

TEENS AND

# *Epilepsy*



EPILEPSY EDUCATION SERIES

This publication was produced by the

  
***Edmonton Epilepsy Association***  
*The Epilepsy Association of Northern Alberta*

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This booklet is designed to provide general information about Epilepsy to the public. It does not include specific medical advice, and people with Epilepsy should not make changes based on this information to previously prescribed treatment or activities without first consulting their physician.

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Special thanks to our Consulting Team, which was comprised of Epilepsy Specialist Neurologists & Neuroscience Nurses, Hospital Epilepsy Clinic Staff, Educators, Individuals with Epilepsy, and Family Members of Individuals with Epilepsy.

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## Why Me?

Have you been diagnosed with epilepsy? Are you wondering how having epilepsy will affect your life? How your friends will react? Whether you can follow your dreams?

Epilepsy is a condition. It is not a lifestyle. Although you'll have to consider having epilepsy in the decisions you make, having epilepsy doesn't mean that you can't pursue your dreams and enjoy life just like your friends.



## What is Epilepsy?

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It is not uncommon for a person to have a seizure. In fact, approximately one in every ten Canadians will have a seizure in his or her life. But people with epilepsy have more than one seizure.

Epilepsy **is** a condition of the brain that is characterized by multiple seizures. Epilepsy is **not** a disease. It is **not** contagious. And it is **not** a psychological disorder.

## What are Seizures?

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The brain is made up of billions of nerve cells or neurons that communicate through electrical and chemical signals. When there is a sudden excessive electrical discharge that disrupts the normal activity of the nerve cells, a change in the person's behavior or function may result. This abnormal activity in the brain that results in a change in the person's behavior or function is a seizure.

A seizure can take many different forms. For instance, a person having a seizure might stare blankly, jerk his or her arm uncontrollably, feel a burning sensation, or have a convulsion.

Some people with epilepsy rarely have seizures. Others have them numerous times a day. For most people with epilepsy, seizures can be successfully controlled with seizure medication.

This means that some people with epilepsy are seizure free.

## *D* Do Other Teenagers Have Epilepsy?

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Epilepsy is more common than most people realize.

Approximately one person in a hundred has epilepsy. In Canada, there are 330,000 people with epilepsy. Epilepsy often begins in childhood.

## *H* How Did I Get Epilepsy?

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In many cases, there is no known cause of epilepsy. In others, doctors can identify a cause of epilepsy. Some of the known causes include:

- Genetic (e.g. inherited genes)
- Birth injury (e.g. lack of oxygen to the baby's brain at birth)
- Developmental disorder (e.g. brain damage to the fetus during pregnancy)
- Brain trauma (e.g. from car accidents, sports injuries)
- Infection (e.g. meningitis, encephalitis, AIDS)
- Brain tumor
- Alcohol and drug abuse



# H How Does the Doctor Know if I Have Epilepsy?

If you have had a seizure, your doctor will ask you for information regarding your medical history. The doctor will want information such as whether you have experienced infection or head injury, if you have a history of drug or alcohol use, and whether there is any family history of epilepsy.

The doctor will also need a description of your seizures and information on when you first started experiencing them. Asking those who were with you during a seizure for a description of what happened and recording that information will help the doctor in the diagnosis and treatment.



In addition to a thorough physical examination, you will likely also have diagnostic tests. An important test in the diagnosis of epilepsy is an **electroencephalogram (EEG)**. This test records the brain's electrical activity. During an EEG, small metal discs are placed on a person's scalp. These are connected with wires to the EEG. The test doesn't hurt and it usually lasts less than an hour. Although an abnormal EEG can confirm a diagnosis of epilepsy, a normal EEG does not rule out the presence of epilepsy. The EEG only records the activity in the brain at the time of the recording.

Other diagnostic tests sometimes used in the diagnosis of epilepsy are **computed tomography (CT)** and **magnetic resonance imaging (MRI)**. These tests provide scans, or pictures, of the brain. These pictures allow the doctor to see whether or not there is a physical condition in the brain such as scar tissue that could be causing the seizures.

Other tests that show how the brain works are also sometimes used especially if surgery is being considered. These include **magnetic resonance spectroscopy (MRS)**, **positron emission tomography (PET)**, **single photon emission computed tomography (SPECT)**, and **magnetic source imaging or magnetoencephalography (MSI or MEG)**.

# *Is There a Cure for Epilepsy?*

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Although drugs do not cure epilepsy, seizures can often be controlled by seizure medication. In other cases, surgery is effective in reducing or stopping seizures. Sometimes those who develop seizures during childhood outgrow their seizures. In some cases, however, seizures remain uncontrolled despite treatment.

# *What is the Treatment for Epilepsy?*

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## *Medication*

Seizure medication is the primary treatment for epilepsy. Drugs don't cure epilepsy, but they often reduce or even stop seizures from occurring by altering the activity of neurons in the brain. The majority of people achieve seizure control with seizure medication.

There are many different types of seizures and there are many different types of seizure medication. Sometimes a doctor will prescribe one drug. In other cases, more than one drug is needed to control seizures. A doctor might try a number of different drugs to find the most effective medication for you.

## Side Effects

A person on seizure medication can experience side effects. Side effects tend to be more common when a drug has just been started, when the dosage has been increased, or when more than one drug has been prescribed.

Side effects can include drowsiness, loss of coordination, headache, decreased appetite, weight gain or loss, double or blurred vision, dizziness, tremor, and even impaired attention or memory.

Long-term use of seizure medication can also result in bone loss that increases the risk of bone fractures.



Sometimes side effects are cosmetic and involve overgrowth of the gums, hair loss, or excessive hair growth. If a skin rash appears, you may be allergic to the medication.

Side effects, including cosmetic side effects that concern you, should be discussed with your doctor. The doctor may be able to prescribe a different drug depending on the type of seizure you are experiencing.

## Seizure Medication Tips

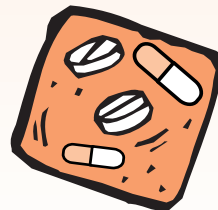
**1** Always take seizure medication as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus, a continuous seizure state that can be life threatening. Reducing the prescribed dosage of seizure medication can also result in problems. Any changes in taking seizure medication should be discussed with your doctor.

**2** Discuss the use of any vitamins or other medications with your doctor or pharmacist. Decongestants, acetylsalicylic acid (ASA) products such as Aspirin, herbal medications, diet pills, and birth control pills can all interact with seizure medication. Even some therapeutic drugs such as antidepressants and antibiotics could interact with your seizure medication.

**3** Don't change from a brand name drug to a generic drug without first consulting your doctor. The use of different fillers, dyes, etc., can result in differences in processing by the body.

**4** A watch with a timer and a weekly pillbox are helpful in reminding you to take seizure medication at the right time.

**5** Remember to refill your prescription ahead of time to assure that you don't run out.



## Seizure Medications

**Some of the well-known seizure medications, listed by generic and (well-known brand name), used traditionally in the treatment of epilepsy include:**

- carbamazepine (Tegretol)
- clobazam (Frisium)
- clonazepam (Rivotril)
- diazepam (Valium)
- ethosuximide (Zarontin)
- phenobarbital
- phenytoin (Dilantin)
- primidone (Mysoline)
- valproic acid (Depakene)

**Some of the seizure medications that have come into use since 1990 include:**

- lacosamide (Vimpat)
- gabapentin (Neurontin)
- lamotrigine (Lamictal)
- levetiracetam (Keppra)
- oxcarbazepine (Trileptal)
- tiagabine (Gabitril)
- topiramate (Topamax)
- vigabatrin (Sabril)
- zonisamide (Zonegran)



**Medications used in the treatment of status epilepticus and/or cluster seizures include:**

- ativan (Lorazepam) in a sublingual (under the tongue) preparation
- diazepam (Diasat) as a rectal gel
- diazepam (Valium) in a rectal injectable solution
- midazolam
- phenobarbital
- phenytoin (Dilantin)

## *Surgery*

Sometimes surgery is an option. Usually in cases involving surgery, seizure medication has not been effective and the injured brain tissue causing the seizures can be identified and safely removed.

Surgery may involve the removal of the part of the brain where the seizures begin. Or it may involve a surgical cut to interrupt the nerve pathways in the brain to prevent the seizures from spreading from one side of the brain to the other. For example, in *focal brain resection* surgery, the area or part of the brain where seizures begin is removed. This surgery may be considered for partial seizures.

The removal of part of the temporal lobe is the most successful and the most common type of epilepsy surgery and is referred to as *temporal lobectomy*. This surgery offers the chance of a cure in many patients and a reduction in seizures in others.

In considering surgery, extensive medical testing and evaluation are necessary to determine where the seizures originate and if it is safe to operate on that area of the brain.

## *Vagus Nerve Stimulation*

A surgical therapy called vagus nerve stimulation (VNS) is also being used in some epilepsy cases. A battery-powered device much like a heart pacemaker is implanted under the skin in the chest. A wire runs from the device to the vagus nerve in the neck. The VNS device stimulates the left vagus nerve which then sends an electrical signal to the brain. The signals help to prevent or interrupt the electrical disturbances in the brain that result in seizures. In some people, this procedure reduces seizure frequency, intensity and/or duration.

## *Ketogenic Diet*

A ketogenic diet that is high in fats and low in protein and carbohydrates is sometimes used to treat epilepsy. The diet creates a chemical change in the body called ketosis that results in the body breaking down fats instead of carbohydrates. In some people, this process inhibits seizures.

The ketogenic diet is usually used to treat children but it has been used to treat teenagers. If you are on the diet, you can only eat a limited range of foods which teenagers sometimes find hard to maintain.

***The diet requires medical supervision.*** It has to be followed carefully and can be harmful if it is not medically supervised. Because of the strictness of the diet, people on it generally need to take nutritional supplements. Use of these supplements has to be monitored by the doctor.

### Complementary Therapies

Stress is a known seizure trigger. Some people find that using a relaxation technique such as yoga or massage therapy helps in seizure control. Others have found that tools such as mental imagery or aromatherapy are helpful. Some find art, music, or pet therapy beneficial. These methods do not replace the treatment prescribed by your

doctor but are sometimes used by people to complement medical treatment. If you do decide to try a complementary therapy, make sure that you discuss it with your doctor first. If you want more information on complementary therapies, contact your local epilepsy association.

# *Can I Do Anything to Help Control My Seizures?*

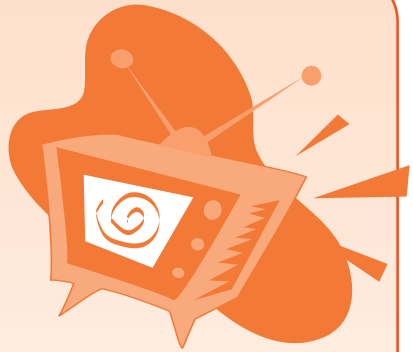
Sometimes people with epilepsy recognize that specific events or circumstances affect seizures. Recognizing your seizure triggers can help you to reduce or avoid seizures. Remembering to take your seizure medication, getting enough sleep, managing stress levels, and eating regularly and nutritiously, are all helpful in seizure control.

## Common Seizure Triggers

- Forgetting to take prescribed seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Menstruation/hormonal changes
- Illness or fever
- Low seizure medication levels
- Medications other than prescribed seizure medications
- Flickering lights of computers, television, videos, etc.
- Excessive alcohol consumption and subsequent withdrawal
- Street drugs (e.g. cocaine, amphetamines, ecstasy, LSD, withdrawal from marijuana)

## Photosensitive Epilepsy

In one type of epilepsy known as **photosensitive epilepsy**, lights flickering at a certain speed and brightness (e.g. from televisions, computer screens, strobe lights, video games, movies) can trigger a seizure. Sometimes natural light patterns such as sunlight reflecting off of water can trigger seizures. Seizures are most often tonic clonic. Treatment includes avoiding the stimulation or, if the epilepsy is severe, medication may be prescribed. Photosensitive epilepsy is often outgrown in adulthood (late 20s or early 30s).



# W *What About My Life?*

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## *Will Having Epilepsy Affect My Schoolwork?*

Talking to your teachers about epilepsy is important. Let them know the type of seizures you experience, how your condition and/or seizure medication might affect your schoolwork, and what the proper procedure is should you have a seizure in school. Your school should also have a medical record on file with information regarding your doctors, medications, allergies, other medical conditions, and a description of your seizures and instructions on what to do if you have a seizure.

People with epilepsy have the same range of intelligence as other people, but students with epilepsy do have a slightly higher rate of difficulty in school and learning problems than those without the condition.

This could be influenced by many factors including:

- the side effects of seizure medicine (e.g. some seizure medications interfere with concentration and memory).
- the student's anxiety (e.g. the anxiety over having a seizure could affect initiative and independence in the classroom).
- teachers' attitudes (e.g. teachers may misunderstand the condition and incorrectly view a student with epilepsy as having less potential than another student).
- an underlying neurological cause of the epilepsy.
- the seizures themselves (e.g. absence seizures could result in an interruption in learning, or memory could be affected following a complex partial or tonic clonic seizure).

If you have concerns over any of these school-related issues, you and your family should discuss these with your teachers, school administrators, and doctor. If people understand some of the challenges you are facing, they will be better able to support and assist you in meeting those challenges. If you would like your peers and teachers to

better understand epilepsy, most epilepsy associations offer in-services to schools in order to educate others.

**Driving is not allowed until you have been seizure free for at least 6 to 12 months and you are under a doctor's care. A shorter period may be considered upon a favorable neurologist's recommendation.**

### *Can I Drive?*

If your seizures are not controlled, there are restrictions to driving. Each province and territory has its own regulations. Driving is not allowed until you have been seizure free for at least 6 to 12 months and you are under a doctor's care. A

shorter period may be considered upon a favorable neurologist's recommendation. If your seizures return, contact your doctor.

*For detailed information on driving standards in each province or territory contact the appropriate provincial or territorial regulatory agency.*

*There are also standards that apply specifically to epilepsy surgery, nocturnal epilepsy, withdrawal from or changes in medication as advised by a physician, and auras, etc.*



Drivers are generally required by law to report any health problems such as epilepsy that would interfere with driving to the appropriate provincial or territorial regulatory agency.



## *What About Working?*

Having epilepsy does not mean that you can't get a job, continue in a job, or be excellent at what you choose to do.

### Making Choices

Before applying for a job, consider how a job will fit into your schedule. Sometimes jobs available to teenagers involve working late hours and that could mean that you won't get enough sleep. A job can also add stress to an already demanding school schedule. A lack of sleep and too much stress are both recognized seizure triggers, so consider your job options carefully.

When considering long-term career options, research your choices. Although your options are many, there may be restrictions in certain careers (e.g. bus drivers, pilots) for safety reasons.

### Discrimination

People are becoming more knowledgeable about epilepsy but workers with epilepsy sometimes still face discrimination and/or an under-utilization of skills in the workplace. An employer may be biased because of a lack of knowledge about the condition or may have concerns over safety, reliability, or liability, yet studies involving people with epilepsy in the workplace do not support those concerns.

Physical disabilities are protected grounds under human rights legislation. The Canadian Human Rights Act does not allow discrimination by an employer due to a disability such as epilepsy. Each province and territory has legislation intended to protect the rights outlined in the Canadian human rights laws.

If you have experienced discrimination in the workplace because of your epilepsy, you can file a complaint with the Human Rights Commission in the appropriate province or territory.

Under Canadian human rights law, however, it is not considered discriminatory on the part of an employer if an act taken by an employer is considered to be reasonable and justifiable under the circumstances. For example, employers are not expected to hire or continue to employ a person whose disability notably increases the probability of health or safety hazards to himself or herself, other employees, and/or the public. For instance, people who have seizures may not be suited to safely working on heights or driving a truck. It is the responsibility of the employer to demonstrate that the person's disability would threaten his or her safety or the safety of others.

### **Duty To Accommodate**

Accommodation is the process through which a worksite is modified to remove barriers for an individual with a disability. Under the Canadian Human Rights Act and under some provincial codes, it is the duty of employers to make reasonable efforts to accommodate individuals with epilepsy in the workplace unless such accommodation would cause undue hardship. Accommodation can be as simple as moving furniture in an office or allowing you to trade work with another employee.

### **Applying For A Job**

In some provinces, legislation restricts pre-employment inquiries. How or when or whether you tell an employer that you have epilepsy is your decision. In most provinces, employers are not allowed in job applications or in interviews to ask about an applicant's physical condition.



When applying for a job, find out about the legislation from the Human Rights Commission in your province or territory. If disclosure is a personal decision in your area, then consider the advantages and disadvantages of disclosing your condition.

For example, being open about your epilepsy in a job interview might focus too much on your condition but it will also have the advantage of giving you peace of mind.

Telling an employer that you have epilepsy after you have started working gives you the opportunity to prove yourself first but the employer may feel that you haven't been honest. If you want to find out more about the advantages and disadvantages of disclosure regarding employment, contact your local epilepsy association.

**If  
disclosure is a  
personal decision in  
your area, then consider  
the advantages and  
disadvantages of  
disclosing your  
condition.**

## *Can I Participate in Sports?*

Most sports and recreational activities are safe for people with epilepsy. Some activities do, however, require extra caution. For example, swimming with a companion, preferably an experienced swimmer, is recommended for anyone who has seizures. If you have uncontrolled seizures, swimming is not advisable without constant supervision. Swimming in a pool is safer than swimming in open water.



Talk to your doctor about the activities you are considering.



Remember to inform coaches, counsellors, lifeguards, etc. about your condition and your current seizure medications. You should also explain to them how to respond should you have a seizure.

It is important to remember to use appropriate safety gear (e.g. helmets, flotation devices, etc.) and to avoid related problems such as low blood sugar, dehydration, or overexertion which could increase the risk of seizures.



## Activities

*Activities to enjoy include:*

- tennis
- volleyball
- track and field
- jogging
- cross-country skiing
- basketball
- hiking
- baseball
- golfing

*Sports that pose some risk:*

- hockey
- soccer
- karate
- football
- boxing

\* Possibility of head injury exists with these sports.

*Activities that are considered dangerous:*

- scuba diving
- rock climbing
- parachuting

## Safety Tips

There is an increased risk of injury in people with epilepsy. If you experience sudden and frequent seizures that affect awareness, you are the most likely to be at risk. For detailed lists outlining safety tips, contact your local epilepsy association. To improve safety:

- Take showers rather than baths. Showers are safer than baths for those with epilepsy, but injuries can still occur. If you experience falls during a seizure, a shower seat with a safety strap should be considered.
- Leave bathroom doors unlocked.
- Use a microwave oven rather than a stove.
- Serve hot liquids or food onto plates at the stove rather than carrying them to the table.
- Put padding on sharp edges of furniture.
- Stand back from roadways and edges of platforms while traveling by bus or subway.



## *Who should I Tell?*

Consider carefully with whom you want to discuss your epilepsy. The decision may depend partly on the type and frequency of your seizures.

Sometimes the decision may be based on how close you feel to the person. Do you spend a lot of time with this person? Are you likely to have seizures while you are with the person? Whether or not people would know how to help should you have a seizure while you are with them may be a deciding factor. Although it might not be necessary to discuss your condition with everyone, it is important that those you are with often know how to help if you have a seizure.

## *What Will Other People Think?*

People sometimes fear what they don't understand. Epilepsy is still misunderstood by many people. Some people think that a seizure always involves body jerking and unconsciousness. They may not be aware that seizures can involve behavior such as blank staring or uncontrolled movements such as chewing or pulling at clothing.

People sometimes think that a person having a seizure is behaving a certain way deliberately or just wants attention. They may treat those with epilepsy with unkindness or avoidance out of a lack of knowledge about the condition.

Misconceptions about epilepsy are often based on inaccurate television and movie portrayals, or outdated views on the condition.

Through public awareness and education, attitudes towards the condition are slowly changing. It has become accepted knowledge that many brilliant historical figures including Joan of Arc, Vincent Van Gogh, and Isaac Newton had epilepsy.

By sharing information on epilepsy with others, you will help people to better understand the condition and increase awareness of how to help if they are with someone who has a seizure.

## *How About Dating?*

Again, only you can decide how, when, and if, it is right to talk to a girlfriend or boyfriend about epilepsy. Again, this may depend on how close you feel to the person or on the type and frequency of your seizures. If you have frequent uncontrolled seizures, you may want to share information early in the relationship. If a person understands what epilepsy is, then he or she may react much more positively than you imagine.

## *What About Sexual Activity and Pregnancy?*

Only in rare cases, does sexual activity trigger seizures. In some cases, seizure medicine may lessen a person's interest in sexual activity or affect sexual function. If seizures are uncontrolled, this could also affect sexual function. If you are sexually active, discuss any concerns with your doctor as a change in medication or other treatments may help.

Some types of seizure medicine could also interfere with the effectiveness of birth control pills and/or could involve the risk of causing harm to a fetus. Most women with epilepsy have healthy babies but there is a slightly higher risk that having epilepsy or taking seizure medication will affect the fetus.

***If you are planning to use or are taking birth control pills, are planning to become pregnant, or are pregnant, it is essential that you talk with your doctor. Changes in medication levels or prescribed drugs may be required.*** Your doctor may recommend taking folic acid as it is thought to prevent birth defects and is recommended for all women of childbearing age.

There is only a slightly higher risk of a child developing epilepsy if a parent has epilepsy. The overall risk of a child having unprovoked seizures is one to two percent in the general population and approximately six percent if a parent has epilepsy.



## Menstruation

Some women find that their seizures increase at the time of their monthly menstruation period. When seizures are more frequent around the time of menstruation, this is referred to as **catamenial epilepsy**.

Noting the dates of your periods on a seizure record chart will help you to determine whether menstruation is a seizure trigger for you.

### *How About Smoking, Alcohol, and Drugs?*

**Smoking** can be hazardous. If you have a seizure while smoking, burns or a fire could result.

**Drinking** excessive amounts of alcohol and the subsequent withdrawal from alcohol can trigger seizures. Although modest occasional drinking of alcohol doesn't seem to increase seizure activity in people who aren't alcoholics or who aren't sensitive to alcohol, drinking alcohol can lower the metabolism. This can result in lower blood levels of the seizure medication that is also metabolized by the liver. Drinking alcohol can also lower your seizure threshold. A seizure threshold is the level at which your brain will have a seizure.

Some doctors recommend that if seizures are not fully controlled, you should not drink alcohol. If you choose to drink alcohol, it is necessary that you continue to take your seizure medication as prescribed.

**Drugs** can also provoke seizures. Withdrawal from marijuana can result in an increase in seizure activity. Cocaine can cause seizures and may do brain damage leading to epilepsy. Amphetamines (e.g. speed), ecstasy, and LSD are also street drugs associated with seizures.

## *Why Do I Feel So Depressed?*

There is an increased risk of depression in people with epilepsy. Depression may be a side effect of medication, or it may occur just before, just after, or between seizures. Depression could also be a reaction to the insensitivity of others or the anxiety caused by not knowing when or if another seizure will occur. If you find that you are not sleeping or eating properly, or are feeling hopeless and have no energy, you should talk about these feelings with people who care about you **AND** with your doctor. They may be able to help.

## *Who Can I Talk To?*

Consider talking to a parent, a teacher, or a family friend. They may offer support and could be able to help you in making decisions. They may also be able to help you find useful information.

## *Where Can I Get Information?*

If you have concerns or questions about epilepsy, contact your local epilepsy association.

Most associations have resources on teens and epilepsy and staff members who can provide you with information.

Epilepsy associations have lots to offer including support programs, educational forums, public awareness, newsletters, resource libraries, referrals, special events, and advocacy.

Associations may be able to put you in touch with epilepsy clinics, support groups, or other teens who are facing similar challenges and they can direct you to valuable resources including websites.



## *How Can I Make A Difference?*

Consider becoming a member of your local epilepsy association. Becoming a member will give you the opportunity to learn more about epilepsy, to volunteer, to network with others in your community, and to share information.

By volunteering with your local epilepsy association, you can make a difference in helping others to better understand epilepsy and in improving the quality of life of those with epilepsy. You may be able to assist with peer support programs, educational activities, and fund raising events.

While your local epilepsy association can be of assistance to you, you can also help change misguided attitudes towards epilepsy and help others living with epilepsy. By getting involved, you can make a difference. Contact your local epilepsy association or call 1-866-EPILEPSY (374-5377) toll-free to connect directly with the association in your area.

**By volunteering with your local epilepsy association, you can make a difference in helping others to better understand epilepsy and in improving the quality of life of those with epilepsy.**

# *T*ypes of Seizures

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There are many types of seizures. The form the seizure takes depends on where in the brain the excessive electrical activity occurs.

If the activity occurs in one part of the brain, it is called a **partial** seizure.

If the electrical activity involves the whole brain, the seizure is called a **generalized** seizure.

Sometimes seizures begin as partial and then spread and become generalized. These are referred to as **partial seizures secondarily generalized**.

Seizures are not painful and are generally not harmful but prolonged or recurrent seizures may cause damage to the brain.

## *Partial Seizures*

Partial seizures take two forms: **simple partial** and **complex partial**. In a simple partial seizure you remain aware of what is going on around you. In a complex partial seizure you are not fully aware.

### **Simple Partial** (formerly called focal)

#### *Person:*

- remains aware
- may experience an unusual sensation, feeling, or movement (called an aura). Auras may involve experiences such as:
  - seeing, hearing, or smelling something that isn't there.
  - sudden jerky movements of an area of the body such as the arm or leg.
  - sudden emotion such as fear, joy, sadness.
  - stomach upset, dizziness, a tingling or burning sensation.

#### *Seizure:*

- begins suddenly
- lasts seconds to minutes
- may progress to a complex partial or generalized seizure.

## **Complex Partial** (formerly called psychomotor or temporal lobe)

### *Person:*

- experiences altered awareness
- may appear dazed or confused
- may experience a dreamlike state
- may experience random movements known as automatisms (such as chewing motions, mumbling, lip smacking, head turning, pulling at clothing).

### *Seizure:*

- may begin with an aura
- lasts between one and two minutes
- often is followed by a period of disorientation and confusion.

## *Generalized Seizures*

A generalized seizure commonly takes one of two forms: **absence** (without convulsions) or **tonic clonic** (with convulsions). **Atonic** and **myoclonic** seizures are two other types of generalized seizures.

## **Absence** (formerly called petit mal)

### *Person:*

- stares blankly usually for less than 10 seconds
- experiences impaired awareness
- may appear to be daydreaming
- may blink rapidly or roll eyes upwards
- sometimes develops tonic clonic seizures.

### *Seizure:*

- can occur many times a day
- often stops occurring in adolescence
- may go unnoticed until a person has a tonic clonic seizure.

## **Tonic Clonic** (formerly called grand mal)

### *Person:*

- often cries or groans as the muscles stiffen and awareness is lost
- falls to the ground
- has a convulsion (jerking, rhythmic movements)
- may lose urinary or bowel control
- may experience shallow breathing, have a bluish or gray skin color, and/or may drool.

### *Seizure:*

- lasts one to three minutes
- is often followed by deep sleep, fatigue, confusion, and/or headache.

## **Atonic**

(sometimes called a “drop attack”)

### *Person:*

- experiences sudden loss of muscle tone
- may fall down, almost fall down, drop objects, or nod head involuntarily.

### *Seizure:*

- lasts for a few seconds.

## Myoclonic

### Person:

- experiences a sudden jerk of part of the body such as the arm or leg
- may fall over.

### Seizure:

- is very brief.

## *Status Epilepticus*

A continuous seizure state, or status epilepticus, is a life-threatening condition. Seizures are prolonged or occur one after another without full recovery between seizures. **Immediate medical care is necessary.** The seizures may be convulsive or non-convulsive.

## *Sudden Unexplained Death in Epilepsy (SUDEP)*

The cause of SUDEP, where death occurs suddenly for no discernible reason, is unknown. This is rare.

## Seizure Record

*Keeping a record of your seizures is very important. A description of the seizures will help your doctor in making a diagnosis as well as in the decision regarding the appropriate treatment.*

*In addition to detailing the characteristics of the seizures, your record will also provide information regarding the frequency and duration of the seizures. It may also help to identify any consistent seizure triggers.*

*Asking those who were with you during the seizure for a description of what happened is useful. Seizure record charts are available from most epilepsy associations or you could use a notebook or create your own chart.*



Certain medical terms are used to refer to the **stages of a seizure**:

- An **aura** results in an unusual sensation, feeling, or movement. An aura is a simple partial seizure that may occur alone or may progress to a complex partial seizure or a generalized seizure. If the aura indicates the onset of a complex partial or generalized seizure, it can sometimes be used as a warning signal to allow you to take the necessary precautions to avoid injury.

- The **ictus** refers to the seizure itself.
- The **postictal** period follows the seizure. You may temporarily experience confusion (postictal confusion), weakness (postictal paralysis), or sleepiness (postictal state).

**In your seizure record**, it is important to record information such as:

- the time the seizure occurred
- the date the seizure occurred
- how long the seizure lasted.



Include any information that describes your behavior before, during, or after the seizure such as:

### **Before the seizure:**

- What were you doing before the seizure?
- Were there any provoking factors (e.g. lack of sleep, exposure to flickering lights from television, strobe lights, etc., recent illness, drug or alcohol abuse, missed medication, missed meals)?
- Did you experience symptoms that preceded the seizure by many hours or days (known as prodrome) such as mood changes, dizziness, anxiety, restlessness?

### **During the seizure:**

- How did the seizure begin?
- Did you experience an aura?
- Was there unusual or involuntary body movement? What part of your body moved first? Next?
- Were you responsive during the seizure?
- Did you experience daydreaming?

- Did you stare blankly?
- Did you experience automatisms (e.g. lip smacking, chewing movements, rapid blinking, head turning, pulling at clothing, random walking)?
- Did your eyelids flutter or your eyes roll?
- Did your body become rigid?
- Did you cry out or yell?
- Was there jerking and if so, did it occur on one side of your body more than on the other?
- Did your skin change color?
- Did your breathing change?
- Did you fall?
- Did you bite your tongue or lip?
- Did you lose bowel or bladder control?

### **After the seizure:**

- Did you experience temporary weakness in any part of the body, fatigue, confusion, and/or headache?
- How long did this period last?
- Was there injury as a result of the seizure?

# First Aid

## What To Tell Others To Do If You Have A Non-Convulsive Seizure (staring blankly, confused, not responding, movements are purposeless)

- 1 Stay with me.** Let the seizure take its course. Speak calmly and explain to others what is happening.
- 2 Move dangerous objects out of the way.**
- 3 DO NOT restrain me.**
- 4 Gently guide me away from danger or block access to hazards.**
- 5 After the seizure, talk reassuringly.** Stay with me until complete awareness returns.

## What To Tell Others To Do If You Have A Convulsive Seizure (characterized by stiffening, falling, jerking)

- 1 Stay calm.** Let the seizure take its course.
- 2 Time the seizure.**
- 3 Protect me from injury.** If necessary, ease me to the floor. Move hard or sharp objects out of the way. Place something soft under my head.
- 4 Loosen anything tight around my neck.** Check for medical identification.
- 5 DO NOT restrain me.**
- 6 DO NOT put anything in my mouth.** I cannot swallow my tongue.
- 7 Gently roll me onto my side as the convulsive seizure subsides** to allow saliva or other fluids to drain away and keep the airway clear.
- 8 After the seizure, talk reassuringly.** Do not leave until I am re-oriented. I may need to rest or sleep.



## Calling An Ambulance

*In assessing the need to call an ambulance, a combination of factors has to be considered. For example, if cyanosis (blue or gray color) or labored breathing accompanies the seizure, then an ambulance may be called earlier. If a person is known to have epilepsy and the seizure pattern is uncomplicated and predictable, then ambulance help may not be necessary.*



### CALL AN AMBULANCE:

- If a convulsive seizure lasts longer than 5 minutes.
- If consciousness or regular breathing does not return after the seizure has ended.
- If seizure repeats without full recovery between seizures.
- If confusion after a seizure persists for more than one hour.
- If a seizure occurs in water and there is any chance that the person has inhaled water. Inhaling water can cause heart or lung damage.
- If it is a first-time seizure, or the person is injured, pregnant, or has diabetes. A person with diabetes may experience a seizure as a result of extremely high or low blood sugar levels.

# Partners in Improving the Quality of Life for Those Who Live With Epilepsy:

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