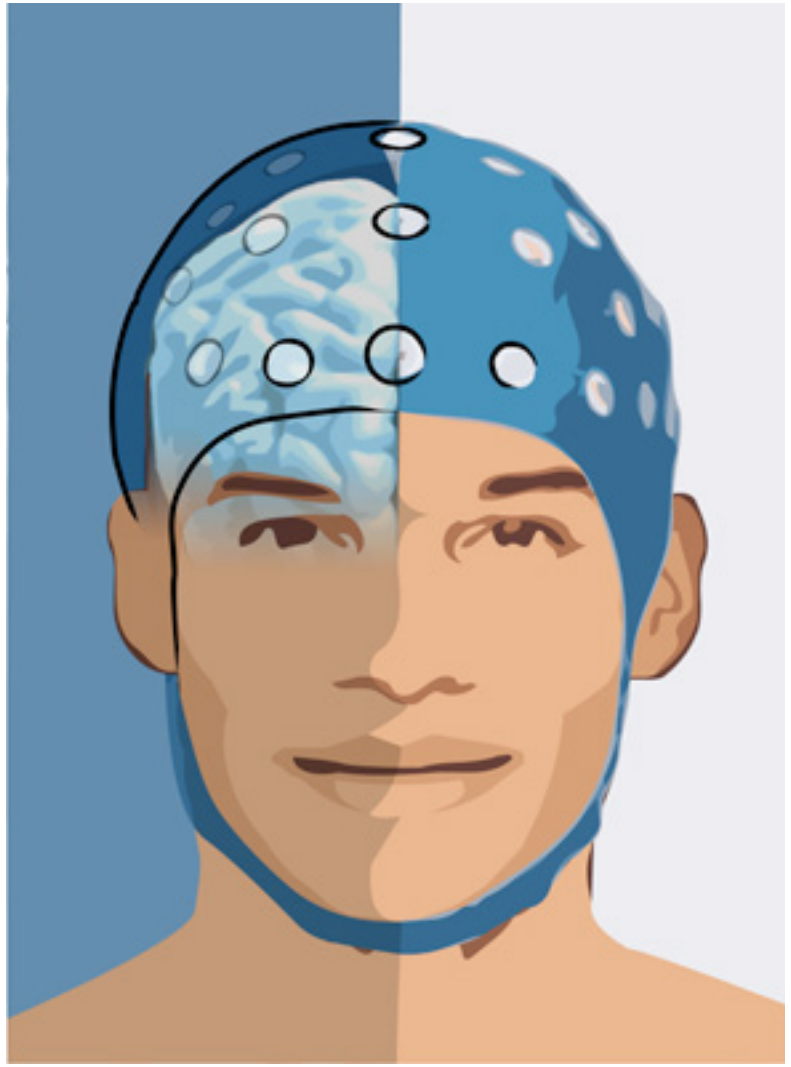
About 150,000 new cases of epilepsy are diagnosed each year in the United States.

The first time you had a seizure, your doctor may have ordered a test that used electrodes or a cap placed on your head to record the electrical activity in your brain. This test is called an **electroencephalogram (EEG)**. It detects the intensity of electrical activity in different areas of your brain, and records them on a paper or digital chart. This helps the doctor see where any irregular electrical activity in the brain may be occurring.

An EEG finding of irregular electrical activity can help the doctor diagnose epilepsy and find the part of the brain where seizures start.

DID YOU KNOW?

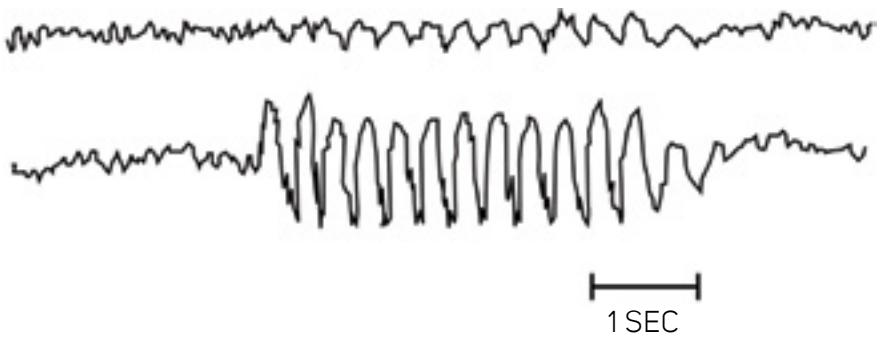
The EEG test uses the same recording principle as the electrocardiogram (EKG), which records electrical activity in the heart.



An EEG reads electrical signals in the brain.

FACT 12

You can have a normal EEG result and still have epilepsy.



An EEG records the normal electric activity of the brain over time (top line) and the activity change associated with the start and end of a seizure (bottom line).

Seizures are unpredictable. So your first EEG may not detect irregular activity if no seizure occurs during the test.

FACT 13

Your first epilepsy diagnosis may change as your doctor learns more about your personal condition.

In order to make your EEG tests more accurate, stressful events such as sleep deprivation or stimulation with flashing light (or both) are sometimes used to make the brain more active. Any irregular brain activity may then be easier to find and can make it easier for your doctor to learn whether you have epilepsy.

Other tests commonly used to help diagnose epilepsy include:

Computerized Axial Tomography (CAT) scan

A CAT scan creates a three-dimensional picture of your brain using low-dose X-rays. If you had a procedure that required you to lie down in a wide, ring-like instrument it was probably a CAT scan. The CAT scan is good for finding minor irregularities in the structure of your brain. Depending on the symptoms you described to your doctor, this test may have been part of your evaluation.

Magnetic resonance imaging (MRI)

An MRI also produces a three-dimensional picture of your brain, but is used to detect different features. If you had a procedure that required you to lie in a small, long tunnel that made a thumping sound, it was probably an MRI. The MRI test is good for seeing subtle differences in brain tissue density that may not be detected in a CAT scan.

Positron emission tomography (PET) scan

PET scans are used to watch chemical reactions in the brain. During a PET scan, a person is injected with a harmless dye that can be detected as it is processed by the body. The PET scan combines the imaging capability of a CAT scan with the ability to see where the injected dye has collected in your brain. This can help doctors find the location of irregular electrical activity.

Magnetic resonance spectroscopy (MRS) scan

MRS scans are similar to MRIs. MRS is used to evaluate chemical activity in specific parts of your brain, and provides additional information about any areas where unusual chemical activity is occurring with irregular electrical activity.

Some studies show that sleep disturbance is almost twice as common in people with epilepsy than in people without epilepsy. Irregular electrical activity in the brain can happen while you're asleep, and even seizures that happen while you are awake can affect your sleep.

Because of this, doctors may prescribe a sleep study for a person with epilepsy. Doctors may call this test a **polysomnography**. In this sleep study, electrical activity is recorded from various body parts, including the brain, the eyes, and the muscles.

DID YOU KNOW?

When all the testing is done, the best way to monitor the progression of your epilepsy is to keep track of your symptoms and activities before and after a seizure, and share your records with your healthcare provider during each office visit.

FACT 14

You can have a seizure while you're asleep, and lack of sleep can trigger seizures.

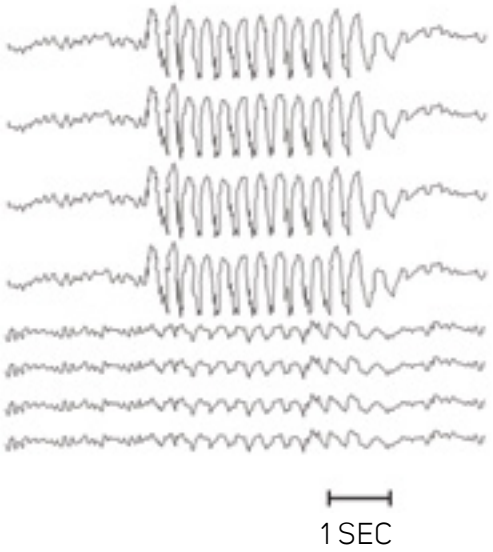
Are there different types of epilepsy? **YES**.

Seizures can be placed into two main categories based on the parts of the brain in which they occur. Your symptoms and test results can help your doctor diagnose your seizure type and help decide the best treatment.

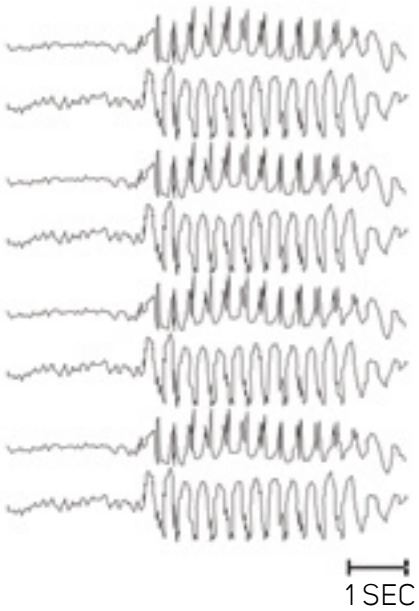
Partial seizures start in one side, or hemisphere, of the brain. Because each side of the brain controls one side of the body, partial seizures typically affect only one side of the body. If the electrical activity originating in one hemisphere travels to other parts of the the brain, more body parts may be involved—this is called a **secondarily generalized seizure**.

Partial seizures often cause muscle stiffness and/or movements and can affect your senses, causing you to experience an **aura**, or odd sensations or feelings that occur just before a seizure. If no loss of consciousness occurs, these are called **simple partial seizures**. If you lose consciousness, it's called a **complex partial seizure**. Complex partial seizures may also cause loss of memory or changes in behavior.

Generalized seizures used to be called **grand mal seizures**. They involve both sides of the brain. In this type of seizure, both sides of the body have muscle contractions followed by limb jerking (**convulsions**). The person also loses consciousness.



EEG recordings during a partial seizure (above) and during a generalized seizure (below).



Different types of seizures come from different areas of the brain.

FACT 15

Generalized seizures with muscle contraction and limb jerking are called **tonic–clonic seizures**. The person often lets out a "cry" when the muscles of the airway contract or may lose bladder control. The **tonic** (contraction) phase is followed by a **clonic** (jerking) phase. Seizures can cause tonic or clonic movements alone, or together.

Other generalized seizure types include **myoclonic jerks**, which are rapid muscular contractions that may look like they are caused by a "shock." **Atonic seizures** happen when the person loses tone (the normal amount of tension) in their muscles. These seizures may cause a body part such as the head or limbs to "go limp."

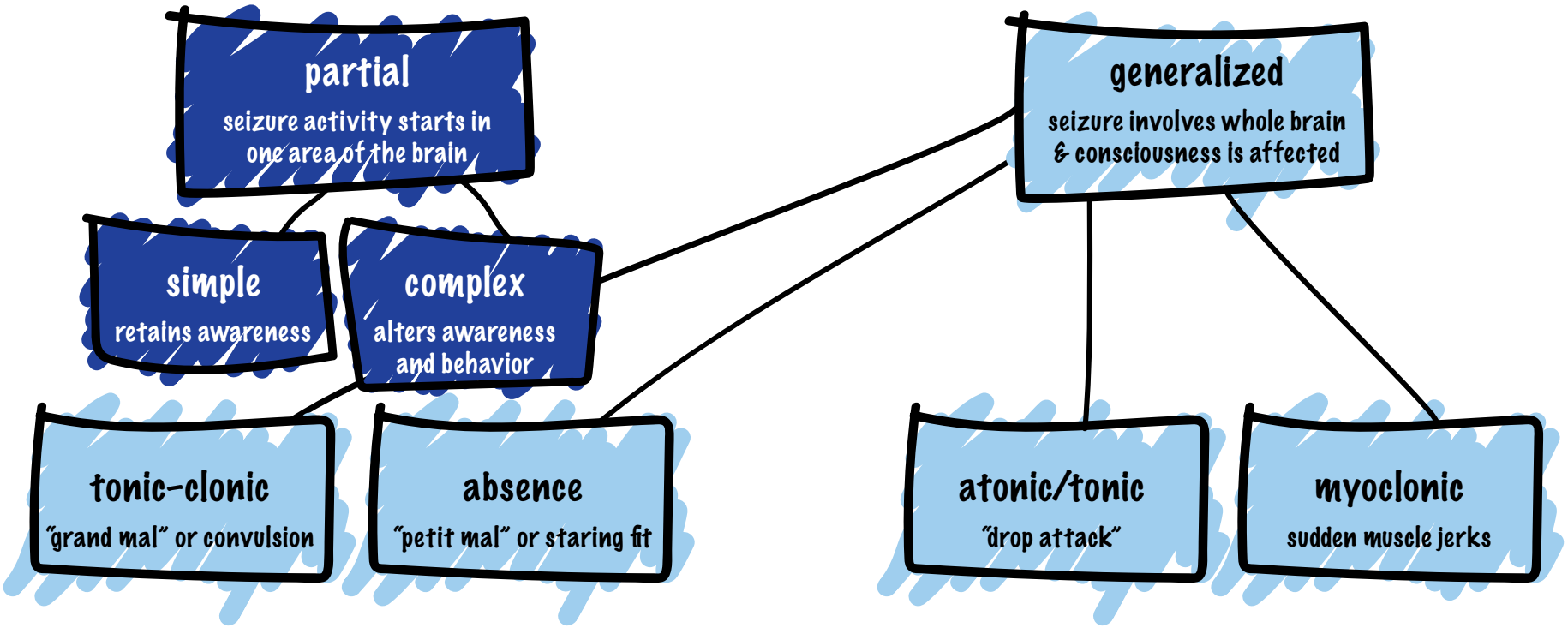
Generalized seizures may result in a sudden blank stare and rolling of the eyes. This type of generalized seizure is called an **absence seizure**. Absence seizures used to be called **petit mal seizures**. They most commonly affect younger children and teens, although adults may have them as well.

FACT 16

Seizures do not always cause muscle convulsions.

Lastly, some uncommon seizure types have more specific names. For example, **Lennox-Gastaut syndrome** may involve various seizure types and cause problems with thinking or memory. These seizures are thought to occur for different reasons, many of which include problems during development; for this reason, they often are found in children. **Febrile seizures** may occur in young children. Rather than irregularities in the brain, these seizures are thought to be caused by fevers, and typically occur during common childhood infections. Single febrile seizures are not believed to increase the risk for epilepsy, although the likelihood may be increased if febrile seizures are severe or happen more than once.

A Visual Classification of Seizure Types



SECTION

3

LIVING with EPILEPSY

seizure triggers
ketogenic diet
photosensitive epilepsy
seizure response plan
resource kit
seizure diary

FACT 17

Epilepsy is not contagious. It can not spread from one person to another.

Epilepsy affects many people. Worldwide, there are estimated to be 50 million people with epilepsy. Within the United States, an estimated 150,000 people are newly diagnosed every year. The onset of epilepsy is related to age, with the very young and the very old being most affected.

About a third of epilepsy cases occur in people 18 years and younger. These young people often experience seizures due to genetic or developmental disorders, such as Lennox-Gastaut syndrome. In contrast, epilepsy in elderly people is often associated with changes in the brain related to diseases such as stroke, Alzheimer's disease, and other diseases that weaken the function of the brain and nervous system.

FACT 18

When evaluating and managing a first seizure in children, doctors use different guidelines than for adults.

DID YOU KNOW?

Epilepsy often affects very young and very old people.

Recognizing triggers and risk factors of seizures

An important first step in being prepared for seizures is identifying specific things that trigger your seizures and knowing the warning signs. Common **seizure triggers** may include missing doses of seizure medicine, lack of sleep, and use of drugs or alcohol. Changes in hormone levels or diet and flashing lights also can trigger seizures for some people. For example, roughly half of women with epilepsy experience increased seizure frequency during their menstrual cycles. Some women with epilepsy may take extra medicine or hormones during their menstrual periods as a preventative strategy.

Food also can alter brain function, and the role of diet is thought to be important in the management of epilepsy. Doctors usually recommend that people with epilepsy follow a balanced diet.

People with epilepsy have different seizure triggers. Some common ones are flashing lights and changes in hormone levels or diet.

FACT 19

Some people (often those who do not respond to therapy with medicine) may be placed on special diets in an attempt to control their seizures. Special diets for people with epilepsy include the high-fat, low-carbohydrate **ketogenic diet** and the modified Atkins diet. These diets may help reduce seizures by increasing production of inhibitory neurotransmitters and making action potentials more difficult to start.

Photosensitive epilepsy is when exposure to flashing lights causes seizures. Photosensitive epilepsy is most common in children, and it affects fewer people as they grow older.

YOU CAN LEARN MORE ABOUT:

On page 82 you can find more information about ketogenic diets.

Exposure to flashing lights, which can trigger a seizure, can occur in ordinary situations like watching television, playing video games, during fire alarms, and concerts. Keeping a reasonable distance away or adjusting the brightness of lighting in spaces where you may be exposed to flashing lights can be helpful if you have photosensitive epilepsy. If you cannot avoid a certain light-related trigger, try covering one eye and turning away from the light source.

FACT 20

Keeping a diary of how you feel and what you were doing before a seizure may help you prevent future seizures.

In addition to different factors in your environment that might trigger your seizures, it is important to consider the sensations you have shortly before a seizure. These might include strange perceptions or feelings. You may experience unusual tastes or smells, an out-of-body sensation, feelings of confusion or disorientation, loss of memory or focus, tingling or numbness, headaches, or loss of bladder control. If you experience any of these, keep track of when they occur and tell your healthcare team. This may help you predict future seizures.

FACT 21

After a first seizure, the likelihood of having another seizure is greatest within the first 2 years.

Can I continue my daily activities with epilepsy?

Although many changes accompany life with epilepsy, keeping many of your regular routines is a realistic goal. One of the most important questions you may have is how epilepsy will affect your everyday activities, such as driving.

Driving is a main concern for people with epilepsy because having a seizure while driving can cause serious injury to you and others on the road. Because of this, laws designed to protect public safety have considered the risk of driving with epilepsy. Depending on where you live, your state's laws may affect you in different ways regarding your ability to drive if you have epilepsy.

FACT 22

A person taking medicine to treat their epilepsy may be more likely to be permitted to drive.

Some states have laws that require doctors to report this information in the interest of public safety. Others do not require reporting, so it is important to discuss with your doctor the effects of your epilepsy on your ability to drive. Check with your local department of motor vehicles for the most up-to-date information about how driving laws may affect you.

If you have a job or are seeking employment, you may be worried about how seizures could affect your ability to work. The Americans with Disabilities Act (ADA) provides protection against discrimination and promotes equal opportunity in the workplace to people with epilepsy.

The ADA prevents employers from asking whether you have epilepsy before they offer you a job or asking for any medical information that is not requested from all employees.

FACT 23

Employers are not allowed to deny you a job just because you have epilepsy.

Employers are not allowed to fire you if your epilepsy does not present a reasonable threat to yourself or others. If there is a reasonable safety risk, your employer may ask for information about your condition, but they are not allowed to share information about your condition with your co-workers. The ADA also requires that employers make reasonable accommodations to allow employees with epilepsy to perform their jobs. If you can perform the essential functions of your job, you should feel safe in your ability to gain or maintain employment.

What should my friends and family know?

Your friends and family members should know about epilepsy and what to do in an emergency, including what to do if you have a seizure. Preparing those around you with the necessary information will help you focus on your well-being and everyday activities.

It is important to consider that people react differently to learning that a family member has epilepsy. Some may feel helpless because they cannot prevent your seizures; others may feel scared and try to protect you from seizure triggers. These emotions are a normal part of any condition like epilepsy, and it helps to communicate your feelings with your family members and listen to theirs.

You should always keep with you a written plan with instructions on what to do in case of an emergency. Your **seizure response plan** should include:

- Personal and emergency contact information
- Types and triggers of your seizures
- A list of the seizure medicines you take
- Instructions on how to treat you when you are having a seizure

FACT 24

Having a seizure response plan can help you and your family be prepared if a seizure occurs.

Work closely with your doctor, nurse, and pharmacist to ensure all necessary information is included and is accurate. Share copies with your loved ones, and if you are the parent of a child with epilepsy, share it with his or her school nurse. Be sure to review and update your plan with your healthcare team on a regular basis.

You can also practice "seizure drills" with family and friends to ensure everyone is familiar and comfortable with handling a seizure-related emergency.

When you are first diagnosed with epilepsy, it's helpful to put together a **resource kit** that you can refer to for information and help with managing your seizures. Here are some tips and suggestions you may find helpful when putting together your personal toolkit:

- Have a management plan for when you have seizures to help you and others know what to do and whom to contact. Be sure to modify or add information to your plan when you are away from home (for example, at camp or on vacation)
- Keep a current list of the names, jobs, and contact information for all the members of your healthcare team
- Maintain an ongoing list of questions for your healthcare team to help you remember to ask for information you need
- Use a medicine schedule to help you remember the amount and time for taking each of your medicines, and whether any lifestyle changes (for example, diet) are needed to make sure your medicine works correctly
- Keep a list of possible triggers and symptoms associated with your seizures to help you identify their cause, type, and frequency. Recording this information as a **seizure diary** will be helpful to your healthcare team

What is a seizure diary?

It's important to track your seizures and symptoms. Writing down how you felt and what you were doing before a seizure can help you recognize possible seizure triggers. It can also help your healthcare team learn more about your seizures and the best ways to treat them. Carry your seizure diary with you, so that others can write down what happens during your seizures in case you don't remember.

Things to remember to track in my seizure diary:

SECTION

4

STARTING MEDICAL MANAGEMENT

antiepileptic medicines
monotherapy
combination therapy
refractory seizures
adherence
nonadherent
acute
chronic
concentration-dependent
idiosyncratic side effects
osteoporosis
osteomalacia
bone mineral density (BMD)

Because of the variety of causes and types of seizures, different antiepileptic medicines are used to manage different seizure types. Your doctor will work with you to find the medicine that is right for you.

Most people with epilepsy begin treatment by taking a single medicine (also known as **monotherapy**), and most people can successfully control their seizures with one medicine. Some people will need two or more medicines to control their seizures (also known as **combination therapy**). When seizures don't stop or get better with medicine, they are called **refractory seizures**.

FACT 25

Doctors who identify and treat diseases of the brain and nervous system are called **neurologists**.

FACT 26

Taking your medicines exactly as directed is one of the most important ways to control your seizures.

YOU CAN LEARN MORE ABOUT:

You can find more information about the importance of medicine adherence in Section Five.

One of the most important ways to help ensure that your epilepsy medicine works is called **adherence** – taking your medicines exactly the way your doctor tells you to. Being **nonadherent** means not taking medicine as prescribed, including taking too much or too little, taking it at the wrong times, or forgetting altogether.

For some people with epilepsy, nonadherence is the main reason their medicine doesn't seem to work. Doctors estimate that more than half of people with epilepsy do not take their medicine as instructed.

DID YOU KNOW?

Having a written plan, ready resources, and a support system of family and friends is important to help ensure you take your epilepsy medicine as instructed.

How do medicines help?

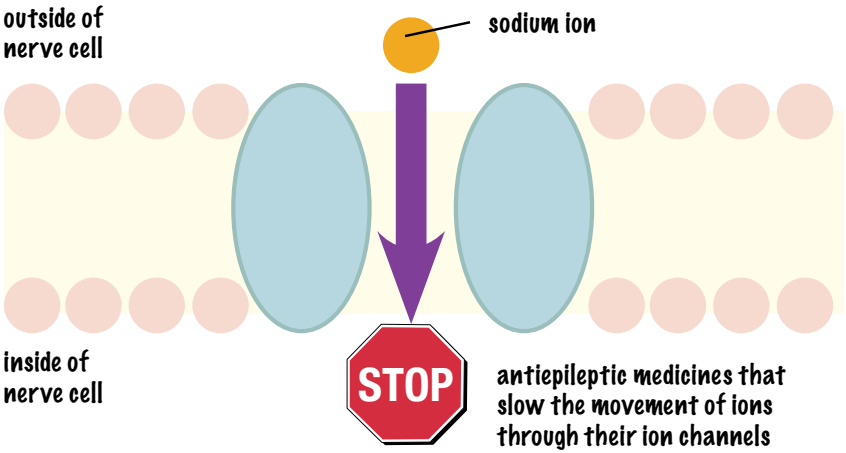
Antiepileptic medicines can help control seizures by altering the irregular electrical and chemical signals that occur in the brain.

The medicines work by changing the way different excitatory and inhibitory molecules work and how neurons maintain proper electrical activity. There are a variety of individual antiepileptic medicines and classes of antiepileptics. For this discussion, we will group them by what they affect—ions, inhibitory neurotransmitters, and excitatory neurotransmitters.

Did You Remember?

In general, antiepileptic medicines work by affecting the ions and neurotransmitters, described in Section One, that play a role in sending electrical signals throughout the brain.

Some medicines work by changing the activity of ion channels to lower the number of action potentials a nerve can carry from one end to another. Medicines that change the movement of sodium ions include carbamazepine, eslicarbazepine, ethotoin, fosphenytoin, lacosamide, lamotrigine, oxcarbazepine, phenytoin, rufinamide, topiramate, valproic acid, and zonisamide. Medicines that affect the movement of calcium include ethosuximide and methsuximide, whereas ezogabine affects the movement of potassium ions. Depending on the nature of your epilepsy, you may respond better to one or another of these medicines.

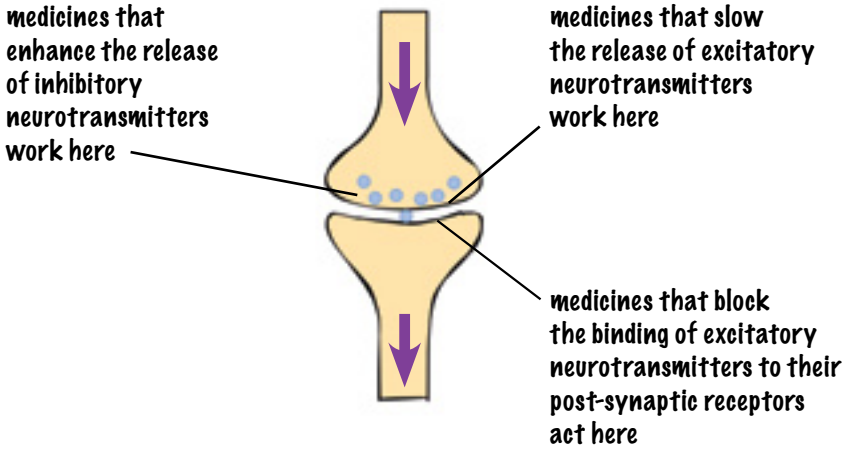


This drawing shows the action of antiepileptic medicines that help reduce seizure activity by affecting the movement of sodium ions.

FACT 27

Seizure medicines are used to treat, not cure, epilepsy.

A second class of antiepileptic medicines prevent the ability of neurotransmitters to stimulate a neighboring nerve cell. This helps return electrical activity to normal levels. Medicines in this class include benzodiazepines (clobazam, clonazepam, clorazepate, diazepam, lorazepam) and barbiturates (mephobarbital, pentobarbital, phenobarbital, primidone). Other antiepileptic medicines produce a similar effect by allowing inhibitory neurotransmitters to work better.



This drawing shows the action of antiepileptic medicines that reduce seizure activity by altering the movement of neurotransmitters.

These medicines include vigabatrin, valproate, and tiagabine. Gabapentin and pregabalin may work by causing the release of these inhibitory neurotransmitters, although doctors aren't sure exactly how these medicines work.

Other medicines may block the actions of excitatory neurotransmitters. These include felbamate, perampanel, and lamotrigine.

Some medicines don't fit clearly into any of the previously described categories—these include levetiracetam.

Which one is right for me?

When determining the best medicine to treat your epilepsy, your doctor will consider such factors as the reason for your seizures, as well as the medicine's action, side effects, and possible interactions with other medicines or lifestyle factors.

FACT 28

Each of the different seizure types responds differently to each type of antiepileptic medicine. You may need to try several medicines to find the best one to control your seizures.

Did You Remember?

Many people with epilepsy start treatment by taking only one type of medicine. Some people take more than one type of antiepileptic medicine.

Sometimes seizures cannot be controlled with medicines, for one reason or another.

FACT 29

What side effects can I expect and what can I do about them?

As with all medicines, you may have side effects when taking antiepileptics. These side effects can generally be grouped into **acute** (occurring rapidly) or **chronic** (occurring over time). The likelihood of having side effects sometimes depends on how much medicine is present in your body, or by the unique ways that your body reacts to the medicine.

Some antiepileptics may be more likely to cause side effects as the amount of medicine in the blood increases, causing what doctors call **concentration-dependent side effects**. These side effects can happen even when you have good seizure control.

Side effects of some antiepileptics are related to the amount of medicine in your body.

FACT 30

DID YOU KNOW?

Depending on the medicine your doctor prescribes to treat your seizures, you may need periodic tests to determine the amount of medicine in your blood.

Why do I need blood tests?

Blood tests tell doctors the amount of antiepileptic medicine in your body. They can help doctors see how well your medicine is working. When your doctor prescribed your antiepileptic medicine, he or she specified how much you should take. This amount was based on a number of factors. The results from blood tests can help your doctor understand how these factors impact your care. It's important to measure the amount of seizure medicine in your body because the same dose can have a different effect in another person. Doctors can adjust medicine doses as needed to minimize possible side effects.

FACT 31

Each person's body processes antiepileptic medicine differently.

DID YOU KNOW?

Careful measurements and dose changes usually are needed to find the right amount of seizure medicine for each person.

Your body weight and body composition (the percentage of water, fat, and muscle in the body) can affect how the epilepsy medicine is processed in your body. So can changes in kidney or liver function, other medical conditions, and even your age.

Side effects that are not related to blood concentration are called **idiosyncratic side effects**. Because of the way some antiepileptics affect the brain's activity, some of their most common side effects include dizziness, fatigue, confusion, vision changes, headache, and appetite changes.

Always tell your healthcare team about any side effects you have so they can determine whether a different medicine may work better.

It is important to take your epilepsy medicines exactly as prescribed because side effects are more likely to occur if you take too much medicine too quickly. For example, if you "double up" on a dose because you missed an earlier one, the chances of having side effects is increased, and they may be more severe than usual.

DID YOU KNOW?

You can take action on your own to reduce the likelihood of having side effects by taking your medicine exactly as prescribed (including antiepileptics and other medicines).

Suicidal thoughts are another possible side effect caused by some antiepileptic medicines. Talk with your doctor about the risk for side effects. **If you have any suicidal thoughts, contact your doctor immediately.**

FACT 32

Taking too much medicine at one time can increase your likelihood of having side effects.

Some long-term side effects from antiepileptics include bone disorders, such as **osteoporosis** (a reduction in the strength of bones) and **osteomalacia** (abnormal softening of bone). Doctors are not sure exactly how antiepileptics cause these problems, although some think it may be caused by a reduction in vitamin D levels.

To assess your bone health, you may have a test to measure your **bone mineral density (BMD)** to see if there are any changes in your bone structure.

If you have bone-related side effects while taking your antiepileptic medicines or if you are at risk for bone disease even before you begin taking medicine, your doctor may prescribe supplemental vitamin D and calcium to reduce the likelihood of having bone problems. Some people may need prescription medicines to help reduce the risk for bone problems.

Did You Remember?

Talk with your doctor about lifestyle changes or other ways you can help ease, prevent, and manage any side effects you have with your epilepsy medicine.

My immediate goals of therapy

The goal in taking antiepileptic medicine is to reduce the number and seriousness of seizures you have, while minimizing the possibility of side effects. It is important to set the goals of your therapy with your healthcare team when you begin taking medicine. Depending on your age, some important goals might include being able to go to a movie without fear of a seizure, enjoying vacation travel, going to college, or getting back to a regular work schedule.

Your goals may change over time, so it is important to have an ongoing conversation with your healthcare team about factors that could affect your goals. These include changes in lifestyle, changes in other aspects of your health, the severity and frequency of your seizures or medicine side effects, and how well your medicine is working.

How can I help control my seizures?

Remember, taking your antiepileptic medicine exactly as directed is one of the most important ways to control your seizures. Because the causes and treatments of epilepsy are very different and specific to each person, it can take time to find the right treatment.

Usually, antiepileptic medicines are prescribed at low doses when you first start therapy. They are increased gradually, if needed, to prevent side effects while controlling your seizures. If you continue to have seizures after taking your first antiepileptic as prescribed, your doctor may try a different medicine.

SECTION

5

The **IMPORTANCE** of **TAKING YOUR MEDICINE** as **DIRECTED**

breakthrough seizures
medicine schedules

Your epilepsy medicine is most likely to work correctly when you take it exactly as directed by your doctor. Being adherent—taking the right amount of medicine at the right time, every day— provides the best chance for the medicine to prevent seizures.

Taking the wrong dose or missing doses sometimes can lead to having a seizure. The most common cause of **breakthrough seizures** (seizures that happen when they are normally controlled by medicine) is missed medicine doses. Breakthrough seizures can happen more frequently than usual, may be more intense than usual, or may develop into longer seizure emergencies. Nonadherence can also lead to side effects if levels of the medicine in your body change too quickly.

There are many reasons that people may have a hard time adhering to their treatment regimen. Taking medicine more than once or twice per day can make it difficult to remember doses. For some people, taking medicine can be an unpleasant reminder of their epilepsy diagnosis.

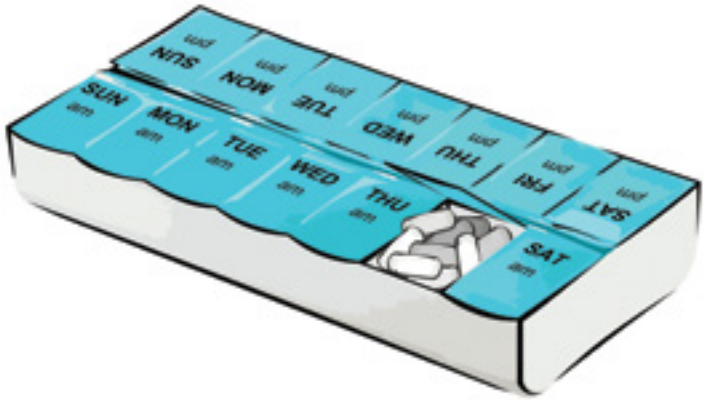
DID YOU KNOW?

Missing just one dose of epilepsy medicine can cause some people to have a seizure.

This table provides some possible strategies for overcoming barriers and staying adherent.

Reason for nonadherence	Strategies to help with adherence
Forgetting when to take your medicine	▪ Set up phone alarms or text reminders ▪ Use a medicine schedule with the times that you should take your medicines ▪ Use a pill box ▪ Take medicines at the same time as routine daily activities such as brushing teeth
Medicine regimen is too hard	▪ Use a medicine schedule with the times that you should take your medicines ▪ Use a pill box ▪ Ask family members, caregivers, or a visiting nurse for help ▪ Talk with your doctor about ways to simplify your medicine regimen
Problems getting medicine from the pharmacy	▪ Use a mail-order pharmacy ▪ Keep a 1-week emergency supply at home ▪ Set up phone alarms or text reminders with medicine refill times and days ▪ Call early to have the pharmacy help with insurance coverage questions
No insurance or can't afford medicine	▪ Talk with a social worker ▪ Investigate state and federal health insurance plans ▪ Contact patient assistance programs
Problems accepting epilepsy diagnosis	▪ Share your feelings with your healthcare team ▪ Talk with a social worker or counselor about coping strategies

Using **medicine schedules** and pill boxes are common ways to help you remember to take your seizure medicine. A medicine schedule should include all of your medicine names, doses, and the time of day that each should be taken, along with any special instructions. You can find medicine schedule templates online or use a mobile app, or you can make your own. Pill boxes can be filled with an entire week's supply of medicine. With a pill box, you can keep your medicine handy and keep track of each dose.



Pill box organizers can help with medicine adherence.

Noting your medicine doses, including missed doses or double doses, in a medicine record or diary can help you identify whether adherence is a problem for you. You can also use the diary to note times when you have seizures or side effects. Having all the information in one place can help you see problems and get ideas for how to minimize any barriers to adherence.

Plan ahead so you are always prepared in case of an emergency.

- **Bring an extra supply of medicine with you whenever you leave home**
- **Keep a 3-day supply in a safe and waterproof container at home**
- **Wear a medical alert bracelet or carry other identification explaining that you have a seizure disorder**

A medical alert bracelet can inform emergency medical personnel that you have epilepsy so they know how best to help you.

Can I change my medicine dose if I do not feel well?

Stopping some medicines suddenly can cause a seizure or withdrawal symptoms. Stopping your medicine can also cause unexpected side effects. If any side effects from your epilepsy medicine bother you, ask a member of your healthcare team what changes can be made safely. Do not stop taking your medicine or change your dose on your own.

What if I miss a dose of my medicine?

If you miss a scheduled dose of your medicine, do not double your dose the next time.

Nothing may happen if you miss a dose of your epilepsy medicine, or you may be more likely to have a seizure. Taking medicine once a day can be easier to remember, and more practical for your lifestyle. Discuss your medicine schedule with your healthcare team if you have trouble remembering to take your medicine during the day. There may be a way to reduce the amount of doses you need to take each day.

Did You Remember?

Taking more than your prescribed amount of medicine at each dose can increase your chance of having side effects, and can cause more severe side effects than usual.

SECTION

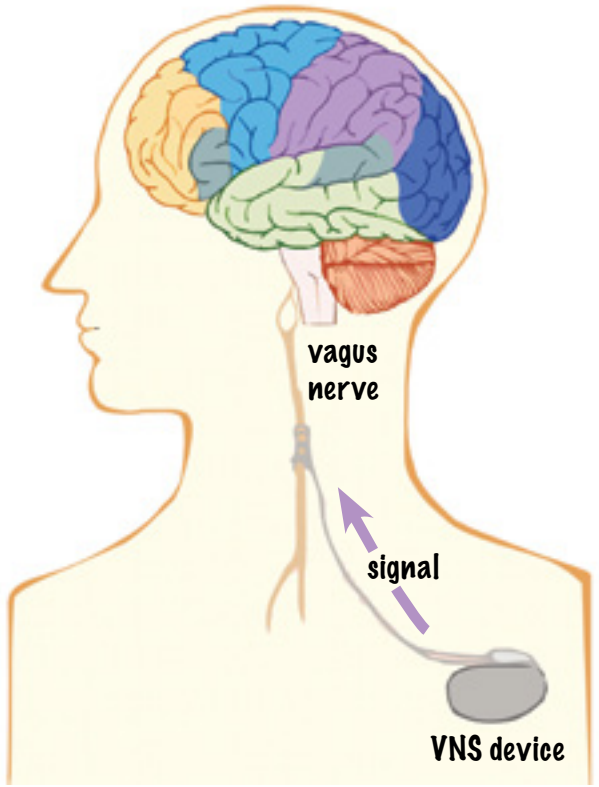
6

Other EPILEPSY TREATMENTS

vagus nerve stimulator
focal seizures
temporal lobe

What is vagus nerve stimulation?

Several techniques for nerve stimulation are used to treat people with epilepsy. The most well known of these is vagus nerve stimulation, or VNS. A **vagus nerve stimulator** is a device that is implanted in the body to reduce the frequency of seizures in adults and teens older than 12 years, who have partial-onset seizures or primary generalized seizures that are not controlled with antiepileptic medicine. The success rate of VNS treatment in people with these types of seizures is about the same as trying another antiepileptic medicine.



A vagus nerve stimulator sends electrical signals to the vagus nerve to help control seizures.

FACT 33

The vagus nerve connects your brain to your heart, lungs, and intestines.

Doctors are not sure exactly how vagus nerve stimulators work to help prevent seizures but it may be related to changes in neurotransmitter levels in brain fluids and increased blood flow to areas of the brain that are involved in seizure activity. VNS devices can also have a positive effect on mood and behavior. The nerve stimulator is programmed by a doctor to send pulses to the vagus nerve at an intensity and frequency that is specific to each person. Some people may have mild side effects with VNS treatment such as hoarseness, cough, sore throat, shortness of breath, or nausea/upset stomach.

When and why might people with epilepsy need surgery?

Surgery is an option for some people, including children, who have seizures that are not controlled with antiepileptic medicines.

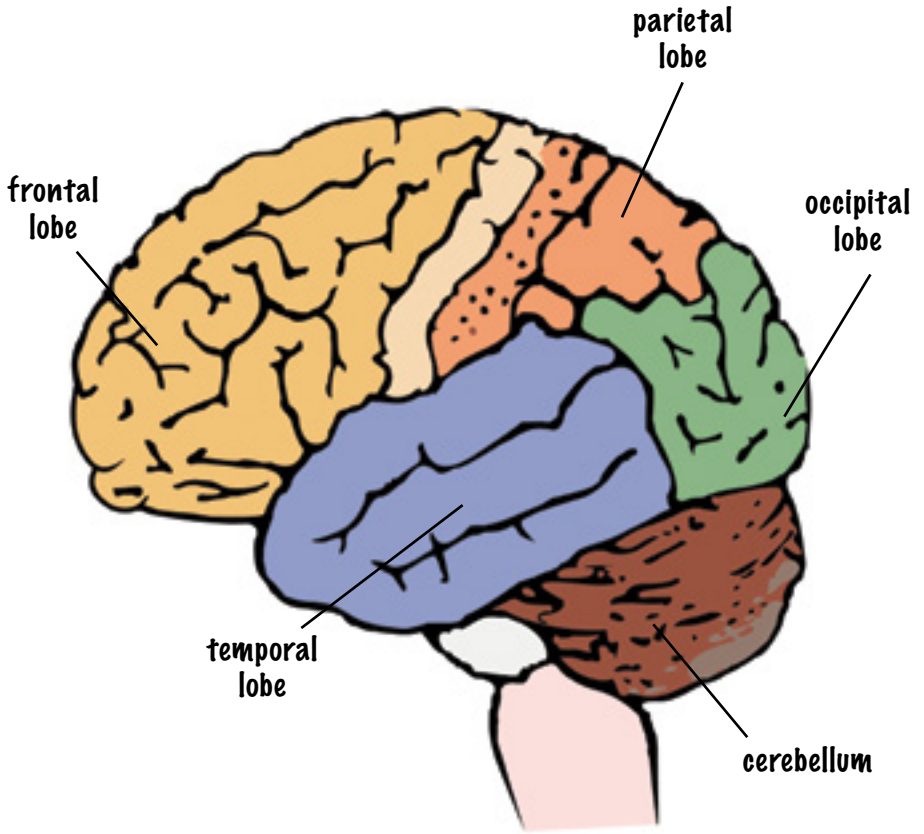
The goal of surgery is to remove the part of the brain that is associated with the seizures. Doctors have found that many people with **focal seizures** (seizures that start in a certain area of the brain), especially those with seizures that start in an area of the brain called the **temporal lobe**, can become seizure-free after surgery. Other people may have fewer seizures after surgery.

Even after surgery, some people may need to continue taking antiepileptic medicine.

Although any surgery carries risks, modern advances in screening procedures before surgery and surgical techniques have greatly reduced the likelihood of complications.

DID YOU KNOW?

Doctors test new medicines, medical devices, surgical procedures, and other therapies in research studies called **clinical trials**. These studies are meant to help find new or better ways to prevent, find, diagnose, or treat a disease in people.



Seizures that originate in the temporal lobe of the brain may be most likely to improve after surgery.

SECTION

7

WHAT TO DO BEFORE, DURING, and AFTER a Seizure

rescue medicines
Diastat®
seizure dogs
status epilepticus

Did You Remember?

Some people have odd sensations or feelings, called an aura, just before a seizure.

Safety and preventing injury are very important during a seizure. Some people with epilepsy experience certain symptoms just before a seizure begins. These symptoms can help warn you that a seizure is about to begin and allow you to notify others and move to a safe place.

FACT 34

Some people stay awake during a seizure and do not lose consciousness.

The events that happen during a seizure vary from person to person depending on the type of seizures they have. Some people may be fully awake and remember the seizure. In this case, the person may only need reassurance that they are safe. If you have this type of seizure (such as simple partial or myoclonic seizures), taking slow deep breaths or using another technique that is calming or relaxing may help you cope with the seizure.

Other people may seem to be awake during a seizure but actually are not aware of what is happening. They may be able to walk but may not be able to control where they are going. People with this type of seizure (such as complex partial or clusters of absence seizures) may need help finding a safe place or not wandering into dangerous areas such as busy streets, train tracks, or swimming pools.

After a seizure, you may feel confused about what happened, have trouble talking, or feel emotions such as fear, frustration, embarrassment, or sadness. Some people feel drowsy or sleepy, sick to their stomach, weak, or have changes in bladder or bowel control. All of these feelings and experiences are normal. It may take a few minutes or several hours to feel like yourself again, but eventually you will recover.

Most seizures only last a few minutes.

FACT 35

First aid during a seizure

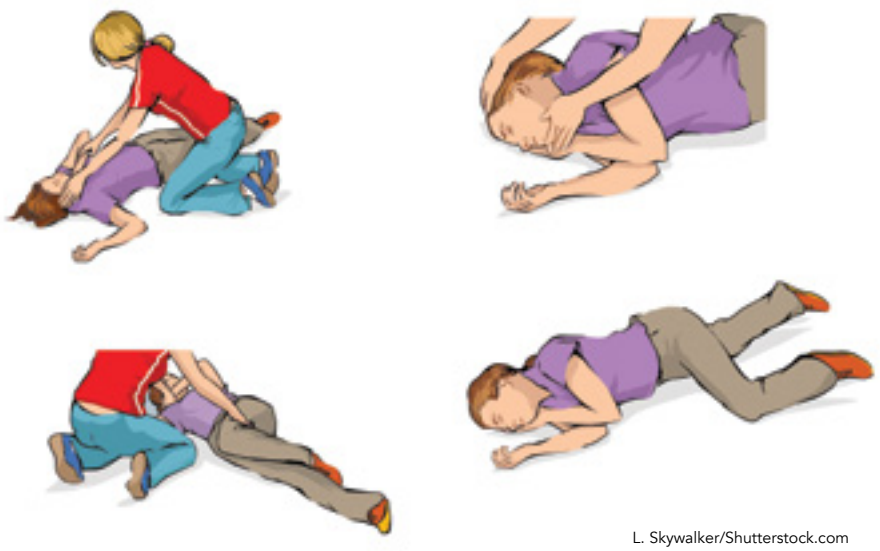
Seizures are not usually life-threatening and generally last only a few minutes, but what happens to your body physically during a seizure can put you at risk for injury. For example, if you lose awareness or muscle control, you can be hurt if you fall to the ground. If the people around you know what to do while you are having a seizure, they can help you stay safe until the seizure ends. Witnessing a seizure can be scary, but it helps when people understand what is happening and know how to help.

Here's what to do if someone loses consciousness during a seizure:

- Ease the person to the floor, or hold them in a hug to prevent them from falling
- Turn the person onto one side. This helps them breathe and prevents stomach contents from getting into the airway
- Remove hard or sharp objects from the area around the person to prevent injury
- Put something soft and flat, like a folded article of clothing, under the person's head
- Remove the person's eyeglasses
- Check to see if the person has a medical bracelet or other emergency information
- Time the seizure
- Stay with the person until the seizure ends

FACT 36

You cannot swallow your tongue during a seizure. This is a myth.



L. Skywalker/Shutterstock.com

The safest position for a person who has lost consciousness during a seizure is laying on their side on the floor.

Here's what NOT to do during a seizure:

- Do NOT hold the person down or try to keep them from moving
- Do NOT put anything in the person's mouth
- Do NOT try to give mouth-to-mouth breaths. Normal breathing usually starts on its own after a seizure
- Do NOT offer the person water or food until they are fully alert

First aid after a seizure

After the seizure ends, do the following:

- Ensure the person is in a safe area where they can rest
- Roll the person onto their side if you could not do so during the seizure
- Loosen ties or any other clothing around the person's neck that might make it hard to breathe
- Stay until the person is fully awake and any confusion has worn off. Speak calmly, and tell the person they've had a seizure and that they are safe
- Help the person get home safely by calling a taxi or another person to bring them home

DID YOU KNOW?

Some people can use rescue medicine to help stop a seizure.

Rescue medicines work quickly to stop seizures and help prevent an emergency. These medicines are not the same as the regular antiepileptic medicines you take to prevent seizures. They cannot be taken in place of your regular seizure medicine.

Rescue medicine is used "as needed" to stop seizures that occur close together, seizures that last longer than usual, seizures that are different than your usual type, or seizures that happen at certain high-risk times. People who use rescue medicine must know their usual type and pattern of seizures, and be able to recognize when they are having a different type of seizure than usual. Your doctor will let you know if you are a candidate for using rescue medicine.

The most commonly used rescue medicines are short-acting benzodiazepines (such as diazepam, lorazepam, and midazolam) because they can get into the blood and brain quickly. Although these medicines can be injected into a vein in the hospital, when used for seizure rescue at home, they are swallowed, dissolved under the tongue or between the cheek and gum, or taken rectally.

Adults usually take rescue medicine by mouth or under the tongue, depending on whether they are alert enough to swallow. The most commonly used rescue medicine in children is rectal diazepam gel (also known by the brand name **Diastat®**). This product comes as a prefilled syringe that is designed to be inserted in the rectum, so it is easy for caregivers to give and convenient to bring on trips or store at locations such as daycare or school.

When is a seizure a medical emergency?

Many people with epilepsy can fully recover without medical assistance as long as they were not injured during the seizure.

Call 911 emergency services if the person:

- Has a seizure that lasts longer than 5 minutes
- Has another seizure soon after the first one, especially if the person does not regain consciousness or "come to" between the seizures
- Is injured during the seizure
- Is not breathing well or seems to be choking
- Has a seizure in water
- Has another health condition such as diabetes or heart disease, or is pregnant
- Has never had a seizure before
- Asks for emergency help

DID YOU KNOW?

Some dogs appear to sense an epileptic seizure before it begins. The activity of these so-called **seizure dogs** helps alert the person so that he or she can prepare for a seizure.

Seizures are especially dangerous when they last longer than 5 minutes or when the person does not fully regain consciousness between seizures. This condition is called **status epilepticus**. Status epilepticus is a medical emergency. Unless rescue medicine is used at home, the person will need to go to the hospital to receive treatment. A long-lasting seizure can cause several serious complications including brain injury, so medical treatment is needed as soon as possible.

Not all seizures require emergency medical help or a trip to the emergency room.

FACT 37

SECTION

8

DIET and EXERCISE CONSIDERATIONS

ketogenic diet
ketones
dietitian

What is a ketogenic diet?

As mentioned in Section Three, people with hard-to-control epilepsy may benefit from following a special diet called the **ketogenic diet**. The ketogenic diet is a controlled nutritional regimen that requires eating four times as much fat and protein as carbohydrates every day. Usually, the body and brain use carbohydrates for energy. Eating fewer carbohydrates makes the body rely on fat for energy instead. When fats are processed by the liver, a byproduct is produced called **ketones**.

DID YOU KNOW?

The ketogenic diet is mainly used in children whose seizures are not controlled with medicine, but it can also be used in adults.

Ketones can help control seizures when there are large amounts of them in the body. People who follow a ketogenic diet can use chemical test strips to check how many ketones are in their blood or urine to see if the diet might be helping.`

If your doctor says it's OK for you to try a ketogenic diet, it may be helpful to work with a **dietitian**. A dietitian can help you make appropriate food choices to meet the diet requirements, and learn some basics such as weighing out food portions.

One drawback of the ketogenic diet is that eating large amounts of fat can cause changes in body weight, as well as cholesterol levels, metabolism, and blood sugar. It can also affect growth and bone development in children. Other side effects such as dehydration, constipation, and kidney stones can occur. A dietitian may be especially helpful when identifying food choices that can prevent or minimize these effects. It may be necessary to take a vitamin supplement while you are on a ketogenic diet.

A chemical test can be used to check the urine for ketones, which are produced when a person follows a ketogenic diet.

Can exercise trigger my seizures?

DID YOU KNOW?

Exercise may help prevent seizures.

Exercise is an important part of a healthy lifestyle, and this is also true for people with epilepsy. Exercise is a trigger for seizures only in rare cases. If your seizures are well controlled, your doctor may give you permission to participate in any type of exercise. If you are still working on getting your seizures under control, it may be best to only engage in less intense types of exercise, such as walking.

Do I have to quit strenuous activities?

There are no hard-and-fast rules regarding strenuous activity in people with epilepsy. With precautions such as taking breaks/resting, eating enough and drinking enough water, and using appropriate protective gear, strenuous activities can be part of a healthy and active life. Talk with your doctor about which recreational activities are safe for your type and pattern of epilepsy and your degree of seizure control. For example, seizures that cause falls (generalized tonic–clonic or atonic seizures) or that cause loss of consciousness or awareness (absence or complex partial) may put you at risk for injury depending on the type of activity.

Most physical activity is safe for people with epilepsy as long as general safety precautions are followed.

FACT 38

You can take some general precautions to help stay safe while exercising:

- **Exercise with a buddy, especially in remote areas or in and around water (for example, when hiking, skiing, boating, and swimming). Wear a life vest near water**
- **Get plenty of rest and stay fueled. Exercising without enough sleep and food intake can cause seizures**
- **Stay cool while exercising by taking frequent breaks (every 15 to 20 minutes if needed), drinking plenty of fluids, and exercising during the coolest part of the day**
- **Use protective equipment, such as a helmet or padding, depending on the activity**
- **Avoid busy streets when exercising outdoors**
- **Wear a medical alert bracelet or carry other medical alert documentation, along with a cell phone or GPS in case you need help**

Some physical activities generally are not safe for people with epilepsy. Some examples include scuba diving, rock or mountain climbing, skydiving, hang gliding, horseback riding, motor sports, and downhill skiing. Your doctor can help you judge the risk of these activities, taking into consideration your type and pattern of seizures.

SECTION

9

The IMPORTANCE of LIFESTYLE MODIFICATION

lifestyle modification
over-the-counter (OTC) medicines
Americans with Disabilities Act
sleep apnea
alcohol withdrawal
seizure emergency

The term **lifestyle modification** simply means making changes in your daily routine to improve your health, such as actions, habits, choices, and preferences. Your diet, exercise/physical activity, sleep habits, alcohol consumption, and medicine use are all parts of your lifestyle that you can change to help improve your health. Making small changes in the most basic aspects of life can help you feel more in control of your epilepsy.

What about over-the-counter medicines?

Always check with your doctor before taking any new medicines, including **over-the-counter (OTC)** and herbal medicines.

FACT 39

Some herbal and OTC medicines can increase your risk for seizures. Always ask your healthcare provider before taking any medicine.

Some OTC medicines can cause an increased likelihood of seizures in some people with epilepsy. The most common of these is diphenhydramine (also known by the brand name Benadryl®), which is used for allergies, is in some cough and cold medicines, and is used as a sleep aid.

Other OTC medicines used for nasal congestion, including pseudoephedrine and phenylephrine, also can cause seizures in some people with epilepsy.

Some OTC medicines, including aspirin, can cause changes in the levels of antiepileptic medicine in your body, which sometimes leads to seizures. Ask your doctor about the use of aspirin, acetaminophen (also known by the brand name Tylenol®), and other OTC pain medicines.

Can I work, drive, and participate in sports?

As discussed in Section Three, many people with epilepsy can drive and continue to work. The **Americans with Disabilities Act** protects people with epilepsy from discrimination or unfair employment-related treatment due to their diagnosis. You are also entitled to reasonable accommodations in the workplace, if needed. Driving laws for people with epilepsy vary by state. Your doctor can help you determine whether your seizures are controlled well enough that it would be safe for you to drive.

People with epilepsy have a similar risk for injury from contact sports as people without epilepsy.

FACT 40

Contact sports (football, rugby, basketball, soccer, ice hockey) do not pose a greater likelihood of injury to people with epilepsy than people without epilepsy. Head injury, concussions, and other injuries can occur in anyone playing contact sports and there is no evidence that minor head trauma worsens seizures. When playing contact sports, you should wear a helmet to protect your head from injury. Your doctor can help you think about the risk of playing a specific sport with your type and pattern of seizures, and help you consider the precautions that might be needed to help keep you, or your child, safe when playing sports.

Maintaining good sleep habits

Lack of sleep can put you at risk for seizures, or for more intense seizures or seizures that last longer than usual. Several sleep-related concerns can affect seizure control, such as not getting enough sleep; not getting good-quality sleep; having seizures at night that disrupt sleep; difficulty falling asleep, medicine side effects, or sleep disorders such as **sleep apnea,** in which breathing stops and starts repeatedly. Substances like caffeine may make sleep difficult.

DID YOU KNOW?

People's sleep needs can vary from 5 to 10 hours per night. Most adults do best with 7 to 8 hours of good-quality sleep per night.

Because of the connection between seizures and sleep, all people with epilepsy, including children, should strive to maintain regular, healthy, sleep patterns. You know that you have gotten enough good-quality sleep when you wake up feeling rested and have enough energy during the day. Implementing some time-tested techniques can help you get enough good-quality sleep, and these ideas are useful for people both with and without epilepsy.

Here are some tips for healthy sleep habits:

- Get regular exercise; try to do strenuous exercise earlier in the day rather than before bed
- Use your bed only for sleep and sex, not for activities that require wakefulness
- Maintain a quiet and dark sleep environment
- Maintain a consistent schedule, including a regular wake time
- Avoid large meals and alcoholic drinks before bed. Avoid caffeine for at least 6 hours before bed
- Try relaxing activities before bed, such as taking a warm shower, meditation, or relaxation exercises
- Get out of bed if you have not fallen asleep after 30 minutes. Try doing something relaxing or quiet for 20 to 30 minutes until you feel tired

Healthy sleep habits can help protect against seizures caused by sleep deprivation.

If these techniques do not work, your doctor may suggest a short trial of sleep medicine to help you. Do not use sleep medicine without consulting your doctor.

What about drinking alcohol?

For most people, small amounts of alcohol may not increase seizures or change antiepileptic medicine levels in the body. Drinking large amounts of alcohol (especially in a short period of time) can increase the likelihood of seizures if **alcohol withdrawal** occurs. The biological process of alcohol withdrawal is what causes seizures, not the alcohol itself. Limiting alcohol consumption to 1 to 2 drinks is usually precautionary enough to prevent alcohol withdrawal in most adults.

Antiepileptic medicines can also lower alcohol tolerance in some people, so less alcohol is needed to cause the same effect. People with epilepsy who are already sensitive to alcohol, have a low alcohol tolerance, or who take antiepileptic medicines with effects that mimic alcohol (such as drowsiness) should drink alcohol with even more caution.

Traveling with my epilepsy medicines

Having epilepsy should not prevent you from traveling for personal or professional reasons, but it's a good idea to plan ahead. Managing your medicines appropriately is a large part of maintaining seizure control while traveling. This usually includes two major considerations: making sure you have enough of your medicine and knowing the proper time to take your medicine, especially when crossing time zones.

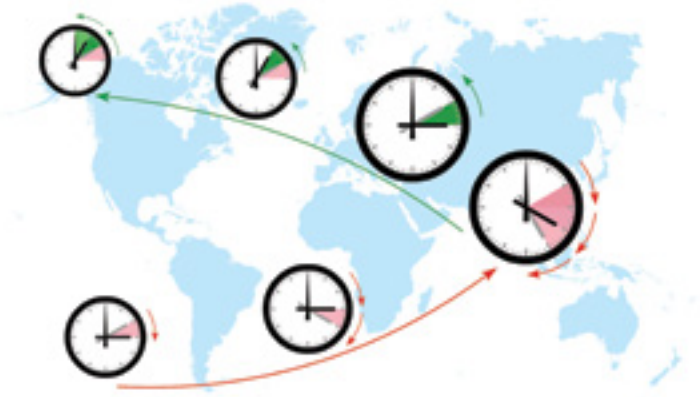
Sticking to your medicine schedule is an important aspect of maintaining seizure control while traveling.

FACT 41

You should bring along an extra supply of your epilepsy medicine when traveling; a good rule of thumb is to bring double the amount that you would normally need for the time period of the trip. Health insurance companies may allow for an extra vacation supply and your doctor may write a special prescription for this if needed. Bringing extra will ensure that you will not run out if some of your medicine is lost. If you will be traveling to another country for an extended period of time, you may need refills. Your doctor or pharmacist can help you determine whether your medicine is available where you are going and how to obtain it in other countries.

If you are traveling by air, consider putting half of your medicine in your checked luggage and bringing half on the airplane with you. All medicine should be kept in a properly labeled bottle for security and safety reasons. Be sure to also take a supply of your rescue medicine if you normally keep some on hand at home.

Knowing when to take your medicines while traveling is also important. Even if you are not crossing time zones, being away from your normal home routine can make it hard to remember to take your medicine at the right time. Bring a list of your medicines to help you remember what to take; this may also be helpful if you need medical help or have a **seizure emergency** while traveling. You can also use a medicine administration schedule to help stay organized, and check off each medicine after you take it during each day of your trip. A pill box can also help you remember to take doses or let you know if you have missed a dose.



Denys Grytsenko/shutterstock.com

Your healthcare team can help you adjust your medicine schedule if needed while traveling, especially when crossing time zones.

If crossing time zones, check with your healthcare team before leaving to determine how to adjust your dosing schedule. You may also need to adjust your dosing schedule during travel if you take medicine more than twice per day or you take different doses of your medicine at different times during the day. It may be helpful to start your new medicine schedule a few days before traveling to get used to it.

DID YOU KNOW?

You may be able to work with your health insurance company to have an extra supply of your antiepileptic medicine while traveling.

Know what to do if you miss a dose of your medicine. Missed doses are usually managed the same way at home and while traveling, but check with your healthcare team to be sure. You should also know what to do if you experience a new or worsened side effect while traveling, and how to adjust your medicine dose if you have a seizure emergency while traveling.

DID YOU KNOW?

Many aspects of travel can increase your likelihood of having a seizure, such as lack of sleep or not getting enough food or water at regular times. Planning ahead can help prevent these common triggers.

Some general travel tips to help minimize the likelihood of seizures while traveling include:

- Minimize travel-related stress when possible
- Keep regular meal times. The effect of some medicines can change depending on whether they are taken with food or on an empty stomach
- Try to avoid sleep interruptions, rest when traveling at night, and add time to rest and adjust to the time change once you reach your destination
- Avoid alcohol and caffeine
- Drink plenty of fluids to help prevent dehydration, which is especially important in warmer climates or if you are taking topiramate or zonisamide. If you are taking a medicine that decreases sodium levels in the body, such as carbamazepine or oxcarbazepine, ask your doctor about the best type and amount of fluid to drink
- Be aware of your surroundings if your seizures are triggered by lights or noises, especially when visiting locations such as amusement parks or sporting events where these triggers are more common
- Consider purchasing travel insurance in case your travel plans are disrupted or changed because of a seizure
- Always wear your medical alert bracelet or carry other medical emergency identification in case you have a seizure while traveling. When traveling alone, notify flight attendants, tour guides, or hotel staff about your epilepsy and provide them with written information about what to do if you have a seizure emergency

SECTION

10

EPILEPSY in CHILDREN

febrile seizures
temporal lobe
limbic
automatisms
autism spectrum disorder (ASD)
stimulus
Individuals with Disabilities Education Act (IDEA)
individualized education program (IEP)

My child had a febrile seizure. Is this different than epilepsy?

Febrile seizures mainly affect children ages 3 months to 5 or 6 years. Although cool baths and fever-reducers may make a child with a fever feel better, they won't help prevent febrile seizures. Children with febrile seizures usually don't need medicine.

Unless a child has risk factors for developing epilepsy, the likelihood that he or she will develop epilepsy is similar to that in children who do not have febrile seizures.

Risk factors for developing epilepsy include:

- Abnormal development
- Having a parent or sibling who has seizures without a fever
- Having febrile seizures that last longer than 15 minutes, happen more than once within 24 hours, and/or affect one side of the body

FACT 42

If a child has febrile seizures, it does not necessarily mean he or she has a higher likelihood of developing epilepsy.

Is repetitive behavior a form of epilepsy?

Some types of epilepsy may be linked with conditions such as depression, anxiety, and obsessive compulsive behavior. Doctors are not sure if the epilepsy itself actually causes these conditions or if the conditions are just more likely to happen in people who have epilepsy.

Depending on which area of the brain is affected by epilepsy, different behavioral conditions may be more likely. For example, people whose epilepsy is located in the part of the brain called the **temporal lobe** may be more likely to have obsessions with being unclean and have compulsions to wash themselves, as well as obsessions with symmetry or exactness and compulsions to make things neat and orderly. People whose epilepsy is located in the **limbic** part of the brain may be more likely to display repetitive movements, also called **automatisms**.

Did You Remember?

Febrile seizures can occur in young children when they have a high fever.

Epilepsy also may occur in people with **autism spectrum disorder (ASD)**, and having ASD may increase a person's likelihood of developing epilepsy. Sometimes repetitive behaviors that accompany ASD are mistakenly thought to be seizures, so a thorough diagnosis is needed to determine if these behaviors are a part of ASD or are actually true seizures.

Will epilepsy delay my child's social or behavioral development?

Although most children with epilepsy have similar social skills to their peers without epilepsy, some children may struggle, especially if their epilepsy develops before the age of 8. Some examples of social skills are cooperation, assertion, responsibility, self-control, and compassion, which are further developed through interaction with peers.

If their epilepsy is controlled earlier on, children have a better chance to develop their social skills. In some cases, children with epilepsy also may be diagnosed with a disorder that could affect their social skill development, including ASD or pervasive learning disorder. Regardless of whether they are linked to epilepsy, learning disorders may affect social skills too.

The intellectual ability of children with epilepsy is similar to that of their peers without epilepsy, but some children with epilepsy may experience learning disabilities or not perform as well academically. Some aspects that may be affected include attention, concentration, memory, and organizational skills. During the time in which a child has a seizure and for minutes to hours afterward, their ability to learn is disrupted as well. This can happen throughout the day, causing many learning disruptions to the child. Fatigue also may play a role in a child's ability to learn.

Children with epilepsy may be more likely to experience emotional and behavioral issues, including anxiety, depression, irritability, hyperactivity, and aggression. Because of this, it is thought that epilepsy is not only characterized by seizures, but also by behavioral disturbances. Some parents have noted behavior changes (for example, increased irritability or aggression) with the addition of a new medicine or a dosage increase of a current medicine.

Behavior changes may signal an oncoming seizure. Aggression and changes in behavior can appear "out of nowhere," or may be the result of a **stimulus**. A stimulus can trigger the onset of a seizure or behavior change. Loud noises, flashing lights, and video games are all examples of possible stimuli.

FACT 43

Epilepsy can affect development of a child's social, learning, and behavioral skills.

DID YOU KNOW?

Children with disabilities caused by their epilepsy can receive special education assistance in the public school system for free.

Parents as advocates of children with epilepsy

Parents are important advocates for their children with epilepsy.

Parents of children with epilepsy should be aware that when their child is excluded from common school activities, the child may feel a sense of isolation and of being "not normal." To promote well-being and appropriate social and physical development, parents should actively advocate for support of their child while he or she is at school. This could mean asking that information on epilepsy be taught in every classroom, and that their child has extra support during recess time. Parents should let teachers and staff know what type of seizures their child has, what they can expect it to look like when the child has a seizure, and what the child's common seizure triggers are. There are forms available online and at physicians' offices that can be given to school staff, including an emergency contact form, epilepsy fact sheet, and an incident report form detailing a seizure incident should it occur. It is important that school staff understand that not all seizures are emergency situations, but they should know when it is time to call 911.

Many children and adults do not understand epilepsy and may ask questions. Parents should teach their children facts about epilepsy so the child can confidently inform others of his or her condition when asked. Informing teachers, staff, and other students of what epilepsy is can help lessen their fears of the condition, and realize that a child with epilepsy is no different than a child without epilepsy.

Parents should be aware of laws on education for children with disabilities. The most applicable law for children with epilepsy is the **Individuals with Disabilities Education Act (IDEA)**. Under this law, parents can request assessment of their child's need for special education services, which are provided for free in preschool and K-12. If it is determined they do require special assistance, children with epilepsy typically fall under the category of "Other Health Impairment," and an **individualized education program (IEP)** can be developed. The IEP involves parents and relevant school staff who meet at least annually to review the details of the IEP (details on student needs, performance, goals, etc.). The IDEA also ensures children receive early intervention services if needed, as well as assistance with the transition from a school setting to adulthood.

SECTION

11

EPILEPSY in TEENS and YOUNG ADULTS

polycystic ovarian syndrome (PCOS)

Going to college

There are some things to consider when a young adult with epilepsy starts college.

For young adults with epilepsy who are starting college, there are some things to consider that can help them prepare and have a successful experience. Getting enough sleep and figuring out at what time during the day they do their best concentrating and studying are just a couple of ways to keep stress at a minimum and can help them maintain control of their epilepsy.

The Affordable Care Act of 2010 allows young adults to remain covered by their parents' health insurance through the age of 26.

FACT 44

Students starting college should visit the school's health center to find out if they have any stress management programs and also to confirm that their health records are on file. When it comes time to fill prescriptions, it is best to call about a week ahead to ensure they are ready for pick-up when needed. Sometimes prescriptions can be filled at the school's health center, or students can choose to fill prescriptions at a local pharmacy or through a mail-order service, if their insurance allows. Mail-order prescription fill can allow for a 3-month supply of medicine, and sometimes this option is less expensive than filling monthly.

Did You Remember?

Missing medicine doses is the most common reason for breakthrough seizures.

Getting on a regular schedule for taking medicine can help prevent missed doses. It is also a good idea to carry an extra dose in a book bag.

Students starting college should also consider their insurance options. The Affordable Care Act of 2010 now allows young adults to stay on their parents' health insurance until the age of 26. If they choose insurance through the college, they need to be aware of the policy about doctor visits off campus and

Did You Remember?

Pill boxes, medicine schedules, and electronic reminders are helpful tools for reminding you to take your medicine.

during breaks and holidays. Some health centers may have less flexible hours and provide more general health services. If the student's epilepsy requires regular monitoring, it might be best to find a neurologist in the area.

It is a good idea for college students with epilepsy to tell their roommate(s) about their condition. If living in a dorm, there is usually a resident assistant (RA), and he or she should also be aware of the condition and what to do in case the student has a seizure. If the student feels comfortable, the RA can have a dorm meeting to talk about epilepsy so residents of the dorm understand it better. Some students with epilepsy have posted first aid instructions and contact information, including parents' numbers, in a common area of their dorm (for example, the dorm fridge). If a seizure occurs, it's helpful if someone knows to time it so that they can call 911 if it lasts longer than 5 minutes. Also, if a roommate or RA is aware of warning signs that a seizure is about to occur, they can help the student to a safe place before they have a seizure.

FACT 45

Drinking alcohol can increase the likelihood of having a seizure.

Some of the social situations in college may involve alcohol. Alcohol can sometimes increase a person's likelihood of having a seizure. The likelihood of having a seizure is even higher when drinking alcohol is combined with not getting enough sleep. A seizure is more likely to happen the day after drinking alcohol, not typically while drinking. For some people, avoiding alcohol altogether may be necessary.

DID YOU KNOW?

There are college scholarships available specifically for students with epilepsy.

There are both national and regional scholarships for students with epilepsy. Searching for scholarships and filling them out can be very time consuming, so it's a good idea to start the process early, ideally during the junior year of high school. School counselors, doctors, support groups, the internet, and the public library are sources of information for scholarships for students with epilepsy. Two pharmaceutical companies, UCB and Pfizer, provide college scholarships for students with epilepsy. The website **www.collegescholarships.org** is a good starting point for researching college scholarships for students with epilepsy.

What if I have to have surgery that is not related to my epilepsy?

Although surgery is sometimes a treatment option for epilepsy, in some cases, people with epilepsy may have to undergo elective or emergency surgery for other reasons. One important consideration for people with epilepsy is that antiepileptic medicines sometimes can interact with medicines used for anesthesia. These interactions can affect how well the medicines work, or increase the risk for a seizure during the surgery. However, anesthesiologists are aware of these interactions and are trained to manage them.

Take your regular medicines on the morning of surgery if your doctor tells you to do so. If multiple oral doses are likely going to be missed during and around the time of the surgery, your doctor may give you medicines intravenously or sometimes as a suppository. Your doctor will work with the anesthesiologist and surgeon to determine how best to manage your medicines around the time of surgery.

Starting a family

People with epilepsy who want to start families often have many concerns with the process, which is natural. The good news is that more than 90% of babies born to mothers with epilepsy are healthy. You can increase the chance of having a healthy baby by planning carefully with the help of a neurologist and receiving good prenatal care. Your gynecologist/obstetrician and neurologist should both be involved in reviewing your medicine regimen before you try to become pregnant.

More than 90% of babies born to mothers with epilepsy are healthy.

FACT 46

Recent research has helped doctors to better manage antiepileptic medicine regimens for women with epilepsy. Do not change or stop taking any medicines unless your doctor tells you to.

Some conditions can make it more difficult to become pregnant. For example, some antiepileptic medicines can lower a man's sperm count, and some women with epilepsy also have a condition called **polycystic ovarian syndrome (PCOS)**. Both conditions are treatable but may make getting pregnant difficult. Doctors can help manage or treat these conditions before beginning the process. Once pregnant, women with epilepsy who are taking antiepileptic medicines can consider registering with the North American Pregnancy Registry to help researchers study the safety of antiepileptic medicine use during pregnancy. The toll-free telephone number is (888) 233-2334.

Can I breastfeed while taking antiepileptic medicines?

Just as there are still unknowns about antiepileptic medicine use during pregnancy, doctors still have limited information on antiepileptic medicine use during breastfeeding. However, the presence of antiepileptic medicine in the breastmilk does not necessarily mean it will affect the baby. Your doctor will help determine any risks of breastfeeding while you are taking antiepileptic medicines.

Will my child have epilepsy, too?

If a parent has epilepsy, the chances of a child developing epilepsy are only slightly higher than for the general population. The likelihood is approximately 1 in 100 for any child to develop epilepsy, and it increases to between 2 and 5 in 100 if one or both parents have epilepsy. However, the risk that a child will have epilepsy also depends on the type of seizures the parent has because some can be passed from parents to their children.

FACT 47

Antiepileptic medicine in breastmilk will not necessarily affect a feeding baby.

For example, juvenile myoclonic epilepsy can be passed to the child from the parents, and the likelihood of transmission is thought to be higher if the mother has it than if the father has it. Risk also depends on what age the parent was when his or her epilepsy started, whether both parents have epilepsy, and whether the parents have another child who was diagnosed with epilepsy.

Things to talk about with my healthcare provider:

SECTION

12

EPILEPSY in OLDER ADULTS

menopause
hormone replacement therapy (HRT)

It may surprise you to know that the number of new cases of seizures is actually highest in people over the age of 60 years, and may occur up to three times more frequently in people 75 years and older than in any other age group. Other illnesses and changes in how the body functions as it ages are two factors that contribute to this higher rate of epilepsy in older adults.

Epilepsy and other conditions

Seizures are sometimes linked to high blood pressure or a previous stroke. Infections, diseases that get worse over time, and cancer also can be reasons for seizures in older people. Some medicines commonly taken by elderly people can cause seizures.

DID YOU KNOW?

Seizures happen more frequently in older adults than in younger people.

The effects of a seizure may be different in older adults than in younger people. For example, instead of limb jerking, which is seen in some seizure types, elderly people may instead have altered mental status, memory lapses, confusion, or syncope. Also, older adults are less likely to experience auras and automatisms, and they may take a longer time to recover from a seizure than younger people.

Considerations for older women

For women, the time before, during, and after menopause can result in changes in their epilepsy. **Menopause** is the time at which menstrual cycles stop, and usually is marked by changes in the reproductive hormones estrogen and progesterone. Epilepsy can affect menopause, too: Women with epilepsy can actually start menopause earlier than women without epilepsy. Some women are very sensitive to changes in levels of reproductive hormones in their bodies, and can have more seizures when this occurs (such as during the time of their menstrual cycles). Women with epilepsy who have had increased seizures around the time of their menstrual cycles are more likely to have more frequent seizures before and during menopause, and then fewer seizures after menopause.

Epilepsy can change around the time of menopause for a woman.

FACT 48

FACT 49

In the United States, more people have epilepsy than autism spectrum disorders, cerebral palsy, multiple sclerosis, and Parkinson's disease combined.

Hormone replacement therapy (HRT), which is used to treat symptoms of menopause, also can affect epilepsy. Hormone replacement therapy consists of giving either estrogen alone or both estrogen and progesterone. During the time of menopause and HRT use, dose adjustments may be needed for women taking antiepileptic medicines.

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SECTION

13

TALKING with your HEALTHCARE PROVIDER

It is important to have open communication with your doctor.

To help prepare for visits with your doctor, write your questions down before the appointment. If a doctor is talking to you about epilepsy and uses a word you don't know, don't hesitate to ask what it means. Sometimes there may not be enough time during the visit to talk about everything you want to, so you may need to make another appointment.

Sometimes patients see doctors who are part of a group practice, where several doctors provide care.

Did You Remember?

Making a list of questions and keeping a journal of your seizures can help you prepare for visits with your doctor

When this is the case, relevant questions may include:

- Which doctor should I see for general medical problems and checkups?
- Will I see a neurologist for my epilepsy?
- What are the limits on how many tests and scans my insurance plan pays for?
- Who can I contact about my overall care?
- Does my plan provide coverage if I have a seizure and end up in the emergency room?

Good questions to ask about treatment include:

- What do I do if I miss a dose or two of my medicine?
- What side effects might I have with my medicine?
- Why did you decide to prescribe these specific medicines for me?
- Can the pharmacist fill for the generic of this medicine?
- What things, if any, should I avoid while taking these medicines?
- Could the medicine be causing my child to do poorly in school?
- Could the medicine be making my child misbehave?

If you would like to try other ways to treat your epilepsy besides those your doctor has prescribed, ask your doctor and pharmacist the following before doing so:

- Is this safe for me to take/do?
- Will this therapy have any effects on the medicine I'm already taking?
- Will vitamins help with my seizures?

When you are thinking of other treatment options, you might ask your doctor:

- Do I need to see a neurologist?
- Does a ketogenic diet work?
- Would I be eligible for surgical treatment?
- Would I be eligible for vagus nerve stimulation?

Good questions related to seizure management include:

- What is the best first aid for my seizure type?
- When should emergency services be called?
- How long should I or someone else wait before calling emergency services?
- Should I let you know each time I have a seizure?

Sharing detailed information with your doctor will help him or her determine the best ways to treat your epilepsy.

FACT 50

It is very important that you discuss your seizures at every doctor visit. He or she will not know if you have any changes in your seizure activity unless you tell them. Don't be afraid to tell the doctor if your seizures are getting worse, or if you are having any other symptoms such as blackouts or odd feelings. Detailed information will help your doctor determine the best ways to treat your epilepsy.

LIST OF TERMS used in this EPILEPSY PATIENT RESOURCE

absence seizures: a type of generalized seizure that causes a brief loss of attention; may result in a sudden blank stare and rolling of the eyes; used to be called petit mal seizures

action potentials: tiny electric impulses that send information from one end of a neuron to the other

acute side effects: side effects that occur rapidly after taking medicine

adherence: taking your medicines exactly the way your doctor tells you to

alcohol withdrawal: a condition caused by drinking large amounts of alcohol, especially in a short period of time, that can increase the likelihood of seizures

Americans with Disabilities Act: a federal law that protects people with epilepsy from discrimination or unfair employment-related treatment due to their diagnosis

antiepileptic medications: medicines used to help control seizures

atonic seizures: generalized seizures that may cause a body part such as the head or limbs to "go limp"

aura: odd sensations or feelings that some people have just before a seizure

autism spectrum disorder (ASD): a group of developmental disorders that can cause social, communication, and behavioral challenges; having ASD may increase the risk of epilepsy and repetitive symptoms associated with ASD may be incorrectly identified as epilepsy

automatisms: repetitive movements seen in some people whose epilepsy is located in the limbic part of the brain

bone mineral density (BMD): a test used to measure the health
of your bones

brain stem: connects the brain and the spinal cord

breakthrough seizures: seizures that happen when they are normally controlled by medicine

cerebellum: area of the brain involved with coordination of skeletal muscle function

chronic side effects: side effects from medicine that occur over time

clinical trials: research studies in which doctors test new medical therapies with the goal of finding new or better ways to prevent, find, diagnose, or treat a disease in people

clonic: the limb-jerking phase of some types of generalized seizures (see tonic–clonic seizures)

combination therapy: taking two or more medicines to treat a condition such as epilepsy

complex partial seizure: partial seizure during which the person loses consciousness; may also cause loss of memory or changes in behavior

computerized axial tomography (CAT) scan: a test that creates a three-dimensional picture; used to find minor irregularities in the structure of your brain

concentration-dependent side effects: side effects that happen as the amount of medicine in your body increases

convulsions: muscle contractions followed by limb jerking caused by some types of seizures

Diastat®: brand name of a commonly used rescue medicine in children

dietitian: an expert who helps people make appropriate food choices

electroencephalogram (EEG): a test that uses electrodes or a cap placed on your head to record the electrical activity in your brain

febrile seizures: an uncommon type of seizure that may occur in young children; rather than irregularities in the brain, these seizures are thought to be caused by fevers and typically occur during common childhood infections

focal seizures: seizures that start in a certain area of the brain; may improve after surgery

generalized seizure: one of two main categories of seizures that affect the whole brain and cause the person to lose consciousness; symptoms include muscle tightening or stiffness, and rapid and uncontrolled muscle movement on both sides of the body; used to be called grand mal seizures

grand mal seizures: (see generalized seizure)

hearing centers: areas of the brain involved with interpreting sound so that we can understand words and melodies

hormone replacement therapy (HRT): used to treat symptoms of menopause; also can affect epilepsy (see menopause)

idiopathic epilepsy: a term used by doctors when the exact cause of irregular electrical activity in the brain is not known; sometimes caused by inherited gene mutations that interfere with normal nerve cell function

idiosyncratic side effects: side effects of some medicines that are not related to the amount of medicine in your blood

Individuals with Disabilities Education Act (IDEA): a federal law under which parents can request assessment of their child's need for special education services; also ensures children receive early intervention services if needed, as well as assistance with the transition from a school setting to adulthood

individualized education program (IEP): a plan in which parents and school staff meet regularly to review the details of a student's needs, performance, and goals (see Individuals with Disabilities Education Act)

ion channel: a hole in the outer wall of a cell through which ions travel; these channels can be controlled by certain seizure medicines used to treat some forms of epilepsy

ion: a type of chemical—like sodium, potassium, and calcium—that moves quickly in or out of a nerve cell to produce the electric impulses that send information from one end of the cell to the other

ketogenic diet: a special type of high-fat, low-carbohydrate diet sometimes used to control seizures in people with epilepsy

ketones: a byproduct produced by the liver when people eat high amounts of fat and low amount of carbohydrates (see ketogenic diet)

Lennox-Gastaut syndrome: an uncommon type of seizure that may cause problems with thinking or memory; thought to be caused by problems during development, they often are found in children

lifestyle modification: making changes in your daily routine to help improve your health, including diet, exercise/physical activity, sleep habits, alcohol consumption, and medicine use

limbic system: people with seizures that start in this part of the brain may be more likely to display repetitive movements (see automatisms)

magnetic resonance imaging (MRI) scan: a test that produces a three-dimensional picture of your brain; used for seeing subtle differences in brain tissue that may not be detected in a CAT scan

magnetic resonance spectroscopy (MRS) scan: similar to MRI, MRS is used to evaluate chemical activity in specific parts of your brain; provides additional information about any areas where unusual chemical activity is occurring with irregular electrical activity

medicine schedule: a tool used to help you remember to take your seizure medicine; includes all of your medicine names, doses, the time of day that each should be taken, and any special instructions

menopause: the time at which menstrual cycles stop, during which women can experience changes in their epilepsy; usually is marked by changes in the reproductive hormones estrogen and progesterone

monotherapy: taking a single medicine to treat a condition such as epilepsy

motor cortex: area of the brain involved with control and coordination of muscle movement (for example, telling your hand to pick up a pencil)

myoclonic jerks: generalized seizures that are rapid muscular contractions that may look like they are caused by a "shock"

neurons: nerve cells found in the brain and spinal cord over which signals travel to control body functions

neurotransmitters: special chemicals released by nerve cells to send information in the form of electric impulses along their lengths, and from cell to cell; different parts of the brain use different types of neurotransmitters to communicate between nerve cells

nonadherent: not taking medicine as prescribed, including taking too much or too little, taking it at the wrong times, or forgetting altogether

osteomalacia: abnormal softening of bone

osteoporosis: a reduction in the strength of bones

over-the-counter (OTC) medicines: medicines you can buy without a doctor's prescription; always check with your doctor before taking any new medicines, including OTC and herbal medicines

partial seizures: one of two main categories of seizures; partial seizures usually affect only one side of the body, and often cause muscle stiffness and/or movements

petit mal seizures: (see absence seizure)

photosensitive epilepsy: a condition in which seizures are caused by exposure to flashing lights; most common in children, this type of epilepsy affects fewer people as they grow older

polycystic ovarian syndrome (PCOS): a treatable condition in some women with epilepsy that can make it difficult to become pregnant

polysomnography: a sleep study in which electrical activity is recorded from various body parts, including the brain, the eyes, and the muscles

positron emission tomography (PET) scan: a test used to observe chemical reactions in the brain

post-synaptic receptors: special areas on nerve cells used by neurotransmitters to either stimulate or block the electrical signals of the next nerve cell in the chain. A seizure can be caused when a neurotransmitter overstimulates or overblocks the next cell. Some medicines used to treat epilepsy can control the interaction between neurotransmitters and their receptors

prefrontal cortex: area of the brain involved with processes that impact behavior and personality

refractory seizures: seizures that don't stop or get better with medicine

rescue medicines: medicines that work quickly to stop seizures and help prevent an emergency, but not taken in place of regular seizure medicine

resource kit: a collection of material that you can refer to for information and help with managing your seizures; may include a management plan for what to do when you have seizures, a list of contact information for the members of your healthcare team, a medicine schedule, and a list of possible triggers and characteristics of your seizures

secondarily generalized seizure: a type of partial seizure in which irregular electrical activity in one side of the brain travels to other parts of the the brain, so that more body parts may be affected

seizure diary: a record of the possible triggers and symptoms associated with your seizures used to help idenitify the cause, type, and frequency of your seizures

seizure dogs: certain dogs that appear to sense an epileptic seizure before it begins; their activity helps alert the person so that he or she can prepare for a seizure

seizure emergency: having a seizure that requires immediate medical attention

seizure response plan: a written plan to keep with you that has instructions on what to do in case of an emergency; should include personal and emergency contact information, types and triggers of your seizures, a list of the seizure medicines you take, and instructions on how to treat you when you are having a seizure

seizure triggers: something specific that can bring about a seizure, such as missing seizure medicine doses, lack of sleep, use of drugs or alcohol, changes in hormone levels or diet, and flashing lights

simple partial seizures: partial seizures in which the person does not lose consciousness

sensory cortex: area of the brain involved with your understanding of sensations from skin, muscle joints, and organs

sleep apnea: a sleep disorder in which breathing stops and starts repeatedly; along with other sleep-related concerns, it can affect seizure control

speech centers: areas of the brain involved with interpreting spoken and written language, and with speech

status epilepticus: a medical emergency in which a seizure lasts longer than 5 minutes or when the person does not fully regain consciousness between seizures

stimulus: something that can trigger the onset of a seizure or behavior change, such as loud noises, flashing lights, and video games

synapse: space between nerve cells through which neurotransmitters travel to send information from one cell to the next

syncope: a condition in which loss of consciousness can be caused by a temporary drop in blood flow; often mistaken for an epileptic seizure because both conditions can happen quickly, without warning

temporal lobe: an area of the brain in which certain seizures start that may improve after surgery

tonic: the muscle contraction phase of some types of generalized seizures (see tonic–clonic seizures)

tonic–clonic seizures: generalized seizures with muscle contraction (tonic) and limb jerking (clonic); the person often lets out a "cry" when the muscles of the airway contract or may lose bladder control

vagus nerve stimulator (VNS): a device that is implanted in the body to help reduce the frequency of seizures in some people with certain types of seizures that are not controlled with antiepileptic medicine

visual cortex: area of the brain involved with converting information from the eyes into images we understand

ADDITIONAL RESOURCES for Further Reading

A diagnosis of epilepsy can be scary at first, but educating yourself (and your child if he or she has been diagnosed), is one of the first steps to taking control. Below is a list of resources to help you and your loved ones learn about epilepsy:

General resources

The Epilepsy Foundation

- http://www.epilepsy.com/
- 24/7 Hotline: 1-800-332-1000

American Epilepsy Society

- https://www.aesnet.org/for_patients

Danny Did Foundation

- http://www.dannydid.org/
- 1-800-278-6101

Resources for parents

http://www.epilepsysociety.org.uk/parents#.VUomJvlViko

http://www.epilepsy.com/information/parents

http://www.cececares.org/for-parents-information-about-epilepsy.html

http://www.cdc.gov/epilepsy/toolkit/

http://www.parentcenterhub.org/repository/epilepsy/

http://kidshealth.org/parent/medical/brain/epilepsy.html

http://www2.massgeneral.org/childhoodepilepsy/child/family_life.htm

Resources for information about treatment

http://www.charliefoundation.org/ (information on ketogenic therapies)

http://www.cureepilepsy.org/home.asp (epilepsy research)

http://www.hope4harper.com/ (epilepsy research)

http://www.ice-epilepsy.org/ (epilepsy research)

https://www.rxhope.com/ (payment assistance program)

http://www.rxassist.org/ (payment assistance program)

http://rxadvocates.org/ (payment assistance program)

https://www.pparx.org/ (payment assistance program)

Resources on technology used for monitoring seizures*

https://www.seizuretracker.com/ (seizure tracker)

https://www.depakote.com/Content/Pdf/Seizure-Diary.pdf (seizure diary)

http://www.dannydid.org/epilepsy-sudep/devices-technology/ (devices and technology)

http://www.epdetect.com/ (mobile application)

http://www.bcepilepsy.com/blog/epilepsy-related-applications-for-smartphones.aspx (mobile applications)

*Devices and trackers are not approved for use by the Food and Drug Administration

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Clinical Pharmacology online database. http://clinicalpharmacology.com

College Scholarships website. http://www.collegescholarships.org

Columbia University Neurology website. http://columbianeurology.org/patient-care/epilepsy

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The Epilepsy Foundation website. http://www.epilepsy.com

The Epilepsy Foundation Eastern Pennsylvania website. http://www.efepa.org

Epilepsy Foundation Michigan website. http://www.epilepsymichigan.org

The Epilepsy Network (TEN) website. http://theepilepsynetwork.com

Epilepsy Society website. http://www.epilepsysociety.org.uk

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