

LIVING WITH

Epilepsy



EPILEPSY EDUCATION SERIES

This publication was produced by the


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, and people with Epilepsy should not make changes based on this information to previously prescribed treatment or activities without first consulting their physician.

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

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

Index

| | |
|--|-----------|
| What is Epilepsy? | 1 |
| What Causes Epilepsy and Seizures? | 2 |
| How is Epilepsy Diagnosed? | 5 |
| What are the Different Types of Seizures? | 11 |
| What is the Treatment for Epilepsy? | 16 |
| How Will Epilepsy Affect My Life? | |
| Personal | 26 |
| Community | 28 |
| Employment | 29 |
| Transportation | 32 |
| Sports and Recreation | 32 |
| Safety | 34 |
| General Health and Seizure Triggers | 35 |
| Sexual Activity and Pregnancy | 36 |
| Common Seizure Triggers | 37 |
| Financial Assistance | 38 |
| Insurance | 39 |
| First Aid for Seizures | 40 |
| Epilepsy Associations | 42 |

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 the option of driving a car or continuing in a job? Will having epilepsy affect your relationships? What are some of the attitudes of society encountered by those with epilepsy?

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

Local epilepsy associations can provide you with information regarding your concerns. Most associations have helpful resource materials as well as a staff committed to answering questions and providing information.

Associations often 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.

Educating yourself and others about your condition, finding the appropriate treatment, developing a support network, and continuing to pursue what brings joy into your life are all important in achieving a fulfilling quality of life.

W What is Epilepsy?

Epilepsy is a condition of the brain that is characterized by recurrent seizures. Approximately one in ten 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 seizures.

Epilepsy is a seizure disorder. It is ***not*** a psychological disorder or 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 behavior. A seizure may take many different forms including 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 form the seizure will take. Seizures may occur rarely or as often as numerous times a day. If the condition is successfully controlled by medication, a person may be seizure free.

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 four million people have epilepsy.

Epilepsy can present at any age although its onset is most often in childhood or in 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 aging of the brain. In more than half of those with epilepsy, seizures can be well controlled with seizure medication.

W 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 but often the cause includes both genetic and acquired factors.

The causes vary according to the age of the onset of epilepsy.

Seizures are classified as *symptomatic* in which the cause is known or *idiopathic* in which the cause is unknown. In approximately 60 to 75 percent of epilepsy cases, no specific cause of the seizures can be identified. In the remaining 25 to 40 percent, some of the causes include:

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

Q Is epilepsy hereditary?

A Some types of epilepsy have a genetic basis. In certain epilepsies, one or more inherited genes may result in the condition.

In other cases, an inherited neurologic disorder that involves structural or chemical abnormalities in the brain can increase the risk of seizures and lead to epilepsy.

Another factor associated with a genetic cause of epilepsy is an inherited susceptibility to seizures. Each individual has a seizure threshold that determines the level at which the brain will have a seizure. Some individuals inherit a lower threshold or lower resistance to seizures resulting in a greater risk of having seizures.

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

Q Can alcohol and drug abuse lead to epilepsy?

A Both heavy alcohol consumption and withdrawal from excessive use of alcohol can provoke seizures in some individuals. Repeated uncontrolled seizures could result in a change in the activity of the networking nerve cells that could eventually result in epilepsy. The risk of later developing epilepsy may also be related to an increased risk of head injury following alcohol abuse.

Use of certain drugs can also provoke seizures or reduce the seizure threshold in some individuals. For example, cocaine often results in seizures and its use may cause brain damage that leads to epilepsy. Other drugs are also associated with provoking seizures including street drugs such as LSD, ecstasy, amphetamines (e.g. speed), 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 a period of 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 causing secondarily generalized seizures.

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

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.

H How is Epilepsy Diagnosed?

Various medical conditions can result in seizures. Before diagnosing epilepsy, a doctor will consider other possible causes of the seizures.

A high fever or a metabolic disturbance could cause seizures to occur. For example, an electrolyte disturbance as a result of severe diarrhea or vomiting, or a glucose imbalance caused by low blood sugar, may result in seizures.

Laboratory tests such as blood tests are sometimes used to find medical conditions other than epilepsy that may be causing 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*.

Medical History

Medical history is important in a doctor's assessment. Typically it involves a family health history and a detailed description of the characteristics, onset, and frequency of the seizures. Determining the type of seizure an individual is having is valuable in both the diagnosis and the prescribing of the appropriate treatment.



Seizure Record

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

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

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



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

- An **aura** results in unusual sensations, feelings, or movement. An aura is a simple partial seizure that may occur alone or may progress to a complex partial seizure or a generalized seizure. If the aura indicates the onset of a complex partial or generalized seizure, it can sometimes be used as a warning signal to allow a person to take the necessary precautions to avoid injury.
- The **ictus** refers to the seizure itself.
- The **postictal** period follows the seizure. An individual may temporarily experience confusion (postictal confusion), weakness (postictal paralysis), or sleepiness (postictal state).

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

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

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

Before the seizure:

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

During the seizure:

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

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

After the seizure:

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

Diagnostic Tests

Diagnostic tests usually include an electroencephalogram (EEG). An EEG is used to record the brain's electrical activity and it 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 the possibilities for epilepsy surgery.

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 too deeply located in the brain to be recorded.



Diagnostic tests used in the diagnosis of epilepsy may include:

EEG (Electroencephalogram)

An EEG is a painless, non-invasive test that is used to measure a person's brain wave pattern. The electrical impulses of the brain are recorded by small metal discs placed on the person's scalp, connected through wires, with the EEG machine. The EEG recordings can detect 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 (over-breathing) and photic stimulation (flashing lights) are routinely used to reveal abnormal changes in the 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, or during sleep.

EEG video ***telemetry***, a technique that combines EEG recording with videotaping, may also be used over longer periods of time to record a clinical seizure on tape. Behavior during a seizure can then be studied in combination with EEG recordings.

CT SCAN (Computed Tomography)

A CT (or CAT) scan is used to detect physical conditions in the brain that may be causing seizures such as tumors 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 so-called contrast medium is sometimes used to make abnormalities on the scan more visible.

MRI (Magnetic Resonance Imaging)

An MRI is used to provide structural information such as the presence in the brain of tumors, scar tissue, or abnormal blood vessels. Magnetic fields instead of x-rays 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 the tunnel-like magnetic chamber.

MRS (Magnetic Resonance Spectroscopy)

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

PET (Positron Emission Tomography)

PET scanning produces three-dimensional computer images of the brain processes at work. An intravenous with a very low dose of a radioactive glucose substance is given to the person. The scanning 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 that is slowly moved into the machine so that the head is inside the circular opening of 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 and then three-dimensional images are taken to view blood flow or metabolism. There are two separate injections. One is given during a seizure and the other is given in between seizures. The SPECT scans are taken an hour or two 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)

This test is used to assess the function of brain tissue. It is similar to the EEG, but magnetic rather than electrical brain waves are recorded in a three-dimensional fashion through sensors located in a machine placed near the person's head.

W What are the Different Types of Seizures?

There are many types of seizures. The different types begin in different areas of the brain and they are grouped into two categories: *partial* and *generalized*.

Partial Seizures

A partial seizure occurs when the excessive electrical discharge is limited to one part of the brain. Partial seizures are the most common type of seizure in adults. Sometimes seizures begin as partial and then spread and become generalized. These are referred to as *partial seizures secondarily generalized*.

The two most common kinds of partial seizures are *simple partial* and *complex partial*. During a simple partial seizure, awareness remains intact. In a complex partial seizure, awareness is impaired.

Simple Partial

(formerly called focal)

During a simple partial seizure, the person remains aware. A simple partial seizure may involve sensory, motor, psychic, or autonomic symptoms. These symptoms result in the person experiencing an unusual sensation, feeling, or movement called an *aura*. The aura may be a distortion in sight, sound, or smell where a person sees, hears, or smells things that aren't there, or it may be sudden jerky movements of one area of the body such as the arm, leg, or face that the person is unable to control. 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* during which the person has the sensation of having experienced something before.

The seizure usually begins suddenly and lasts seconds to minutes.

An aura is a simple partial seizure that may occur alone or may progress to a complex partial seizure or a generalized seizure. If the aura indicates the onset of a complex partial or generalized seizure, it can sometimes be used as a warning signal to allow a person to take the necessary precautions to avoid injury.

Complex Partial

(formerly called psychomotor or temporal lobe)

During a complex partial seizure, the person experiences altered awareness and may appear dazed and confused. A dreamlike experience may occur.

In some cases, the individual will be unable to respond or will do so incompletely or inaccurately. In other cases, the individual will lose contact.

The seizure often begins with an unusual sensation, feeling, or movement referred to as an *aura*. An aura can take many forms including a strange feeling in the upper abdomen, a feeling of fear, or an hallucination. An aura is a simple partial seizure that can occur alone or as the onset of a complex partial seizure. In a complex partial seizure, the aura often occurs just before awareness is altered and it is often used as a warning.

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

Once the pattern has been established, the same set of actions often occurs with each seizure. The seizure usually lasts for between one and two minutes and is often followed by a postictal period of disorientation and confusion.

Generalized seizures

A generalized seizure is characterized by the involvement of the whole brain. The excessive 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

(formerly called petit mal)

These seizures most often begin in childhood. In many children with absence seizures, the seizures stop during adolescence.

This type of seizure results in a blank stare usually lasting 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, and then continue talking without realizing that anything has occurred. Following the seizure, alertness is regained quickly.

These seizures are sometimes misinterpreted as daydreaming or inattentiveness. Rapid blinking may accompany the seizure and the eyes may roll upwards.

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 run in families.

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

Tonic Clonic

(formerly called grand mal)

The *tonic phase* of this seizure type typically involves a crying out or groan, a loss of awareness, and a fall as consciousness is lost and muscles stiffen. The second phase or *clonic phase* of the seizure typically involves a convulsion and there is jerking and twitching of the muscles in all four limbs. Usually the movements involve the whole body.

Urinary or bowel control may be lost and there may be shallow breathing, a bluish or gray skin color, and drooling.

The seizure usually lasts from one to three minutes. Awareness is regained slowly.

A postictal state often follows a tonic clonic seizure. This may involve fatigue 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 partial seizure (secondarily 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, partial seizures are the most common type experienced.

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

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 tone. This can result in the person falling down 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 be dangerous because of injury.

A *myoclonic* seizure results in a sudden jerk of part of the body such as the arm or leg. The person may fall over. The seizure is very brief. People who do not have epilepsy sometimes experience a sudden jerk of the body when they are falling asleep. This is common and is known as benign nocturnal myoclonus. It is not an epilepsy-related seizure.

Status Epilepticus

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

SUDEP

The cause of *Sudden Unexplained Death in Epilepsy (SUDEP)*, where death occurs suddenly for no discernible reason, is unknown. This is rare.

W What is the Treatment for Epilepsy?

In well over half of those with epilepsy, seizures are controlled with *monotherapy* or the prescribing of one drug. In others, *polytherapy* or the prescribing of more than one drug, is effective in controlling seizures.

Surgery is considered in up to 15 percent of individuals with epilepsy when treatment with various seizure medications does not result in an individual being seizure free.

Depending on the type of epilepsy, some patients will outgrow their epilepsy and they will be able to discontinue their medication. For others, excellent control of seizures will continue for years with regular use of seizure medication. Other individuals will benefit from surgery or from a specialized approach combining medication with surgery in order to obtain optimal control.

In some cases, however, seizures remain uncontrolled despite treatment.

Seizure Medication

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 seizure medication. In recent years there have been significant improvements in seizure medications.



Seizure Medications

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

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

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

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

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

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

Due to the number of different types of epilepsy, there are many different medications. Monotherapy is preferable in the treatment of epilepsy but sometimes more than one drug, or polytherapy, is required.

Occasionally it may be necessary for individuals on seizure medication to have blood tests. If seizures are not controlled or reoccur, a doctor may order a test to check the level of a seizure drug in the blood.

Side Effects

Some seizure medication may produce mild or complicated side effects. The side effects tend to be more common when a drug has just been started, when the dosage has been increased, or when more than one drug has been prescribed.

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

Allergic side effects are less common and may include skin rash or reactions that may affect the liver, blood cells, or bone marrow. Skin rash may often be the first sign of an allergic reaction to a drug.

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 adverse side effects of each drug consult your doctor, pharmacist, or contact your local epilepsy association.

Discontinuing Medication

Discontinuing (or stopping) seizure medication can cause serious complications and should only be done with a doctor's advice and supervision.

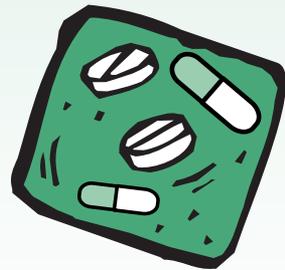
Sudden discontinuation of medication could result in withdrawal seizures or status epilepticus, a continuous seizure state that can be life threatening. Reducing the prescribed dosage of seizure medication can also result in problems.

**Discontinuing
(or stopping) seizure
medication can cause serious
complications and should only
be done with a doctor's advice
and supervision.**

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 seizure medication can only be done if a number of factors have been carefully considered.

Seizure Medication Tips

- 1** Always take your seizure medication as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus. Any changes in taking seizure medication should be discussed 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 seizure medication. Even some therapeutic drugs such as antidepressants and antibiotics could interact with your seizure medication. To learn more about possible interactions and/or adverse side effects, ask your doctor, pharmacist, or local epilepsy association for detailed information on each seizure medication.
- 3** Don't change from a brand name drug to a generic drug without first consulting your doctor. The use of different fillers, dyes, etc., can result in differences in processing by the body.
- 4** A watch with a timer and a weekly pillbox are helpful in reminding you to take seizure medicine at the right time.
- 5** Keep a one to two week supply of your seizure medication to assure that you don't run out.



Surgery

Typically, patients considered for surgery have seizures that are **medically refractory** or **intractable**. This means that they do not respond to medical treatment such as the use of seizure medication. 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, or 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, however, 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 the 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 partial seizures.

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

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. The corpus callosum is the tissue band that connects the two sides of the brain.

Multiple subpial transections have been used in treating partial seizures and involve a series of cuts underneath the cerebral cortex to disconnect the neuronal pathways.

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.

The device is similar to a heart pacemaker. A wire runs from the device to the vagus nerve in the neck. The VNS device stimulates the left vagus nerve which then sends an electrical signal to the brain. The signals help to prevent or interrupt the electrical disturbances in the brain that result in seizures.

A doctor programs the device to deliver periodic doses of stimulation, such as 30 seconds of stimulation followed by five minutes of no stimulation.

The individual or a caregiver can start or stop the stimulation by hand with the use of a special magnet. If a person experiences an aura or feels that a seizure is beginning, the magnet can be passed over the chest where the generator is located. This will activate extra stimulation to attempt to stop the seizure or reduce how long the seizure continues or its intensity.

Individuals using the device should ask the doctor how long the battery will last in order to allow for replacement when necessary. Replacement of the battery requires minor surgery.

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

The procedure has successfully reduced seizure frequency, intensity, and/or duration in some individuals when used with previous seizure medication.

There can be some adverse side effects including hoarseness, sore throat, shortness of breath, and coughing. Typically these side effects occur during stimulation. If the hoarseness is persistent or uncomfortable, the doctor should be notified.

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.

Ketogenic Diet

A strict ketogenic diet high in fats and low in protein and carbohydrates has been used in the treatment of difficult-to-control epilepsy in children. Occasionally it is used in the treatment of 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 to avoid deficiencies. Use of these supplements must be monitored by a doctor. Studies indicate that approximately one-third of children strictly adhering to the diet are seizure free or close to it, one-third experience a reduction in seizures, and one-third are unresponsive.

Complementary Therapies

There are many complementary therapies that some individuals have found helpful in seizure control. Although some of these methods may not have been scientifically proven, there are people with epilepsy who have found that they help in reducing seizures. A number of the methods were developed centuries ago before current treatments were available.

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.

**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.**

Advocates of a self-control approach in dealing with epilepsy believe that playing an active role will not only alleviate feelings of powerlessness but may also be effective in controlling seizures. Through persistence and careful observation, some individuals have developed the ability to use tools such as mental imagery, odors, or relaxation techniques to prevent or delay seizures.

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. People have sometimes found this approach helpful.

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.

Some approaches such as the use of marijuana to control seizures are highly controversial. Although there are anecdotal reports that suggest a benefit in controlling seizures with marijuana use, and marijuana is a substance that has been researched and experimented with over the years, there is no significant medical support for its use in epilepsy therapy. It is associated with significant health and behavioral side effects and withdrawal from marijuana can result in an increase in seizure activity.

Choosing A Doctor

Establishing a *positive relationship with your doctor* is very important. It is helpful to have a doctor in whom you have confidence and with whom you can talk openly. It is useful to take a list of questions when visiting your doctor in order to assure 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 centers, 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.

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 seizure medication. If you are struggling with depression, discuss your feelings with your doctor.

Assistance

Local epilepsy associations have valuable resources on many aspects of epilepsy and they may be able to link 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 pre-programmed cell phone or beeper in case you need help. If seizure medication or seizures affect memory, using a watch with an alarm, a day-timer, and a medication dispenser may be helpful.

Sharing with Others

Consider carefully with whom you will discuss your epilepsy. The decision involving who should be told may depend partially 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 if you have a seizure while you are with them may be a deciding factor. While it may not be necessary to discuss your condition with everyone, it is important that those you are with frequently know what to do if you have a seizure.

Be Positive

Living with epilepsy can result in personal challenges, but it does not have to result in an inability to have a rewarding and full life. Learning about epilepsy and sharing that information with others, finding the medical treatment that is best for you, developing a network of family and friends who support and care about you, and pursuing what matters in your life, are all important.

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
- The use of high doses of one or more seizure medications.

Community

One of the challenges facing those with epilepsy is the public's lack of knowledge about the condition.

Misconceptions based on historical perceptions, lack of public awareness, and inaccurate television and movie portrayals do result in

incorrect assumptions about epilepsy. Sometimes these create the misguided perception that those with epilepsy are mentally disabled or are more likely to be violent. Sometimes the forms that seizures take can be mistaken to be deliberate acts. 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 the condition are slowly changing. It has become accepted knowledge that many brilliant historical figures including Vincent Van Gogh, Feodor Dostoyevski, and Isaac Newton had epilepsy.

By sharing information on epilepsy with others, you will both help people to better understand the condition and increase awareness on how to help if they are present when someone has 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 choose to do.

Making Choices

Having epilepsy may have little or no effect on pursuing a rewarding career. Although there may be some 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 alter employment decisions. Some people with epilepsy have found that starting a business, job sharing, or working as part of a co-op offers alternatives.

If your seizures do prevent you from working, there are many ways to use your skills including volunteering, developing a hobby, or pursuing an artistic talent.

Discrimination

Although the public is becoming more knowledgeable about epilepsy, people with epilepsy sometimes face discrimination and/or an under-utilization of skills in the workplace. Although physical disabilities are protected grounds under human rights legislation and the Canadian Human Rights Act does not allow discrimination by an employer due to a disability such as epilepsy, a lack of knowledge about the condition may result in a bias on the part of an employer. An employer may have concerns over safety, reliability, or liability yet studies on individuals with epilepsy in the workplace do not support those concerns.

Each province and territory has legislation intended to protect the rights outlined in the Canadian human rights laws. 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.

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. Employers are not expected to hire or continue to employ a person whose disability notably increases the probability of health or safety hazards to himself or herself, other employees, and/or the public. For instance, an individual subject to epilepsy-related 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 individual'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 a person 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. 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 or when or whether you disclose your epilepsy to an employer. Employers are not allowed in job applications or in interviews 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.

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

Telling an employer that you have epilepsy after you have started working provides you with the opportunity to prove yourself first but the employer may feel that you have not been honest.

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



Transportation

There are restrictions to driving if your seizures are not controlled. If epilepsy has been diagnosed, 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 favorable neurologist's recommendation.

If seizures return, contact your doctor.

The regulations are much stricter for professional drivers (e.g. driving passenger-carrying or commercial vehicles).

There are provincial differences in 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, and auras, etc.

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

If you are not eligible to drive, explore public transportation systems or taxi use. Some communities offer door-to-door transportation for individuals unable to use public transport due to a disability. Some travel companies provide free transportation for an escort capable of providing the required assistance if it is 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. They reduce the stress that sometimes triggers seizures and also maintain fitness and bone mass levels.

Activities

Activities to enjoy include:

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

Sports that pose some risk:

- hockey
- soccer
- karate
- football
- boxing

* Possibility of head injury exists with these sports

Activities that are considered dangerous:

- scuba diving
- rock climbing
- parachuting

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 related problems such as 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 sudden and frequent seizures that affect awareness, you are the most likely to be at risk. Precaution in your home, workplace, educational settings, and while traveling, may be necessary.

Open flames, stoves, irons, and cigarette 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 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.

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

If you experience sudden seizures, assuring that you stand back from roads or the edge of platforms while traveling by bus or subway is necessary. When traveling by air, informing airline officials of your condition in advance will allow for preparation in case of a seizure.

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 still very difficult to obtain and expensive to train, seizure service dogs are successfully being used by some people with epilepsy. The dogs are trained to respond once a seizure starts by seeking help or assisting in protecting the person during the seizure. Studies suggest that some dogs seem capable of predicting a seizure and of 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. Monitoring what may trigger a seizure is helpful for people with epilepsy. Lack of sleep or too much stress can affect seizure control. Eating regularly and maintaining a well-balanced and nutritious diet are important. A poor and irregular diet may affect seizure medication levels.

Excessive alcohol consumption and subsequent withdrawal, and use of street drugs can trigger seizures.

And in those with photosensitive epilepsy, flashing or flickering lights induce seizures and can be triggered by the lights of computers, video games, or television.

Some women experience an increase in seizures around the time of menstruation. 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.



Will 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 in individuals who are not alcoholics or who are not sensitive to alcohol. Alcohol use can, however, lower the metabolism which results in lower blood levels of the seizure medication that is also metabolized by the liver.

Drinking alcohol can also lower the seizure threshold. A seizure threshold is the level at which the brain will have a seizure. Some doctors recommend that individuals with uncontrolled seizures abstain from alcohol consumption. If you choose to consume alcohol, it is essential that you continue taking your seizure medication as prescribed.

Sexual Activity and Pregnancy

Only in rare cases does sexual activity trigger seizures. 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 seizure medicine can interfere with the effectiveness of birth control pills or carry the risk of causing harm to a fetus. Most women with epilepsy have healthy babies but there is a slightly

Common Seizure Triggers

While some people are not able to identify specific events or circumstances that affect 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 seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Menstrual cycle/ hormonal changes
- Illness or fever
- Low seizure medication levels
- Medications other than prescribed seizure medications
- Excessive alcohol consumption and subsequent withdrawal
- Flickering lights of computers, television, videos, etc.
- Street drugs (e.g. cocaine, amphetamines, ecstasy, LSD, withdrawal from marijuana)

higher risk that having epilepsy or taking seizure medication will affect the fetus.

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

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

Financial Assistance

Most people with epilepsy are able to financially support themselves. If a person is unable to work due to seizures, then there are a number of provincial and federal financial resources available.

If there is a severe and prolonged disability resulting in an inability to work regularly in any job, the Canada Pension Plan (CPP) pays a monthly benefit to people who have contributed to the plan and who are disabled according to Canada Pension Plan legislation. It also pays monthly benefits for their dependent children.

If you are taking birth control pills, are planning to become pregnant, or are pregnant, it is essential that you talk with your doctor. Changes in medication levels or prescribed drugs may be required.

Some provinces offer additional financial assistance through a monthly benefit to persons who qualify and 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 on an ongoing basis.

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 are very 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 supplementary health benefit plans covering prescription drugs, ambulance, etc. at low or subsidized rates.



First Aid for Seizures

What To Do If Someone Has A Non-Convulsive 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 complete awareness returns.

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.** The person will not swallow his or her tongue.
- 7 Gently roll the person onto his or her side as the convulsive seizure subsides** to allow saliva or other fluids to drain away and keep the airway clear.
- 8 After the seizure, talk to the person reassuringly.** Do not leave until the person is re-oriented. The person may need to rest or sleep.



Calling An Ambulance

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



CALL AN AMBULANCE:

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

Epilepsy Associations

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

Consider becoming a member of your local epilepsy association. Epilepsy associations have much to offer including support groups, programs, 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 programs, 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 Edmonton Epilepsy Association has produced a series of epilepsy educational booklets, including:

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 Professionals and Caregivers

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).

Free Canada-wide distribution of these booklets is made possible by a sponsorship from UCB Canada Inc.

© Edmonton Epilepsy Association, 2018

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

Canadian League
Against Epilepsy



La Ligue
Canadienne
Contre l'Épilepsie

Your Local Contact Information:

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