TEENS AND
Epilepsy

EPILEPSY EDUCATION SERIES

This publication was produced by the

EEA Edmonton Epilepsy Association | The Epilepsy Association of Northern Alberta

Phone: 780-488-9600 Toll Free: 1-866-374-5377 Fax: 780-447-5486
Email: info@edmontonepilepsy.org Website: www.edmontonepilepsy.org

---

This booklet is designed to provide general information about Epilepsy to the public. It does not include specific medical advice. People with epilepsy should not make changes based on this information. Always consult your physician prior to making any changes.

Special thanks to our consulting team, which included epilepsy specialist neurologists & neuroscience nurses, hospital epilepsy clinic staff, educators, individuals with epilepsy, and their family members.

Contents

Why Me?

Have you been diagnosed with epilepsy? Are you wondering how having epilepsy will affect your life? How will your friends react? Will you be able to follow your dreams?

Epilepsy is defined as recurrent, unprovoked seizures. You are not the only one. About 1 in every 100 people have epilepsy.

What is Epilepsy?

It is not uncommon for a person to have a seizure. In fact, approximately 1 in every 10 Canadians will have a seizure in his or her life. But people with epilepsy have more than 1 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?

The brain is made up of approximately 100 billion nerve cells that communicate through electrical and chemical signals. When there is a sudden excessive electrical discharge that disrupts the nerve cells ‘normal activity, a change in the person’s behaviour or function may result. This abnormal electrical activity in the brain is called a seizure.

There are many different types of seizures. For instance, a person having a seizure may 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 many times a day. Seizures can be successfully controlled with anti-seizure medication in at least 65% of the people with epilepsy.

This means that many people with epilepsy are seizure-free for long periods, as long as they take their medication as prescribed.

Do Other Teenagers Have Epilepsy?

Epilepsy is more common than most people realize.

Approximately 1 person in 100 has epilepsy. Epilepsy often begins in childhood.

How Did I Get Epilepsy?

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

- Genetic factors (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 tumour
- Alcohol and drug abuse

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. He or she will ask you about previous illnesses and head injuries, whether there is a history of drug or alcohol use, and if there is any family history of epilepsy.

You will also need to provide a detailed 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 with an accurate diagnosis and treatment.

Keep in mind that not every blackout episode is a seizure. Consider fainting spells, anxiety attacks, diabetes, etc. 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 connected to a recorder are placed on the scalp. Although an abnormal EEG can confirm a diagnosis of epilepsy, a normal EEG does not rule out the presence of epilepsy.

Other diagnostic tests used 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 explanation for the seizures.

Additional tests are sometimes used, especially when 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?

Although drugs do not cure epilepsy, seizures can often be controlled by anti-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?

Medication

Anti-seizure medication is the primary treatment for epilepsy. Drugs don't cure epilepsy, but they may reduce or prevent seizures. The majority of people achieve seizure control with anti-seizure medication.

There are many different types of seizures, and there are many different types of anti-seizure medication. Sometimes a doctor will prescribe one drug. In other cases, more than one drug is needed to control seizures. You may have to try different combinations.

Side Effects

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

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

Side effects that concern you should be discussed with your doctor. The doctor may be able to prescribe a different drug.

Anti-Seizure Medication Tips

1 Always take anti-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 anti-seizure medication can also result in problems. Any medication changes 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 anti-seizure medication. Even some therapeutic drugs such as antidepressants and antibiotics could interact with anti-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 affect how the medication works.

4 A timer and a pill organizer or dosette are helpful in reminding you to take anti-seizure medication at the right time.

5 Remember to refill your prescription ahead of time to ensure that you don’t run out.

Anti-Seizure Medications

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

- carbamazepine (Tegretol)
- clobazam (Frisium)
- clonazepam (Rivotril)
- diazepam (Valium)
- ethosuximide (Zarontin)
- phenytoin (Dilantin)
- valproic acid (Depakene/Epival)

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

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

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

- ativan (Lorazepam) by sublingual absorption or intravenously
- midazolam (by injection, IV, or nasal spray)
- phenobarbital (by injection)
- phenytoin (Dilantin) (by injection)

Surgery

Sometimes surgery is an option. Usually, in cases involving surgery, anti-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 focal seizures.

The removal of part of the temporal lobe is one of the most common types of epilepsy surgery, and is referred to as a **temporal lobectomy.** This surgery offers the chance of a cure in many patients and a reduction in seizures in others. Less invasive selective open surgeries are possible.

Increasingly, laser-guided surgeries (Laser Interstitial Thermal Therapy) are being done for select seizure types. This is preferable to other surgeries, as it is less invasive, requiring minimal time in the hospital.

Ketogenic Diet

A ketogenic diet that is high in fats and low in carbohydrates and controlled proteins, 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 reduces seizures.

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

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. 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. Some people report positive benefits with cannabis. Many of these therapies are controversial, with limited scientific support.

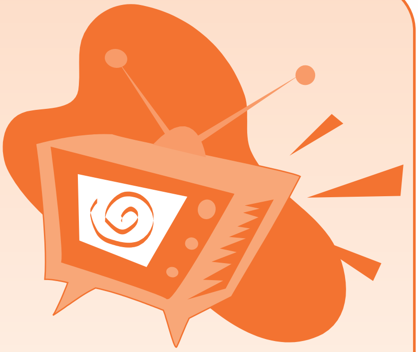
Can I Do Any thing to Help Control My Seizures?

Sometimes, people with epilepsy recognize that specific events or circumstances affect seizures. Identifying your seizure triggers can help you to reduce or avoid seizures. Remembering to take your anti-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 anti-seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Menstrual cycle/hormonal changes
- Illness or fever
- Low anti-seizure medication blood levels
- Medications other than prescribed anti-seizure medications
- Flickering lights or strobing lights
- Excessive alcohol consumption and subsequent withdrawal
- Recreational drugs

Photosensitive Epilepsy



In **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. These seizures are most often generalized. Treatment includes avoiding these triggers. Medication may be prescribed, or you may wish to try special lenses, such as the Z1 Blue Glasses.

What About My Life?

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 anti-seizure medication might affect you, and what the proper procedure is should you have a seizure at school. Your school should also have a medical record on file with information regarding your doctor, medications, allergies, other medical conditions, and a description of your seizures.

In principle, school achievement should not be affected by epilepsy. There are other factors which may play a role, including:

- the side effects of anti-seizure medicine (e.g., some anti-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., seizures may interfere with memory, learning, and attention).

If you have concerns about school-related issues, you and your family should discuss them 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 any challenges. If you would like your peers and teachers to better understand epilepsy, most epilepsy associations offer educational in-service training.

Can I Drive?

If your seizures are not controlled, you may not drive. 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 neurologist's favourable recommendation. If your seizures return, contact your doctor.

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 neurologist's favourable recommendation.

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

Drivers are generally required by law to report any health problems (such as epilepsy) that would interfere with driving.

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 the jobs available to teenagers involve working late hours which means 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 underuse of skills in the workplace. An employer may be biased because of a lack of knowledge about the condition or have concerns over safety, reliability, or liability. 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, 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, when, or if 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.

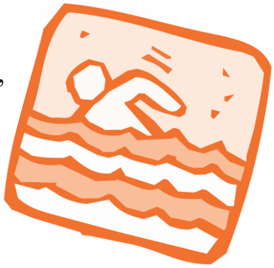
When applying for a job, find out about the legislation from the Human Rights Commission in your province or territory. If disclosure is a personal decision in your area, consider the advantages and disadvantages of disclosing your condition.

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, 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 anti-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 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
- Swimming Alone
- Parachuting
- Rock Climbing

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 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. There are safety taps available.
- 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 travelling by bus or subway.

Who Should I Tell?

Consider carefully with whom you want to discuss your epilepsy and when. 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 behaviour 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 understand the condition better 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, anti-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 anti-seizure medicine could also interfere with the effectiveness of birth control pills and/or involve the risk of harming a fetus. Most women with epilepsy have healthy babies, but there is a slightly higher risk that having epilepsy or taking anti-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 of prescribed drugs may be required. Your doctor may recommend taking folic acid to prevent birth defects.

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 1%-2% in the general population and approximately 6% if a parent has epilepsy.

Menstruation

Some women find that their seizures increase at the time of their monthly menstruation. When seizures are more frequent around this time, it is called **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. The essential hormones involved with the menstrual cycle are progesterone and estrogen. A high level of progesterone is present prior to menstruation and lowers the seizure threshold. The estrogen effect is opposite.

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 occasional, modest 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 increase liver metabolism. This can result in lower blood levels of the anti-seizure medication. Drinking alcohol can also lower your seizure threshold.

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 anti-seizure medication as prescribed.

Drugs can also provoke seizures. Withdrawal from marijuana can result in an increase in seizure activity. Cocaine can cause seizures. Many street drugs are 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 are there to help.

Who Can I Talk To?

Consider talking to a parent, a teacher, or a good 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 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, volunteer, network with others in your community, and 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 fundraising events.

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.

While your local epilepsy association can be of assistance to you, you can also 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.

Types of Seizures

There are many types of seizures. The type of seizure depends on where in the brain the abnormal electrical activity occurs.

If the activity occurs in one part of the brain, it is called a **focal onset** seizure. If the electrical activity involves the whole brain, it is called a **generalized** seizure.

Sometimes seizures begin as focal and then spread throughout the brain. These are referred to as **focal to bilateral tonic-clonic seizures.**

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

Focal Onset Seizures

Focal seizures take two forms: **focal aware** and **focal impaired aware.**

Focal Aware

- You remain aware
- You 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.
- The seizure begins suddenly
- The seizure lasts seconds to minutes
- The seizure may progress to a focal impaired aware seizure or a generalized seizure.

Focal Impaired Aware

- You experience altered awareness
- You may appear dazed or confused
- You may experience a dreamlike state
- You may experience random movements known as automatisms (such as chewing motions, mumbling, lip-smacking, head-turning, pulling at clothing).
- The seizure may begin with an aura
- The seizure lasts between 1 and 2 minutes
- The seizure is often 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

- You abruptly stare blankly, usually for less than 10 seconds
- You experience impaired awareness
- You may appear to be daydreaming
- You may blink rapidly or roll your eyes upwards
- You may outgrow these seizures in your teens
- The seizure stops abruptly
- These seizures can occur many times a day
- These seizures may go unnoticed until a person has a tonic-clonic seizure.

Tonic-Clonic

- You emit a cry or a groan as your muscles stiffen and awareness is lost
- You fall to the ground
- You have a convulsion (jerking, rhythmic movements)
- You may lose urinary or bowel control
- You may bite your tongue
- You may experience shallow breathing, have a bluish or grey skin colour, and may drool.
- The seizure lasts 1-3 minutes
- The seizure is often followed by deep sleep, fatigue, confusion, and/or headache.

Atonic (sometimes called a “drop attack”)

- You experience a sudden loss of muscle control
- You may fall, almost fall, drop objects, or nod your head involuntarily.
- The seizure lasts for a few seconds.

Myoclonic

- You experience a sudden jerk of part of the body, such as the arms or the legs
- You may fall over.
- The seizure is very brief.

Consistency With Your Medication

It is very important that people with seizures do not reduce or stop their anticonvulsant medication without medical advice, because this may cause very sudden uncontrollable seizures.

Seizure Record

Keeping a record of your seizures is important. A description of the seizures will help your doctor in making a diagnosis and starting treatment.

In addition to describing the seizures, your record will also provide information regarding the frequency and duration of the seizures. It may also help to identify any 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 make your own.

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

- An **aura** is an unusual sensation, feeling, or movement. An aura is a focal aware seizure that may occur alone or may progress to a focal impaired aware or generalized tonic-clonic seizure. The aura may 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 behaviour 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 a 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 or both sides of your body more than the other?
- Did your skin change colour?
- 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, or headache?
- How long did this period last?
- Was there injury as a result of the seizure?

First Aid for Seizures

What to Do if Someone has a Nonconvulsive Seizure

(staring blankly, confused, not responding, movements are purposeless)

1. **Stay with the person.** 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 the person.**
4. **Gently guide the person away from danger or block access to hazards.**
5. **After the seizure, talk reassuringly to the person.** Stay with the person until the person wakes up.

What to do if Someone has a Convulsive Seizure

(characterized by stiffening, falling, jerking)

1. **Stay calm.** Let the seizure take its course.
2. **Time the seizure.**
3. **Protect from injury.** If necessary, ease the person to the floor. Move hard or sharp objects out of the way. Place something soft under the head.
4. **Loosen anything tight around the neck.** Check for medical identification.
5. **DO NOT restrain the person.**
6. **DO NOT put anything in the mouth.**
7. **Gently roll the person onto his or her side when the convulsions have stopped, after making sure they are still breathing to allow saliva and other fluids to drain from the airway.**
8. **After the seizure, talk to the person reassuringly.** Do not leave until the person is reoriented. The person may need to rest or sleep.

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 nonconvulsive.

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 grey colour) or laboured 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 1 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 complications.
- 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.

Epilepsy Education Series

A Brief Guide Introducing the new classification of epilepsy

Classification systems used for animals, plants and diseases have led to an improved understanding while allowing more effective communication among caregivers, researchers, patients, and other interested parties.

This also applies to the classification of seizures, epilepsy types, and epilepsy syndromes.

Hippocrates recognized that the cause of seizures was in the brain approximately 400 BCE. He understood that the seizures could result from severe brain trauma, and he observed that one-sided seizures resulted from trauma on the opposite side of the brain. He also reported the connection between seizures, alcohol, and genetic factors. Most seizures were considered to be idiopathic: an interaction between phlegm and black bile. Hippocrates wrote "On The Sacred Disease," but also asked: Why are seizures divine and other diseases not?"

In the middle of the 19th century, the terms 'Grand Mal', and 'Absence' were being used in French hospitals, and the Western world followed.

The most recent classification with which most of us are familiar was drawn up 28 years go by the Commission for Classification and Terminology of the International League Against Epilepsy (ILAE).

Early in 2017, the ILAE published a position paper in which a revised terminology framework was proposed. The epilepsy types recognized include focal, generalized, combined generalized and focal, and unknown. Terms such as 'complex partial seizures' will be simplified to 'focal onset, impaired awareness', 'simple partial seizures' become 'focal onset, aware'.

Robert S. Fisher, MD, PhD, who was the chairman of the Classification Committee, reported the ILAE approval of the new classification during the 70th Annual Meeting of the American Epilepsy Society.

Those interested in reading more about the new classification system may look up "The 2017 ILAE Classification of Seizures - Epilepsy Foundation" on the internet for a clear and concise review. Understandably, it will be a challenge for many to adjust to this new terminology after working with one system for 28 years.

To familiarize the reader with the essential changes in the proposed terminology a partial list of old and new terms is provided.

OLD TERMINOLOGY	NEW TERMINOLOGY
Tonic-Clonic Seizure, “Grand Mal”	Generalized Tonic-Clonic of Unknown Onset
Absence / “Petit Mal”	Generalized Absence (typical, atypical, myoclonic, or with eyelid myoclonia)
Simple Partial Seizure	Focal Aware Seizure
Complex Partial Seizure	Focal Impaired Awareness Seizure
Psychomotor Seizure	Focal Impaired Awareness Seizure
Atonic / “Drop Attack”	Focal or Generalized Atonic
Secondary Generalized Tonic-Clonic	Focal to Bilateral Tonic-Clonic (onset can be aware or impaired aware)
Infantile Spasms	Focal, Generalized, Unknown Onset Epileptic Spasms
Arrest, Freeze, Pause	Behaviour Arrest

Only some of the old terms have been listed. Simple deduction tells us that Limbic Epilepsy, for example, is a Focal Impaired Awareness Seizure, similar to the Gelastic Epilepsy (bouts of unnatural laughter) and Dacrystic Epilesy (excessive tearing).

Epilepsy Associations

If you have concerns, questions, or ideas to share regarding epilepsy, contact your local association. Epilepsy associations can provide you with, or direct you to, up-to-date medical and lifestyle information about epilepsy. New information, research, and medical technology are continually improving the understanding of treatment for epilepsy.

Consider becoming a member of your local epilepsy association. Epilepsy associations have much to offer including support groups, programmes, educational forums, public awareness, newsletters, resource libraries, referrals, special events, and advocacy. 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. Most epilepsy associations require volunteers to assist in areas such as peer-support programmes, educational activities, administrative duties, and fundraising events. Volunteers are also needed to serve on committees and Boards of Directors.

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

Epilepsy Education Series

The Epilepsy Educational Booklet Series Includes:

- Epilepsy: An Overview
- Living with Epilepsy
- Epilepsy: A Guide for Parents
- Let’s Learn About Epilepsy: An Activity Book for Children
- Teens and Epilepsy
- Epilepsy: A Guide for Teachers
- Women and Epilepsy
- Seniors and Epilepsy
- Epilepsy: A Guide for Health Care Providers
- Epilepsy: Seizures and First Aid
- Safety and Epilepsy

For more information, or to order copies of these booklets,
contact your local Epilepsy Association
at 1-866-EPILEPSY (374-5377).

All booklets are available as a free downloadable pdf from
www.edmontonepilepsy.org

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

Canadian
epilepsy
Alliance

Alliance
canadienne de
l'épilepsie

1-866-EPILEPSY

info@canadianepilepsyalliance.org

www.canadianepilepsyalliance.org

Canadian League
Against Epilepsy

CLAE
LCCE

La Ligue
Canadienne
Contre l'Épilepsie

905-415-3917

info@claegroup.org

www.claegroup.org

EEA

This Epilepsy Booklet Series is a project by the
Edmonton Epilepsy Association
www.edmontonepilepsy.org
11215 Groat Road Edmonton, Alberta T5M 3K2
Phone: 780-488-9600
Toll Free: 1-866-374-5377   Fax: 780-447-5486
info@edmontonepilepsy.org

ucb

Inspired by **patients.**
Driven by **science.**

Free Canada-wide distribution of this publication was made possible by a sponsorship from UCB Canada Inc.