

LIVING WITH

# *Epilepsy*



EPILEPSY EDUCATION SERIES

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**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.**

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**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.**

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# *Living With Epilepsy*

If you have epilepsy, you may have questions regarding the condition and how it may affect your life. How is epilepsy diagnosed? What are some of the available treatments? Will having epilepsy affect your job or driving? Will having epilepsy affect your relationships? What are some of the attitudes you will encounter in public?

For some individuals, having epilepsy will require few changes in lifestyle. For those with uncontrolled seizures, their lives may change significantly.

Local epilepsy associations have helpful resource materials as well as a staff committed to answering questions and providing information.

Associations may offer in-services to worksites and schools in order to educate others about the condition. Associations may also be able to link you with self-help and support groups, and with trained professionals.

Living with epilepsy can result in personal challenges, but it does not have to result in an inability to have a full and rewarding life.

To achieve a fulfilling quality of life, educate yourself and others about your condition, find the appropriate treatment, develop a support network, and pursue that which brings joy into your life.



# W *What is Epilepsy?*

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**Epilepsy is a condition of the brain that is characterized by recurrent, unprovoked seizures.** Approximately 1 in 10 Canadians will experience at least one seizure during a lifetime. A single seizure, however, is not epilepsy. Epilepsy is a condition that is defined by multiple, unprovoked seizures.

**Epilepsy is a seizure disorder.** It is **not** a psychological disorder **nor** a disease, and it is **not** contagious. 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 seizure may result.

**Seizures cause a change in function or behaviour.** A seizure may consist of a blank stare, muscle spasms, uncontrolled movements, altered awareness, odd sensations, or a convulsion. The location in the brain of the abnormally discharging nerve cells determines the type of seizure. Seizures may occur rarely or frequently. In 65% of people with epilepsy, seizures are completely controlled with medication.

**Epilepsy is one of the most common chronic neurological disorders.** An estimated one percent of the general population has epilepsy. Based on that estimate, 330,000 people in Canada have epilepsy. In North America, almost 4 million people have epilepsy.

**Epilepsy occurs in all age groups,** although its onset is most often in childhood or the later years of life. Sometimes those who develop seizures during childhood outgrow their seizures. In the elderly, there is an increased incidence due to strokes and age of the brain.

# What Causes Epilepsy & Seizures?

Epilepsy is caused by a number of factors that affect the brain. The cause of epilepsy is sometimes genetic and sometimes acquired.

The causes vary according to the age of onset.

Seizures are classified as **symptomatic** when the cause is known and **idiopathic** when the cause is unknown. In approximately 60% - 75% of epilepsy cases, no specific cause of the seizures can be identified. In the remaining 25% - 40%, causes include:

- Genetic factors
- Birth injury (e.g., lack of oxygen at birth or trauma)
- Developmental disorder (e.g., brain damage to the fetus during pregnancy caused by malnutrition, alcohol, medications, maternal infection)
- Brain trauma (e.g., car accidents, sports injuries)
- Infection (e.g., meningitis, encephalitis, AIDS)
- Brain tumour
- Stroke
- Cerebral degenerative disorder (e.g., those associated with Alzheimer's Disease)
- Alcohol and drug abuse

## **Q** Is epilepsy hereditary?

**A** In certain epilepsies, one or more inherited genes may be involved.

Sometimes, an inherited neurologic disorder that involves structural or chemical abnormalities in the brain can be the cause of seizures.

Susceptibility to seizures may be inherited. Each individual has a seizure threshold.

The overall risk of a child having unprovoked seizures is 1-2% in the general population and approximately 6% if a parent has epilepsy.

## **Q** Can alcohol and drug abuse lead to epilepsy?

**A** Alcohol consumption and withdrawal from excessive alcohol use can provoke seizures. Repeated uncontrolled seizures may result in a change in the activity of the networking nerve cells, which could result in a diagnosis of epilepsy.

The use of certain drugs can provoke seizures or reduce the seizure threshold. For example, cocaine often results in seizures and its use may cause brain damage leading to epilepsy. Other drugs are also associated with provoking seizures including, street drugs and withdrawal from marijuana.

## Q How does having repeated seizures result in a worsening of epilepsy?

**A** Consider the brain as a large network of nerve cells that continually creates balanced electrical activity.

In tests done on laboratory animals, researchers repeatedly stimulate the brain's temporal lobe with electricity over many days. The initial stimulation is done with very low voltages, not causing any clinical seizures. Several days or weeks later, spontaneous epilepsy-related seizures occur.

The process that takes place after the stimulation until the first seizure occurs is called “**kindling**.”

Somehow the nerve cell network has changed and has created a seizure focus.

Eventually, the electrical activity may spread from the focus throughout the brain resulting in focal to bilateral tonic-clonic seizures.

**In tests done on laboratory animals, the process that takes place after the stimulation until the first seizure occurs is called “**kindling**.” Somehow the nerve cell network has changed and has created a seizure focus.**

Evidence is accumulating that a similar process takes place in the human brain.



# H How is Epilepsy Diagnosed?

Before diagnosing epilepsy, a doctor will consider other causes.

A high fever or metabolic disturbance could cause seizures. For example, an electrolyte disturbance (resulting from severe diarrhea, vomiting) or a glucose imbalance (caused by low blood sugar) may result in seizures.

In addition to a thorough physical examination, the procedures used to establish a diagnosis of epilepsy usually include a **medical history** and **diagnostic tests** (blood work and imaging studies).

## *Medical History*

Typically the doctor will ask about your family health history and obtain a detailed description of the characteristics, onset, and frequency of the seizures. Determining the type of seizure an individual is experiencing is valuable for diagnosis and treatment.



## Seizure Record

*Keeping a record of your seizures is useful. A description of the seizures will help the doctor make a diagnosis and decide on the best treatment.*

*A record will provide information regarding the frequency and duration of the seizures, and may help identify seizure triggers.*

*Asking those who were present during the seizure for a description is helpful. Seizure record charts are available from most epilepsy associations, or you could create 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 awareness seizure or generalized seizure. An aura may be used as an important warning sign allowing time to take precautions to avoid injury.
- The **ictus** (Latin for 'stroke' or 'attack') refers to the seizure itself.

- The **postictal** period follows the seizure. An individual may temporarily experience confusion, weakness, or sleepiness.

**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, strobing lights, etc., recent illness, drug or alcohol abuse, missed medication, missed meals)?
- Did you experience symptoms that preceded the seizure by 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, if so, did it occur on one side or both sides of your body?
- 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?
- Did you experience fatigue, confusion, and/or headache?
- How long did the recovery (after the seizure) last?
- Was there injury as a result of the seizure?

## *Diagnostic Tests*

Diagnostic tests usually include an electroencephalogram (EEG). An EEG is used to record the brain's electrical activity, which is an important tool in the diagnosis of epilepsy.

Neuroimaging tests are often used to provide pictures of the brain. Computed tomography (CT) and magnetic resonance imaging (MRI) scans provide pictures of the brain structures.

Other neuroimaging tests such as magnetic resonance spectroscopy (MRS) and positron emission tomography (PET) show how the brain functions and are used to evaluate epilepsy surgery possibilities.

It is important to note that sometimes a diagnostic test does not detect abnormalities. For example, a person with epilepsy may have a normal EEG because abnormal activity is not present during the recording or the activity is located too deeply in the brain to be recorded.



## *Tests used in the diagnosis of epilepsy may include:*

### EEG (Electroencephalogram)

An EEG is a painless, non-invasive test used to measure electrical activity in the brain. This is recorded by small metal discs placed on the scalp which are connected to the EEG machine. The EEG can show abnormalities in the brain's electrical activity.

Although an abnormal EEG can confirm a diagnosis of epilepsy, a normal EEG does not rule out the presence of epilepsy. The EEG records the activity in the brain at the time of the recording. Usually the recording session lasts for less than an hour.

Hyperventilation and photic stimulation (flashing lights) are routinely used to reveal abnormalities in brain activity. Sleep deprivation may also be used.

**Ambulatory EEG** units are sometimes used to monitor a person for longer periods of time. The individual wears a portable EEG unit that records brain activity during normal activities at home, at work, and during sleep.

EEG video **telemetry**, a technique that combines EEG recording with videotaping, may also be extended to record a clinical seizure on tape. Behaviour during a seizure can then be studied in combination with the EEG recordings.

### **CT SCAN (Computed Tomography)**

A CT scan is used to detect abnormalities which may be causing the seizures, such as tumours or scar tissue. The CT machine takes a series of x-rays to show the brain's structures.

Typically, the person lies on a CT scan table while the surrounding scanner takes the x-rays. An intravenous injection with a contrast medium can be used to make abnormalities more visible.

### **MRI (Magnetic Resonance Imaging)**

An MRI is used to provide structural information such as the presence of tumours, scar tissue, or abnormal blood vessels. Magnetic fields are used to produce precise two- or three-dimensional images of the brain. The MRI shows a more detailed picture of the brain than the CT scan. Sometimes both studies are needed. During the procedure, the individual usually lies on a scanning table in a tunnel-like magnetic chamber.

## **MRS (Magnetic Resonance Spectroscopy)**

Essentially, an MRI with a different computer programme, the MRS provides information about chemical activity in the brain. This information is used to detect metabolic abnormalities in the brain during, after, and between seizures.

## **PET (Positron Emission Tomography)**

PET scanning produces three-dimensional computer images of the brain processes at work. An intravenous injection with a very low dose of a radioactive glucose substance is administered. The images show how much glucose is being used by different parts of the brain. These images provide information on the chemistry, blood flow, and glucose consumption of the brain that is useful in locating the origin of the seizures. Usually, the individual lies on an examination table and is slowly moved into the machine until the head is inside the scanner.

## **SPECT (Single Photon Emission Computed Tomography)**

This test helps to locate the site where the seizure begins. A compound with a small amount of radioactive substance is injected into a vein, then three-dimensional images are taken to view blood flow or metabolism. There are two separate injections. One is given during a seizure, the other is given between seizures.

The SPECT scans are taken 1-2 hours after the injections. The scans are then compared to identify the changes in blood flow. The individual lies very still on a bed while a large camera takes pictures.

## **MSI or MEG (Magnetic Source Imaging or Magnetoencephalography)**

“MEG provides a noninvasive tool to study epilepsy and brain function. When it is combined with structural imaging, it is known as magnetic source imaging (MSI). MEG measures small electrical currents arising inside the neurons of the brain.”

Source: [epilepsy.com](http://epilepsy.com)

# W What are the Different Types of Seizures?

Seizures are grouped into two categories: **focal** and **generalized**.

## *Focal Seizures*

A focal seizure occurs when an abnormal electrical discharge is limited to one part of the brain. Focal seizures are the most common type of seizure in adults. Sometimes seizures begin as focal and then become generalized. These are referred to as **bilateral tonic-clonic generalized seizures**.

The two most common types of focal seizures are **focal aware** and **impaired awareness** seizures.

### Focal Aware Seizures

A focal aware seizure may involve sensory, motor, psychological, or autonomic symptoms. These symptoms may result in an unusual sensation, feeling, movement, thought, or a change in perception called an **aura**. Any warning experienced by the person prior to a seizure is called an aura. This may include, for example, a hallucination with respect to vision, smell, or sound. A person may experience a sudden overwhelming emotion such as joy, sadness, fear, or anger. Others may experience stomach upset, dizziness, a shiver, a tingling or burning sensation, pallor, or flushing. Occasionally, there will be the experience of *déjà vu* or *déjà vécu* during which the person has the sensation of having experienced something before.

Focal aware seizures usually begin suddenly and can last from seconds to minutes.

An aura is a focal aware seizure that may occur alone, progress to a focal impaired awareness seizure or a generalized seizure. An aura may be used as a warning, allowing the person to take the necessary precautions to avoid injury.

### Focal Impaired Awareness Seizures

The person may appear dazed and confused, experiencing a dreamlike state.

In some cases, the individual will be unable to respond or will do so partially or inappropriately.

This type of seizure also often begins with an aura, as described earlier.

Random, purposeless movements over which the individual has no control, called automatisms, often characterize the seizure. These may include chewing motions, mumbling, lip-smacking, head-turning, pulling at clothing, picking motions in the air, or wandering. Occasionally, there are more dramatic behavioural changes such as screaming, undressing, or laughing.

Once the pattern has been established, the same set of actions often occurs with each seizure, and become typical. The seizure usually lasts from 1-2 minutes and is often followed by a **postictal period** of disorientation and confusion.



## Generalized Seizures

Generalized seizures occur when an abnormal electrical discharge is widespread and involves both sides of the brain. The seizure may or may not be convulsive. A generalized seizure commonly takes one of two forms: **absence** (without convulsions) or **tonic-clonic** (with convulsions).

### Absence Seizures

These seizures most often begin in childhood, and about 2 out of 3 of children outgrow them in adolescence.

This type of seizure results in a blank stare and usually lasts less than 10 seconds. The seizure starts and ends abruptly, and awareness is impaired during the seizure. A person may suddenly stop talking, stare blankly for a few seconds, then continue talking without realizing that anything has occurred. Following the seizure, alertness is regained quickly.

**A generalized seizure is characterized by the involvement of the whole brain. Excessive electrical discharge is widespread and involves both sides of the brain. The seizure may or may not be convulsive.**

These seizures can be misinterpreted as daydreaming or inattentiveness. Rapid blinking may accompany the seizure and the eyes may roll upward. This type of seizure does not usually result in a fall.

An individual may experience as many as several hundred absence seizures in a day. Although absence seizures are often outgrown, some people with absence seizures develop tonic-clonic seizures. Absence seizures tend to be hereditary.

## Tonic-Clonic Seizures

The **tonic phase** of this generalized seizure type typically involves a loss of awareness and a fall as consciousness is lost and muscles stiffen. A guttural noise or groan may precede the seizure. The second phase, or the **clonic phase** of the seizure typically involves a series of convulsions with jerking and twitching of the muscles in all four limbs. Usually, the movements involve the whole body.

A loss of bladder or bowel control may occur and there may be shallow breathing, a bluish or grey skin colour, and drooling.

The seizure usually lasts from 1-3 minutes. Awareness is regained slowly and may take up to an hour.

The postictal state may include fatigue, nausea and confusion, and the person may experience a severe headache. Often the person will want to sleep.

These seizures may be primary generalized (meaning that the seizure begins on both sides of the brain simultaneously) or, they may follow a brief focal seizure (bilateral tonic-clonic generalized).

Although the tonic-clonic seizure is the one most often associated with epilepsy, it is not the most common type of seizure. In adults, focal seizures are the most common type of seizure experienced.

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Other types of generalized seizures include **atonic** and **myoclonic** seizures.

An **atonic** seizure is sometimes called a “drop attack.” The seizure involves a sudden loss of muscle control. This can result in the person falling or almost falling down, dropping objects, or nodding the head involuntarily. Typically, these seizures last for a few seconds. There tends to be no warning so the seizures can cause injury.

A **myoclonic** seizure results in a sudden jerk of a part of the body such as the arm or leg. The individual may fall and the seizure is very brief.

Myoclonic seizures are sometimes confused with **benign nocturnal myoclonus**: the sudden jerk of the body when a person is falling asleep. This is not epilepsy.

## ***SUDEP***

The cause of **Sudden Unexplained Death in Epilepsy (SUDEP)**, where death occurs suddenly for no discernible reason, is unknown. This is rare. Ontario Epilepsy states that 1 in a 1000 with controlled epilepsy die per year. 1 in a 100 people with uncontrolled epilepsy die per year.

# W What is the Treatment for Epilepsy?

In well over 50% of those with epilepsy, seizures are controlled with **monotherapy** (one medication). In others, **polytherapy** (more than one medication) is effective in controlling seizures. Approximately 65% of people with epilepsy achieve complete seizure control with medication.

Surgery may be considered in up to 15% of individuals with intractable seizures.

Depending on the type of epilepsy, some patients will outgrow it allowing them to discontinue their medication. **DISCONTINUATION OF MEDICATION SHOULD ONLY BE DONE WITH A DOCTOR'S GUIDANCE.** For others, excellent control of seizures will continue for years with regular use of anti-seizure medication. Other individuals will benefit from surgery or from a specialized approach combining medication with surgery to obtain optimal seizure control.

In some cases, seizures remain uncontrolled despite treatment.

## *Anti-seizure Medication*

Anti-seizure medication is the primary treatment for epilepsy. Drugs do not 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 anti-seizure medication. In recent years there have been significant improvements in anti-seizure medications, especially with respect to the adverse effects.



## Anti-seizure Medications

**Some of the well-known anti-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)
- 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 (sudden occurrence of multiple seizures in a short time period) include:**

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

Occasionally it may be necessary for individuals on anti-seizure medication to have blood tests. If seizures are not controlled, blood levels of the medication may have to be monitored.

## **Side Effects**

Anti-seizure medications may produce mild or severe side effects. They are more common when a drug has just been started, when the dosage has been increased, or more than one drug has been prescribed.

Side effects are sometimes related to the blood level of the drug. **Dose-related** effects can include: drowsiness, loss of coordination, fatigue, headache, decreased appetite, nausea, drooling, tremor, weight gain or loss, double or blurred vision, dizziness, and impaired attention and memory. Others are cosmetic and include overgrowth of the gums, hair loss, or excessive hair growth.

**Allergy-related** side effects are less common and may include skin rash or reactions that affect the liver, blood cells, or bone marrow. Skin rash is often the first sign of an allergic reaction to a medication and should be taken seriously.

**Chronic** side effects are those developed after using medication for long periods. These may include loss of bone density (osteoporosis), weight gain, hair loss, loss of balance, and cognitive impairment.

**Physicians should be consulted regarding side effects.**

**For more information on the possible side effects of each drug, consult your doctor, pharmacist, or contact your local epilepsy association.**

## Discontinuing Medication

**Discontinuing or reducing anti-seizure medication can cause serious complications and should only be done with a doctor's advice and supervision.**

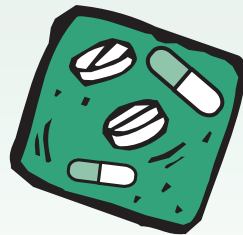
Sudden discontinuation of medication may result in withdrawal seizures or status epilepticus (a continuous seizure state that is a life threatening condition. Seizures are prolonged or occur one after another without full recovery between seizures).

Some doctors will advise people with epilepsy to discontinue medication after two years without a seizure. Other doctors do so after four or five years of medication without a seizure.

Safe reduction of anti-seizure medication can only be done if a number of factors have been carefully considered. **CONSULT AN EPILEPTOLOGIST**

## Anti-Seizure Medication Tips

- 1** Always take your anti-seizure medication as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus. Any changes in your medication should be made with your doctor.
- 2** Discuss the use of any other medications or vitamins with your doctor or pharmacist. Decongestants, acetylsalicylic acid products (ASA) such as Aspirin, herbal medications, diet pills, and birth control pills can all interact with anti-seizure medication. Some drugs, such as antidepressants and antibiotics may cause interactions. To learn more about possible interactions and/or side effects, ask your doctor, pharmacist, or local epilepsy association for detailed information on each 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 result in differences in processing by the body.
- 4** A timer and a dosette or pill organizer will help remind you to take anti-seizure medicine at the right times.
- 5** Keep a 1-2 week supply of your anti-seizure medication on hand to ensure that you don't run out.





## *Surgery*

Typically, patients considered for surgery have seizures that are **medically refractory** or **intractable**, meaning that medical treatment does not fully control the seizures. In some cases, the person's quality of life while on medication is poor and surgery may be an option.

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.

Surgery is irreversible and changes in personality or cognitive abilities, disturbances in sensation, vision, or speech could result. Although the risk of severe neurologic complication is low, as with any surgery, there is always the possibility of serious complications.

When successful, surgery can be very effective in improving seizure control. With recent technological advances, surgery has become safer and more widely used.

### Types of Surgery

Surgery may involve the removal of the part of the brain where the seizures originate or it may involve a surgical cut to prevent seizures from spreading from one side of the brain to the other by interrupting nerve pathways.

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 the most successful and the most common type of epilepsy surgery. It is referred to as **temporal lobectomy**. A temporal lobectomy offers the chance of a cure or a reduction in seizure frequency.

**Corpus callosotomy**, a surgical technique that involves cutting the corpus callosum to disconnect the two hemispheres in the brain, is sometimes performed to prevent seizures from spreading from one hemisphere to another. Seizures generally do not completely stop after this procedure (they continue on the side of the brain in which they originate). The corpus callosum is the tissue band that connects the two sides of the brain.

**Multiple subpial transections** are rarely used in treating focal seizures and involve a series of cuts to disconnect the pathways of neurons in the brain.

### **Minimally Invasive Epilepsy Surgery**

The options discussed thus far all involve open brain surgery. There are other options, which are less invasive with fewer negative after-effects. MRI Guided Laser Surgery (Laser Interstitial Thermal Therapy) is a relatively new and innovative approach for the treatment for intractable epilepsy. A laser is guided into the brain adjacent to or within the epileptic focus. Only a very small cranial incision is required. Thanks to stereotactic MRI support, the localization of the wire can be very precise. By heating the wire within very strict parameters, the epileptic cells can be selectively targeted, again under MRI guidance. The non-invasiveness of this procedure allows the patient to go home after a minimal or no hospital stay. A significant advantage of this procedure is that it may be repeated if necessary. There are no serious adverse effects associated with this technique.

### ***Vagus Nerve Stimulation***

Vagus Nerve Stimulation (VNS) is a surgical therapy that involves the implantation of a battery-powered device called a Vagus Nerve Stimulator 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 signal helps to prevent or interrupt the electrical disturbances in the brain that result in seizures.

VNS is not suitable for everyone with epilepsy. It is used in patients who do not respond to medication and who are not suitable for epilepsy-related surgery.

\*Source: [webmd.com/epilepsy/guide/corpus-callosotomy#1](http://webmd.com/epilepsy/guide/corpus-callosotomy#1)

## *Ketogenic Diet*

A strict ketogenic diet high in fats and low in carbohydrates, with controlled proteins, and carbohydrates has been used in the treatment of difficult-to-control epilepsy in children.

Occasionally it is used in teenagers and adults. A chemical change is created in the body called **ketosis** resulting in the body breaking down fats instead of carbohydrates. This process inhibits seizures in some people. The diet requires medical supervision. It does not provide all of the vitamins and minerals necessary for health so nutritional supplements are required. Supplements must be monitored by a doctor and a dietitian.

**The ketogenic diet creates a chemical change in the body called ketosis resulting in the body breaking down fats instead of carbohydrates. This process inhibits seizures in some people. The diet requires medical supervision.**

## Z1 Blue Glasses

In photosensitive epilepsy, flashing, flickering, and strobing lights can induce seizures. Strobe effects can also occur in nature, for example on water. Sunlight on a tree-lined road may cause a similar effect. The intensity of this stimulus may be reduced by closing one or both eyes and by wearing Z1 Blue glasses.

## Complementary Therapies

There are complementary therapies which people have found useful in reducing seizures.

**It is important to remember that all therapies should be discussed with a doctor. Complementary therapies are used to supplement and not to replace accepted treatments.**

The alternative approaches listed below have **little or no scientific evidence supporting them.**

**Always** discuss complementary therapies with your doctor prior to trying them out.

Some individuals have found that yoga, massage therapy, or meditation is helpful.

Others advocate aromatherapy, herbal remedies, or vitamin therapy, while a number have had positive results from art, music, and pet therapy. Individuals have also found that techniques such as acupuncture and hypnosis are effective in seizure control.

Reflexology is a technique involving the application of pressure to points on the foot or hand that are believed to correspond to different parts of the body. For example, by massaging a certain part of the foot, a reflexologist tries to bring about a response in a part of the body. Some have found this approach helpful.

**It is important to remember that all therapies should be discussed with a doctor. Complementary therapies are used to supplement and not to replace accepted treatments.**

Biofeedback uses EEG recordings to help a patient develop a level of brain activity believed to raise the seizure threshold. Supporters of this approach believe that one can learn to control brain waves and that once a successful approach has been learned, the person may eventually be able to exert control without the assistance of the EEG recordings.

All established anti-epileptic drugs have shown better seizure control in animal experiments than in people with epilepsy. Marijuana has not shown effective anti-epileptic activity in animals. Marijuana does have calming, relaxing effects in some people. It may reduce tension and stress, which may prevent the onset of a seizure. However there is currently no medical or scientific support. Marijuana is associated with significant health and behavioural side effects and withdrawal from medical marijuana can increase seizure activity.

## *Choosing A Doctor*

Establishing a **positive relationship with your doctor** is important. It is helpful to have a doctor in whom you have confidence and with whom you can talk openly. It is useful to bring a list of questions when visiting your doctor to ensure that you are prepared and that your concerns are addressed.

Often your general practitioner will refer you to a neurologist. Neurologists specialize in the area of medicine relating to the nervous system and its disorders. In some centres, a patient may be referred to an epileptologist who is a neurologist with specialized training in epilepsy.

Occasionally people feel that they are not getting the treatment they would like, and in those cases, requesting a second opinion may be important. Often, your local Epilepsy Association is an excellent source for additional information and advice.

# H How Will Epilepsy Affect My Life?

## *Personal*

### Feelings

A range of emotions may accompany a diagnosis of epilepsy. You may feel depressed, angry, or frustrated. You may be concerned about your plans for the future. You may find that family or friends respond negatively to your condition out of fear or a lack of knowledge.

Depression is more common in individuals with epilepsy than it is in the general population. This could be due to psychosocial factors, the seizures themselves, and/or the anti-seizure medication. Ask your doctor for advice if you are struggling with depression.

### Assistance

Epilepsy associations have valuable resources on many aspects of epilepsy and they may be able to connect you with self-help and support groups and with trained professionals. For some individuals with epilepsy, little change in lifestyle is necessary. For others, there may be significant change.

### Helpful Tools

Some helpful tools include wearing a medical identification bracelet or necklace and carrying a preprogrammed cell phone in the event you need help. If anti-seizure medication or seizures affect memory, using an alarm, a day-timer, and a pill organizer or dosette may be helpful.

### Sharing with Others

Consider carefully with whom you will discuss your epilepsy. This decision will depend on the type and frequency of your seizures. How much time do you spend with the person? How likely are they to be with you when you have a seizure?

It is important that the people around you know the correct first aid procedures for a seizure.

## **Be Positive**

Living with epilepsy may have its challenges. It is important for you to keep your life as productive as possible, drawing on the support systems you have in place when necessary. A positive attitude will help you lead a full and rewarding life.

# **D** *Does Epilepsy Affect Cognitive Function and Development?*

The association between epilepsy and cognitive function is a complex one. Cognitive function involves mental processes such as remembering, perceiving, and thinking. Although most people with epilepsy do not experience significant impairment in cognitive function, some do experience changes. Factors that may have a negative impact on cognition and development are:



- Pre-existing cognitive impairment as a result of birth trauma, or previous illnesses (e.g. meningitis).
- Severity and frequency of seizures including a history of status epilepticus.
- High doses of one or more anti-seizure medications.

## *Community*

Generally, people do not know a lot about epilepsy. You will encounter this regularly.

Misconceptions are based on historical perceptions, a lack of public awareness, and exaggerated television and movie portrayals.

Sometimes they create the misguided perception that those with epilepsy are mentally disabled or more likely to be violent. Sometimes seizures are thought to be deliberate actions, they are not.



As a group, people with epilepsy have the same range of intelligence as the general public. As in any cross-section of the population, people with epilepsy have varying intellectual abilities.

Through public awareness and education, attitudes towards epilepsy are slowly changing.

By being open with others about your epilepsy, you will help public understanding. It is important for people to know what to do if they are present during a seizure.



## *Employment*

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

### **Making Choices**

Having epilepsy may have little or no effect on pursuing a rewarding career. There are understandable restrictions in certain careers (e.g., bus drivers, pilots) for safety reasons. There are many options in employment choices.

In some cases, uncontrolled seizures, the side effects of medication, or the inability to drive, may affect employment. Some people with epilepsy have found that starting their own business, job-sharing, or working as part of a co-op offers interesting alternatives.

If your seizures prevent you from working, there are many ways to use your skills including volunteering, pursuing a hobby, developing your talents, or mentoring the newly diagnosed and individuals entering new life stages.

### **Discrimination**

Although the public is becoming more knowledgeable about epilepsy, people still face discrimination and/or an under-use of skills in the workplace. Ignorance on the part of the employer may lead to bias. The Canadian Human Rights Act protects Canadians from discrimination ensuring equal opportunity for all Canadians and having their needs accommodated. If you encounter specific problems in the workplace, consult your local Epilepsy Association for advice.

Each province and territory has legislation intended to protect your rights. Anyone who has experienced discrimination in the workplace because of a disability may file a complaint with the Human Rights Commission in the appropriate province or territory.

It is not considered discriminatory on the part of an employer if the actions are considered reasonable and justifiable under the circumstances, particularly as they relate to safety. 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, an individual subject to epilepsy-related seizures may not be suited to safely working at heights or driving a truck. It is the responsibility of the employer to demonstrate that the individual's disability would threaten his or her safety or the safety of others.

### **Duty To Accommodate**

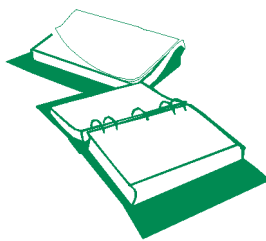
Under the Canadian Human Rights Act and some provincial codes, it is the duty of employers to make reasonable efforts to accommodate individuals with epilepsy in the workplace unless such accommodation would cause undue hardship. Accommodation can be as simple as changing the arrangement of furniture, trading work with another employee, or working in pairs. Details on how safety can be improved in a job through reasonable accommodation are available through local organizations offering employment assistance for persons with disabilities and through The Canadian Council on Rehabilitation and Work (CCRW).

## Applying For A Job

In some provinces, legislation restricts pre-employment inquiries. It is your decision how, when or whether you disclose your epilepsy to an employer. Employers are not allowed to ask about an applicant's physical condition. Contact the Human Rights Commission in your province or territory for information regarding disclosure.

When applying for a job, find out about the legislation in your area. Then consider the advantages and disadvantages of disclosing your condition and make your decision.

If you would like to find out more about the advantages and disadvantages of disclosure regarding employment, contact your epilepsy association.



## *Transportation*

You should not drive if your seizures are not controlled. Driving is generally 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 favourable recommendation from a neurologist. For example, if your seizures are all nocturnal (during sleep only) for three years, you may be permitted to drive. If you have a provoked seizure, for example, as a result of illness or sleep deprivation, you will not necessarily lose your driver's licence.

If seizures return, contact your doctor.

The regulations are much stricter for professional drivers.

**There are differences in provincial regulations.**

**For detailed information on driving standards in each province or territory contact the appropriate provincial regulatory agency. There are standards that apply specifically to epilepsy surgery, nocturnal epilepsy, withdrawal from or change in medication in collaboration with a physician, auras, etc.**

Drivers are required by law to report any health problems (such as epilepsy) to the appropriate provincial regulatory agency.

Some communities offer door-to-door transportation for individuals unable to use public transport due to a disability. Some transportation companies provide a free ride/seat to accommodate an escort if one is deemed medically necessary. Friends or family may also be able to help.

## *Sports and Recreation*

Many sports and recreational activities are safe and beneficial for people with epilepsy. Sports help to maintain fitness and reduce the stress that sometimes triggers 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

There are, however, some sports and recreational activities that are not advised or extra caution may be necessary. For example, some activities pose a greater risk than others due to the possibility of head injury. Or if a person has uncontrolled seizures, then swimming is not advisable without constant supervision. Swimming with a companion, preferably an experienced swimmer, is recommended for anyone who has seizures. Swimming in a pool is safer than swimming in open water.



Participation in sports and recreational activities should be discussed with your doctor.

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

## *safety*

There is an increased risk of injury in people with epilepsy. If you experience seizures that affect awareness, you are more at risk. Precautions in your home, workplace, educational settings, and while travelling, may be necessary.

Open flames, stoves, hot surfaces, and smoking all pose risks.

Using a microwave rather than a stove, carpeting the floors, padding the edges of tables and other furniture, and taking showers rather than baths, are just a few of the precautions that will make your home safer. Showers are safer than baths, but injuries can still occur. There are safety taps available. If you experience falls during a seizure, a shower seat with a safety strap should be considered.

If you have warnings before seizures, you may have the opportunity to lie down on your side on a carpeted or other soft surfaces.

If you experience sudden seizures (not preceded by an aura), ensuring that you stand back from roads or the edge of platforms when travelling by bus or subway is necessary. When travelling by air, informing airline officials of your condition in advance will allow for readiness in case of a seizure. Consider travelling with a companion.

New safety aids are continually being developed. High tech devices such as seizure-specific alarms triggered by seizure movements in bed, electronic tracking devices, and adapted showers that use infrared technology to shut off the water supply if a person falls are a few.

Although difficult to obtain and expensive to train, seizure service dogs are successfully used by some epilepsy patients. The dogs are trained to respond once a seizure starts by seeking help or assisting in protecting the person during the seizure. Some dogs are capable of “predicting” a seizure and then alerting the individual.

Detailed lists of safety tips are available from most epilepsy associations.

## *General Health and Seizure Triggers*

It is important to maintain a healthy and well-balanced lifestyle. Lack of sleep, stress, and poor eating habits can lower the seizure threshold and cause seizures. Alcohol and drug use or poor compliance with prescribed medication, may also result in poor seizure control.

Hormonal changes during the menstrual cycle are likely the cause of seizure frequency. Usually around ovulation. This is referred to as **catamenial epilepsy**.

There are specific health-related issues associated with certain groups including seniors, children, and women that should be discussed with a physician.



## *W*ill Drinking Alcohol Trigger Seizures?

While excessive use of alcohol and subsequent withdrawal can trigger seizures, modest occasional alcohol consumption does not seem to increase seizure activity. Alcohol can, however, increase liver metabolism resulting in lower blood levels of the anti-seizure medication.

Drinking alcohol can also lower the seizure threshold. Individuals with uncontrolled seizures should consider abstaining from alcohol consumption. If you choose to consume alcohol, it is essential that you continue taking your anti-seizure medication as prescribed.

## *Sexual Activity and Pregnancy*

Only in rare cases does sexual activity trigger seizures. Anti-seizure medication may, however, lessen a person's interest in sexual activity or affect sexual function. If seizures are uncontrolled, this could also affect sexual function. These concerns should be discussed with your doctor. A change in medication or other treatments may help.

Some types of anti-seizure medicine can interfere with the effectiveness of birth control pills or carry the risk of causing harm to a developing fetus.



## Common Seizure Triggers

While some people are not able to identify specific events or circumstances that precede seizures, others are able to recognize definite seizure triggers. It is useful to learn your seizure triggers so that seizures can be avoided.

### Some common seizure triggers include:

- Forgetting to take prescribed anti-seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, and emotional upset
- Menstrual cycle/hormonal changes
- Illness or fever
- Low anti-seizure medication blood levels
- Medications other than prescribed anti-seizure medications
- Excessive alcohol consumption and subsequent withdrawal
- Flickering or strobing lights
- Recreational drug use
- Other drugs: cocaine, amphetamines, opioids

If you are taking birth control pills, are planning to become pregnant, or are pregnant, it is essential that you consult with your doctor. Changes in medication or the medication dosage may be required. Folic acid prevents congenital disabilities (spina bifida) and is recommended for all women of childbearing age.

The risk of a child having unprovoked seizures is 1% - 2% in the general population and approximately 6% if a parent has epilepsy.

## *Financial Assistance*

Living with epilepsy may lead to financial concerns (e.g., cost of medications).

If a person is unable to work due to seizures, there are a number of provincial and federal financial resources available.

If you are unable to maintain regular employment, you may qualify for benefits or specific programs. Please consult your epilepsy association to discuss your concerns. There are also federal programs for which you may qualify.

**If you are taking birth control pills, are planning to become pregnant, or are pregnant, it is essential that you consult with your doctor.**

**Changes in medication or in the medication dose may be required.**

Some provinces offer additional financial assistance through a monthly benefit to persons who are unable to work as a result of a severe and permanent disability.

There is also a federal disability tax credit available that offers tax assistance to individuals who have severe and prolonged disabilities and who need life-sustaining therapy.

## *Insurance*

Applications for life and car insurance are increasingly being considered on an individual basis. Contacting various agencies before submitting an application and asking for information regarding policies and costs is useful in finding an appropriate provider. By investigating the options first, you will be able to compare what various companies offer. An insurance agent who deals with more than one company may be helpful. If your application is rejected, don't assume it will be by a different insurer.

Some employers offer long-term disability insurance.

Most provincial governments provide supplemental health benefit plans covering prescription drugs, ambulance, etc. at low or subsidized rates.

# 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.

# E *Epilepsy Education Series*

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## 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 ago 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

# Epilepsy Associations

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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 treatment and understanding 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.

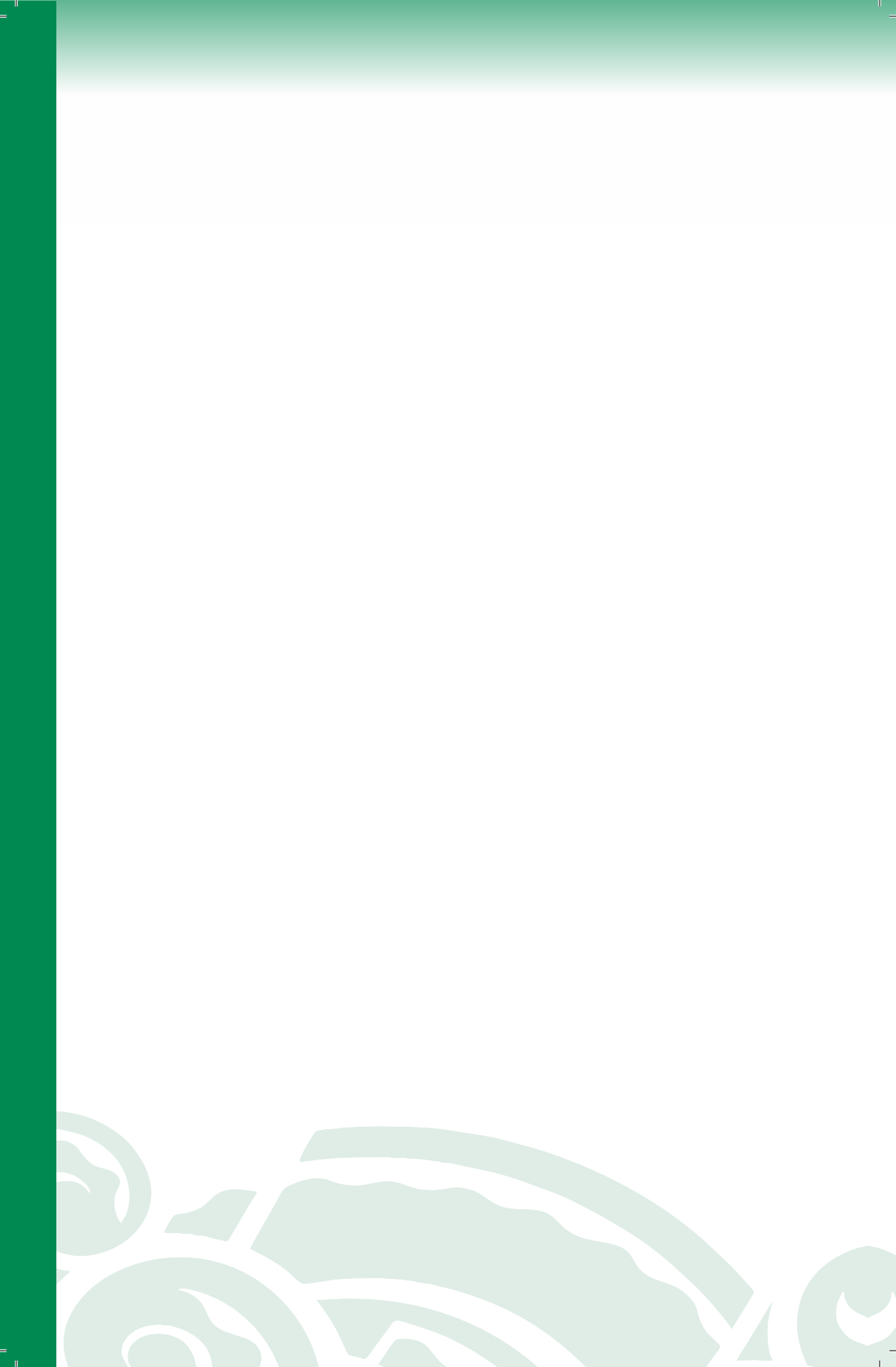
By volunteering with your local epilepsy association, you can make a difference in helping others to better understand epilepsy, and in improving the quality of life of those with epilepsy. Most epilepsy associations require volunteers to assist in areas such as peer-support programmes, educational activities, 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.



## Tips for Professionals and Caregivers

- Accept your limitations and ask for help if you need it.
- Monitor your emotional and physical well-being. Caring for another can be draining. If you need support, talk to a friend, family member, or professional. By taking care of yourself you will be better able to take care of another.
- Watch yourself for symptoms of stress such as sleep problems, headache, irritability, and withdrawal. Adequate sleep, exercise, and proper nutrition can all help to reduce stress.
- Take time out for yourself to do the activities you enjoy such as exercising, reading, or going out with friends.
- Be patient with yourself.
- Join a support group. Your local epilepsy association may be able to direct you to a group or put you in touch with others who are facing similar challenges.
- Learn about epilepsy. Information can be empowering.



## 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](http://www.edmontonepilepsy.org)

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