

TEENS & EPILEPSY

A GUIDE TO
UNDERSTANDING
AND LIVING
WITH EPILEPSY

epilepsy
ALLIANCE
FLORIDA
THE POWER OF LOCAL

Enjoy Life!

Have epilepsy? You can do just about anything your friends can—sports, dating, hanging out, working, even driving. But, before you do, you have to know: What's safe? And what isn't?

Why me?

Just found out about your epilepsy? Anyone can have epilepsy, regardless of age, race, sex or social conditions. Epilepsy may be part of your life, but it doesn't define who you are. There's more—much more—to you than your epilepsy! Lots of famous people—athletes, authors, artists, politicians, professionals—have epilepsy. Are you going to let epilepsy stop you from doing what you want?

It's a shock!

Admit it! Finding out about your epilepsy was a real shock. What can you do about it? Take charge of your life by learning as much as you can about epilepsy. Broadcast the news! Once you explain what epilepsy is, people are often more understanding and supportive. They'll treat you—like everyone else!

You're Not Alone!

More than 430,000 Floridians live with epilepsy. That's about 2% of Florida's population. About 50% of people with epilepsy are diagnosed before age 10.



EPILEPSY FAST FACTS



426,000 individuals suffer from epilepsy across the state with **84,000** of those sufferers being children.



Epilepsy is the **fourth most common** neurological disease in the United States after migraine, stroke, and Alzheimer's disease.



Epilepsy is **more common than** Parkinson's disease, Multiple Sclerosis, Cerebral Palsy, and Autism combined.



1 in 26 people in the United States will develop epilepsy at some point in their lifetime and **1 in 10** will have a seizure.

What's Epilepsy?

Epilepsy isn't contagious. In epilepsy, the brain's electrical circuitry doesn't work properly. Normally, the brain sends electrical signals throughout the body to control movement. In epilepsy, the brain sometimes creates an electrical storm—called a seizure—that scrambles these signals.

While it lasts, a seizure affects how your brain works. That's why you can suddenly experience uncontrolled body movements, unusual sensations, or changes in behavior or awareness.

During a seizure, you may stare into space or be unable to speak or experience strange smells, sounds or sights—without losing consciousness.

What causes seizures?

When it comes to epilepsy, this question doesn't always have an answer. In most cases, no one knows what causes epilepsy. So, seizures are lumped into two groups: those with causes we don't know (idiopathic or primary seizures) and those with causes we do know (symptomatic or secondary seizures).

Idiopathic (primary) seizures

are more common in children and teens.

No one knows what causes these seizures. Some people may inherit a genetic tendency to develop epilepsy. Environmental factors may trigger seizures in someone with a genetic susceptibility for epilepsy

Symptomatic (secondary) seizures

are more common in adults.

They usually occur after a head injury or medical illness, such as:

- Brain tumor or stroke
- Head injury—the more severe the injury, the greater the chance of developing epilepsy
- Brain injury to the infant during delivery
- Infection or systemic illness in a pregnant woman, affecting the fetal brain
- Aftermath of infection (meningitis, viral encephalitis)
- Poisoning due to substance abuse (alcohol or street drugs) or other toxic substances.
- Low calcium or abnormal metabolism.
- Other metabolic cause

What Triggers Seizures?

Certain activities and environmental or physical factors can trigger a seizure. Some triggers are avoidable; some aren't.

Avoidable Triggers

- Missing your medication
- Missing even one dose of your antiepileptic drugs can cause a seizure
- Suddenly stopping your medication without your doctor's advice can be very dangerous

Lack of Sleep

Sleep patterns are linked to electrical activity in the brain, so lack of sleep may trigger, intensify or prolong seizures

Drug or alcohol abuse, caffeine, over-the-counter drugs

Together with antiepileptic drugs, common ingredients in cold, diet, sleep and allergy medications may trigger seizures

Poor nutrition

Very low levels of sodium, blood sugar, calcium or magnesium may lower the seizure threshold

Flashing lights and patterns

Only a very small percentage of people with epilepsy are affected

Unavoidable Triggers

- Short, rapid breathing (hyperventilation)
- Stress Fevers, colds or infections
- Menstrual cycle (catamenial seizures)
- Menopause





Types of seizures

Some people may get a warning (aura) beforehand, during most seizures, you're totally unaware of what's going on. Afterward, there's no memory of what happened. That's why reading about what happens during different types of seizures can be scary. With simple partial seizures, you are totally aware of what's happening and do remember your seizures after.

The more you know, the better you'll feel

Seizures aren't painful, though some people who have simple partial motor seizures may experience muscle or abdominal pain, and they rarely cause brain damage. Knowing about seizures can help you to explain what happens to your friends and family. They can help you to monitor your seizures—instead of being afraid that you'll get hurt. This information helps your doctor to know the facts about your epilepsy and to prescribe the most appropriate treatment for you.

Focal seizures start in one specific part or focal point of the brain.

Focal Onset Aware seizures

You may experience unusual sensations or movements while fully conscious, such as:

- Uncontrolled stiffening or jerking of the arms and legs
- An odd taste, smell or pins and needles
- Feeling like you want to throw up
- Intense emotions—like fear, sadness or anger
- A “rising” feeling in your tummy

Focal Onset Impaired Awareness seizures

You are not fully conscious or lose consciousness during these seizures. They usually last from 30 seconds to 3 minutes. Afterward, you feel confused for a few minutes, have a headache or feel drowsy. You may experience:

- A dreamlike state—be unaware and unresponsive to questioning
- Unusual, repetitive movements—like picking at your clothes

Generalized seizures involve the entire brain. A secondarily generalized seizure begins in one part, then spreads throughout the brain.



Types of seizures

Tonic-clonic (Grand mal)

You may cry out, fall down, become rigid, and lose consciousness. Your arms and legs may jerk, and breathing may become shallow. You may lose bladder or bowel control, drool or bite your tongue. This seizure lasts anywhere from 30 seconds to a few minutes. Afterward, you may feel confused or drowsy, need to sleep or have a headache.

Absence

This brief seizure resembles daydreaming. It happens so fast that it often goes unnoticed. You look like you're not paying attention. If this happens at school, you'll miss information or instructions.

Myoclonic

A sudden startle movement may cause you to drop objects.

Tonic

This seizure usually lasts less than one minute. You may lose consciousness. Your muscles stiffen, but there's no jerking of arms or legs. If you're standing, you may fall to the ground.

Atonic

A sudden drop. Loss of muscle control makes you fall hard to the ground. This seizure lasts a very short time.

Tell Your Doctor

If you think you have epilepsy, bring this information to your doctor's appointment:

- A detailed description of your seizures:
 - How and when did they start?
 - How long do they last?
 - How often do they happen?
 - How severe are they?
 - What triggers them?
 - What do you experience before and during the seizure?
 - Do you have a warning (aura) before a seizure?
- Your past medical history
 - Any problems at birth, serious infections or head injuries
- Family history of epilepsy or any medical disorders, including seizures
- Any history of drug use
- Your sleep pattern
 - Do you have any trouble sleeping?

Epilepsy? NOT!

Some medical conditions are often mistaken for epilepsy. Ask your doctor, if you're concerned about any of these conditions:

- Dizziness
- Lack of sleep
- Fainting
- Daydreaming
- Sleepwalking or night terrors
- Pseudoseizures (non-epileptic seizures)
- Panic attacks (caused by anxiety)
- Hyperventilation (rapid breathing due to stress) Angry outbursts
- Involuntary movements such as tics
- Other movement disorders
- Hypoglycemia (low blood sugar)



Medical Tests

Computerized Axial Tomography (CAT or CT Scan)

- Uses low-dose x-rays
- Reproduces a 3-D computer image of the brain
- Shows what the brain looks like but not how it works
- Tracks an injection of dye to show more detail

Positron Emission Tomography (PET) & Single- Photon Emission Computed Tomography (SPECT)

- Shows how the brain works
- Used when brain surgery is considered to treat your seizures
- Tracks an injection of radioactive material by computer scanning
- Shows how quickly the brain metabolizes certain substances

Magnetic Resonance Imaging (MRI)

- Detects very small brain abnormalities, e.g., tumours or scar tissue
- Shows more detail than CT scans
- Is not an x-ray
- Uses a powerful magnet and computer to form a distinct image of brain tissue
- Helps to locate where seizures originate
- Is safe and has no side effects
- Shows a detailed picture of brain structures but not how they work
- Tracks an injection of dye to show more detail

Electroencephalogram (EEG)

- Measures and records electrical brain activity on a graph
- Takes one or two hours
- Shows abnormal brain activity, such as abnormal changes in brain-wave voltages
- Produces normal results in about 20% of people with epilepsy, because their seizures arise from deep in the brain

Video EEG

- Records brain's electrical activity on EEG
- Records what you experience during a seizure on video



How Do You Treat Epilepsy?

There are 5 ways to treat epilepsy:



Antiepileptic
(anticonvulsant)
drug therapy



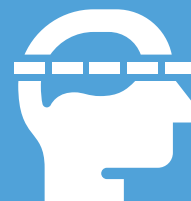
Vagus nerve
stimulation
(VNS)



Responsive
neurostimulation
(RNS)



Ketogenic diet



Surgery

Medication for Epilepsy

Medicine is the most common treatment for epilepsy. Medication cannot cure epilepsy, but it can control your seizures in more than 70% of people with epilepsy.

Before prescribing antiepileptic drug therapy, your doctor reviews a number of factors:

- What type of seizures do you have?
- How often do you have seizures?
- What drugs are best for someone of your age and weight?
- What other medication are you taking?
- What other medical conditions do you have?

After selecting a medication to treat your seizures, your doctor will figure out how much of it you'll need—the right dosage to control seizures. Usually, the dosage is gradually adjusted until your seizures are controlled without side effects.

Help your doctor find the medication that's right for you.

Everybody reacts differently to medication. If you have side effects, your doctor may change your medication to get it right for you.

- Pay attention to how your body reacts to medication
- Take notes of any changes, even if they're not related to your medication
- Be honest with your doctor—with team work, you can find what's right for you!

Take your medication

It's the best way to live with epilepsy. When your seizures are controlled, you can hang with your friends, drive, do sports—and more. Keep your seizures under control, so you can enjoy life!

Medication for Epilepsy

Most common side effects

- Drowsiness
- Weight gain or loss
- Learning and/or attention deficit disorders
- Sleep disturbances
- Dizziness
- Tremors
- Poor coordination
- Allergic reactions (e.g., rash)

Make the most of your medication

- Use self-discipline, and control your epilepsy—don't allow it to control you
- Stick to a schedule—use a pill box to remind you
- Never stop taking your medicine suddenly—it's dangerous. Talk to your doctor first.
- Be patient! You'll probably have to try different drugs before finding the right one
- If you take any other medications or supplements, ask your doctor or pharmacist about drug interactions
- Ask about side effects
- Always refill your prescription on time



What's Vagus Nerve Stimulation (VNS)?

If your seizures don't respond to drug therapy, vagus nerve stimulation may work for you. To stimulate your vagus nerve—a nerve that carries signals from your brain to your body—doctors implant a flat, round device (like a pacemaker) under the skin of your upper chest below the collarbone (between your neck and shoulders). Every few minutes, it sends electrical energy to the vagus nerve. A computer and programming wand control the implant. You can activate it with a small magnet that you carry in your pocket which may stop the seizure at its onset.

Side effects:

- Hoarseness
- Discomfort and/or tickling in the throat
- Voice change in tone, until the stimulation cycle ends
- Risk of infection from surgery (1 % to 2% of patients)
- Chest tightening
- Cough

What's Responsive Neurostimulation (RNS)?

(RNS) is an epilepsy treatment that doesn't require the surgical removal of brain tissue. RNS uses an implanted device to help prevent seizures before they begin, similar to how a pacemaker detects and treats abnormal heart rhythms. With RNS, surgeons implant a small battery-powered device called a neurostimulator in the patient's skull. The neurostimulator monitors the brain's electrical activity, and when activity that could lead to a seizure is detected, it delivers a pulse of electrical stimulation through the leads. The electrical pulse may stop the seizure before it begins.

Side effects:

Because responsive neurostimulation involves brain surgery to implant the device, there are associated risks. Once the responsive neurostimulation system is implanted and activated, there are not any significant side effects. Some patients might experience minor discomfort during the initial programming and adjustment to the device. Doctors will work to ensure the patient is comfortable.

What's The Ketogenic Diet?

When seizures don't respond to drug therapy, a doctor may recommend this high-fat, low-carbohydrate diet. It is not often recommended for teenagers. It causes metabolic changes in your body.

Never start it on your own—without supervision. This very strict diet may be harmful, if not followed properly. Your doctor will refer you to a specialist.

How it works

- Blood sugar levels will be closely monitored
- A certified nutritionist carefully calculates food intake
- At first, blood sugar levels are checked every 4 to 6 hours
- You must take sugar-free vitamins and calcium
- You must weigh and record all food
- You must drink lots of water or caffeine-free soda

Side Effects:

- Kidney stones
- Poor immune response
- Low blood sugar

Questions About Surgery?

Epilepsy surgery—removing small bits of abnormal brain tissue—is an option when drug therapy doesn't help. When seizures make your life miserable—when you can't live a normal life or concentrate at home or school—your doctor may suggest surgery.

Only a small number of people with uncontrolled seizures are considered for epilepsy surgery.

Beforehand, your doctor needs to know whether:

- You have focal seizures
- Seizures always come from a particular spot in your brain
- That specific spot can be removed without damaging your speech or movement

Your Relationships

Dare to talk about epilepsy. As a teen, you're dealing with lots of issues—like dating or what your friends think about you. You may feel like you have to change who you are to fit in—just be part of a group. You don't want to stand out or be different because you have epilepsy. But epilepsy doesn't define who you are—it's just one of many special things about you. And differences are what make the world an interesting place!

Who? And when?

Whom do you want to tell? When's the best time? The people who care most about you and whom you see more often will want to know about your epilepsy— family, friends, roommates, neighbors, and co-workers are great sources of support.

Ask these questions when you're trying to decide:

- Who loves me and wants me to live the best possible life?
- Whom do I see most often?
- Who will notice changes that signal the start of my seizures or a reaction to my medication?
- Who can help me with small chores or errands that may not be safe for me to do by myself?
- Who can I rely on in an emergency to get help, check my medication record, and contact my family and doctor?
- Who can I trust with a key to my home to come and check on me?
- Who can I count on to drive me to my doctor's office or emergency?

Dating

When it comes to dating, everyone gets nervous. The more comfortable you feel about yourself, the more comfortable others will feel with you. You're the only one who can decide when the time is right to talk about epilepsy. If you have frequent seizures, you may wish to tell your girlfriend or boyfriend about epilepsy early in your relationship. If you do, they'll know what's happening and how to help when you have a seizure. Certain people—your teachers and swimming instructors—should always know about your epilepsy. By daring to talk about epilepsy, you can help people to understand it and teach them how to help you to stay safe during a seizure.



If you have a seizure, your friends can make sure you're safe by:

- Staying calm
- Moving things away from you
- Putting a pillow or cloth under your head
- Turning you on your side
- Loosening things around your neck
- Never putting anything in your mouth
- Not holding you
- Never leaving you alone

My parents are driving me crazy!

Got overprotective parents? All parents just want the best for their children, and some can be overprotective when their child has epilepsy. Ask your doctor or nurse to talk with your parents—together you can put together an activity plan that won't place you in danger. Assure your parents that you'll take extra precautions to keep safe when doing sports or when going out with friends.



What You Need to Know About Sex

You and your period

Catamenial epilepsy occurs when seizures increase around the time of menstruation. Keep a record of when your seizures occur during your menstrual cycle, for many months, to find out if you've got catamenial epilepsy.

Hormones and Seizures

- Estrogen may excite brain cells, increasing the risk of seizures
- Progesterone has the opposite effect

Birth Control

If you're sexually active but not ready to start a family, ask your doctor or nurse about birth control. Some antiepileptic drugs can reduce the effectiveness of birth control pills. If that's the case, your doctor may prescribe a stronger birth control pill or suggest a different contraceptive method, e.g., a diaphragm, spermicidal cream or condoms.

Pregnancy

Pregnancy should always be planned, and you should talk to your doctor before deciding to get pregnant. If planning a family, visit your doctor as soon as you hear the news. Don't stop taking your medication without your doctor's consent. If you do, you're taking a big risk. During pregnancy, more frequent seizures may cause serious damage to your health and the baby's. It is recommended that all females of childbearing age take folic acid, and a higher dose is required if you take AEDs.

Epilepsy, drugs and birth defects

Most babies born to women with epilepsy are healthy. There is a small risk that epilepsy or the use of antiepileptic medication will affect the fetus. Talk to your doctor about these risks:

- Antiepileptic medication can increase the risk of serious birth defects
- Pregnant women with epilepsy have a 4-6% risk of having a child with birth defects
- The risk increases if you're taking more than one type of antiepileptic medication

What You Need to Know About Sex

Sexual dysfunction

Not interested? No sex drive? Trouble during sex? Hey, it's a common problem for men and women—not just people with epilepsy. Your medication may directly affect regions of the brain that control sexuality or reproductive hormones.

Psychological Causes

Some teens fear that sex will spark a seizure, especially if seizures are triggered by hyperventilation or physical activity. Are you afraid that your partner will find out about your epilepsy during sex and reject you? Stress can cause sexual problems. Is there a link between promiscuity—too much sexual activity at a young age—and the need to feel accepted because of your epilepsy? If so, you need to do some serious thinking about your sexual behavior.

Your sexual health

For women only

If your seizures start in the temporal lobes, you're more likely to have reproductive disorders. The temporal lobes are closely linked to areas of the brain that regulate hormones.

Common types of reproductive disorders are:

- Polycystic ovaries (many cysts on the ovaries)
- Early menopause
- Irregular or no ovulation



The Physical You & Epilepsy

Mood swings

Epilepsy may alter your moods, emotional state—even your memory. You know that seizures can change your mood, and antiepileptic drugs can change the chemistry in your brain.

Everyone has bad days, but sometimes dealing with the day-to-day brings on feelings of shock, fear, denial, anger, anxiety or depression. Don't ignore or deny these feelings. They're a real part of your condition—and you can find ways to deal with them effectively.

Feeling sad, angry or frustrated? The best thing for that? Talk with people who care about you—friends and family—or people who can give you support—the school counsellor, seizure-clinic nurse or your doctor.

Come on, share! Keeping everything inside is hard on you—sharing problems make them more bearable. Talk with people who care. Together, you can find solutions to what's bothering you.

Are you sad or something more?

A lot of “yes” answers? Talk to your doctor.

- Do you have feelings of helplessness and hopelessness?
- Are you unable to experience happiness?
- Do you have sleeping problems (oversleeping or not being able to sleep)?
- Do you have a low sexual drive?
- Is your appetite lousy (overeating or loss of appetite)?
- Do you have a lack of energy?
- Are you feeling unmotivated?
- Do you have suicidal thoughts?

What causes mood swings?

- Changes in brain chemistry
- Hormones
- Genetics
- Medications
- Stress
- Significant life events
- Difficulty adjusting to epilepsy
- Dealing with imposed limitations and restrictions
- Unpredictable nature of seizures
- Feelings of helplessness/loss of control

Stressed Out?

You may be tempted to skip meals or sleep less in order to have more time for your studies or for your part time job, but this can be harmful to you by increasing your stress level which can cause hyperventilating, sleep disruptions, or can alter brain activities.

You know you're stressed when...

- You feel an adrenaline rush
- Breathing speeds up
- Heart pounds faster
- Body feels tired and strained
- You have trouble concentrating

Relax!

- Listen to music
- Read a book
- Yoga
- Sleep
- Sports/regular exercise
- Aromatherapy



You and Your Look

Let's face it! Your looks are real important to you. So you should know—some antiepileptic drugs can change how you look. Check out this list of side effects for antiepileptic medications. If this is you—and you're not happy about it—talk to your doctor. But don't stop taking your medication! Your doctor may be able to give you a different medication to control your seizures – without the side effects.

- **Weight gain:** Not eating won't do the trick— monitor your weight and get some exercise!
- **Temporary hair loss or thinning or excessive hair growth**
- **Thickened gums:** Good dental hygiene and regular check-ups can put this off
- **Menstrual irregularities**
- **Slight tremors**

Education

You and school

Most teens with epilepsy finish high school and go on to college or university—if that’s what they want.

You and the teacher

Your teachers and the school administration need to learn about first aid for seizures. Help them out! Give them pamphlets and information on epilepsy. Some associations offer information sessions for schools— to demystify epilepsy. When you start university, get a letter from your doctor that details your medical history and medications.

Memory problems?

Do you have memory problems? That’s common, particularly if you have tonic-clonic seizures or take high doses of antiepileptic meds. If remembering is a real challenge— and source of frustration—there are helpful strategies that you can use.

Living on your own

- Living in a university residence? Tell your fellow residents about your epilepsy, and make sure they know about first-aid treatment
- Telling your roommates will help them be better prepared to handle a seizure
- Eat healthy and exercise
- Get enough sleep
- Avoid typical on-campus “me-too” traps like alcohol and drug abuse

Tips for success

- Stay ahead—don’t leave things until the last minute
- Take a lighter class load
- Keep a monthly schedule of deadlines to meet
- Avoid part-time work until you graduate
- Avoid all-night cramming sessions



Getting a Job

You can find work and be a good employee—epilepsy doesn't have to get in the way.

People with epilepsy are often more productive on the job. They take less time off than their co-workers. The big question is: When do you tell the boss about your epilepsy? Only you can make that choice, depending on the job and your comfort level.

Do it now or later?

Before you're hired:

Advantages

- Honesty
- Peace of mind
- Discuss epilepsy
- Reduce risk of discrimination

Disadvantages

- Discrimination
- Disqualification!
- Emphasis on epilepsy

On the job:

Advantages

- Can prove yourself first
- Control information
- Reduce risk of discrimination
- Educate others about epilepsy

Disadvantages

- Boss's distrust/fear
- Inability of co-workers to respond
- Discrimination
- Misunderstandings
- Safety concerns

Choosing a career

Human rights codes prevent any discrimination against people with epilepsy. People with epilepsy are successfully employed in a variety of jobs that might be considered highrisk: police officer, firefighter, welder, butcher, construction worker, etc. Epilepsy is a highly variable disorder and it is difficult to generalize about safety issues.

Under the ADA, employers may not exclude employees for safety reasons unless there is specific medical documentation, reflecting current medical knowledge, that the individual would pose a "direct threat" to health and safety.

Workplace safety

Most businesses have safety rules to protect you and your co-workers from on-the-job injuries. Check them out! Some businesses levy fines for breaking the rules.

Common safety rules & regulations

- Discuss epilepsy with your co-workers
- Provide information about first aid for seizures
- Avoid heights
- Check for safety features when working with heavy machinery
- Limit exposure to flashing lights and use dark glasses, if needed
- Reduce stress as much as possible
- Give your doctor's phone number and names of relatives to contact
- Wear a Medical Alert bracelet

Auto Safety

Responsible driving

Can't wait to drive? To have the freedom to go where you like, when you like? You can look forward to driving—and that independence—when:

- You are seizure free for a period of two years but may apply to the Medical Advisory Board (MAB) after six months for reconsideration if you are regularly monitored by a physician and seizure free
- Your antiepileptic drugs do not cause any side effects that are hazardous to driving
- You are under medical supervision
- Your seizures are controlled—on or off medication

Florida Reporting

Florida has no provision requiring doctors to report patients, to a central state agency, who have been treated for or diagnosed as having epilepsy. Any physician, person or agency having knowledge of a licensed driver or applicant's mental or physical disability to drive may report the person to the Department of Highway Safety and Motor Vehicles. FLA. STAT. ANN. § 322.126(2) (2020).

This summary is not a substitute for legal advice. For further information, please consult your state Department of Motor Vehicles.

Auto Safety

They have to know

Before you learn to drive, your doctor must appraise your seizure frequency. If you meet these criteria, your doctor may want to submit a report to the DMV. They'll want to know that:

- Your antiepileptic drugs do not cause any side effects that are hazardous to driving
- You are under medical supervision
- Your seizures are controlled—on or off medication

Cars can carry, and cars can kill. Don't turn your car into a weapon. Driving is only one declaration of independence. There are safer ways to live your own life!



Follow these safe driving guidelines:

- If you have a seizure, don't drive yourself to the doctor, ask someone to help you
- If your medication has been changed, wait to see if any side effects occur before you begin driving again
- If you have a seizure after getting your license, don't drive; it's against the law
- If epilepsy makes it impossible for you to drive, take public transportation, bicycle, or car pool
- If you need a ride, ask a friend or family member— they'll be glad to help

Insurance Costs

Automobile insurance is very expensive for all teens, and coverage varies. Some companies refuse to insure people with epilepsy; others are more progressive. Failing to advise your insurance company that you have epilepsy can invalidate your policy in case of accident (bzzzz—you lose coverage).

Safe at Home

Worried about safety issues around the house? That's common—especially when you're newly diagnosed with epilepsy. You can improve your safety by changing a few old habits.

If you live alone, think about getting a monitor or safety device that works like an alarm or connects to a central security system. Wear an identification bracelet or pendant. Ask your doctor or pharmacist about new services or products for independent living.

Play it Safe at Home

- Keep bathroom and bedroom doors unlocked
- Take showers rather than baths to avoid the possibility of drowning during a seizure
- Any glass doors should be made from safety glass or plastic
- Don't walk around with boiling water
- Take your plates to the stove instead of taking the saucepan or fry pan to the table
- Microwave cooking is safer than gas or electricity
- Use cooker, fire and radiator guards
- Turn pot and pan handles inwards
- Keep away from fireplaces and radiators to avoid getting burned
- Avoid sharp-edged furniture



Fun & Relaxation

Getting physical: Sports

Thinking about holding back? Forget it! You can participate in all kinds of sports. Take a few precautions before you start any activity. Tell your coach, close friends and teammates about your epilepsy so they are prepared to help during a seizure.

Each sport has specific safety rules that must be strictly obeyed—for your security. Moderate- and high-risk sports require supervision at all times. You know it sucks, but always wear your helmet!

Low risk sports

- Jogging
- Aerobics
- Cross-country skiing
- Dancing
- Hiking
- Golf
- Ping-pong
- Bowling
- Field hockey (helmet)
- Most track and field events
- Baseball(helmet)

Moderate risk sports

- Downhill skiing
- Swimming
- Horseback riding (helmet)
- Bike riding (helmet)
- Basketball
- Canoeing (life vest) not alone
- Ice-skating or hockey (helmet)
- Tennis
- Gymnastics
- Roller-blading (helmet)

High risk sports

- Mountain or rock climbing
- Bungee jumping
- Skydiving
- Scuba diving
- Caving
- Football moderate
- Boxing moderate
- Hang gliding
- Surfing/windsurfing
- Solo flying
- White water boating/kayaking



Light sensitive?

Photosensitivity means you're super-sensitive to natural and artificial light—it can trigger seizures. Only 3 to 5% of people with epilepsy are photosensitive—girls more often than guys. Mostly, it develops in kids and teens between 9 and 15. People usually stop reacting to light in their late 20s or early 30s. If you're photosensitive, be careful in places with flashing lights—night clubs or night driving.

Facts about TV

- Watching TV is the most common photosensitivity trigger for seizures
- Reduce your risk by watching television in a well-lit room
- Sit at least 2.5 meters away from the TV (depending on screen size)
- Use a remote control
- Smaller screens (less than 14") reduce your exposure to light

Computer and video games

- They are not normally a threat for people with epilepsy
- The risk of seizures depends on the material being displayed
- The higher the frequency of the display screen, the less risk
- Do not read from the computer screen for a long time
- Anti-glare screens do not reduce the risk of seizures

Travel Tips

- **Ask about vaccinations**—How will they affect your epilepsy and the effectiveness of your medication?
- **You can take it with you!** Carry your prescription, names of contacts and a doctor's letter that explains your type of seizures
- Find information about the health-care system at your travel destination. **Are you covered?**
- **Travel insurance:** shop around to find the best deal
- **Wear** a medical bracelet or necklace for epilepsy Keep medication in its original packaging (shows your name, drug name, prescribed dose)
- **Watch out for a time change**—Take your medication every 12 hours
- **Plan** for rest/nap time
- Inform your traveling companion about **first aid** for seizures
- Avoid **too much** alcohol and **too little** sleep
- **Find out** if your medication is available where you're going



Drugs

DON'T PLAY WITH YOUR BRAIN

If you're going to abuse any of these drugs, you're in for some serious trouble with drug-related side effects. Your antiepilepsy medication is powerful stuff, and it can do uncool things to your head when you mess with these drugs:

- **Nicotine** damages lungs and blood vessels; leads to cancer; makes your heart beat faster; gives you indigestion and ulcers. Ask yourself what happens if you drop your cig during a seizure. You'll fire more than your brain.
- **Caffeine** raises blood pressure; makes you restless; gives you headaches
- **Heroin** taken in large amounts causes oxygen deprivation, leading to seizures
- **Recreational Marijuana** Cannabidiol (CBD), one of the components of marijuana, has been approved by the FDA to treat certain types of seizures. That said, marijuana bought on the street may be laced with other substances with unknown seizure potential. Further, using marijuana with other psychoactive drugs may increase seizure risk. The short-term effects of marijuana include: Problems with memory and learning, distorted perception, difficulty in thinking and problem-solving, and loss of coordination.
- **Ecstasy**'s short-term effects include heart problems, exhaustion, dehydration, and feelings of dismay. Long-term use causes paranoia, tension, mental disability and seizures.
- **Amphetamines** (speed), even in low doses, causes high blood pressure, appetite loss and abnormal breathing patterns that last for hours or days. High doses cause tremors, dizziness and coordination deficiencies.
- **Cocaine/Crack** causes anxiety, exhaustion, tremors, paranoia and blurred vision. An overdose can cause heart problems, seizures and death.
- **Hallucinogens** cause mood swings, tremors and difficulty sleeping. LSD may cause coordination problems, a faster heartbeat and seizures

Alcohol

TOO MUCH alcohol seriously compromises your meds. It reduces the effectiveness of antiepileptic drugs and lowers your seizure threshold. MODERATION is the key.

Brain benders

- Too much drinking, less sleep and poor nutrition can trigger seizures
- When drinking, your body has a higher resistance to medication
- Withdrawal seizures may occur from 6 to 72 hours after your last drink
- Drinking too much booze can increase seizure frequency

Myths About Epilepsy

Now YOU know all about epilepsy, so let's deal with common myths and misunderstandings. People are becoming more aware of epilepsy, and these facts will help you to answer their questions.

Myth: Epilepsy is a mental illness.

Fact: NOPE! Epilepsy is a physical disorder that has nothing to do with mental health or intelligence.

Myth: Epilepsy is contagious.

Fact: WRONG! It is impossible to "catch" epilepsy from someone who is having a seizure.

Myth: Sticking a spoon in the person's mouth while they're having a seizure will stop them from swallowing their tongue.

Fact: NO WAY! The tongue can't be swallowed during a seizure. Putting something in the person's mouth could break a tooth or injure their gums. It may also cause the tongue to block the air way if an object is inserted incorrectly.

Myth: People with epilepsy look different.

Fact: THAT'S JUST SILLY. People with epilepsy look just like everyone else.

Myth: People with epilepsy can have a seizure at any time.

Fact: THAT DEPENDS. Each individual is different—some people go for years without having a seizure; other have them frequently.

Myth: A seizure can be stopped by restraining the person.

Fact: BOGUS! Never restrain anyone during a seizure— you can hurt them. Move the person away from any sharp objects or hard surfaces.

Myth: Epilepsy means having convulsions.

Fact: THAT DEPENDS! Convulsive seizures are only one type of seizure. Seizures can also cause a short loss of consciousness, involuntary jerking movements, sudden spasms or sensory changes.

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