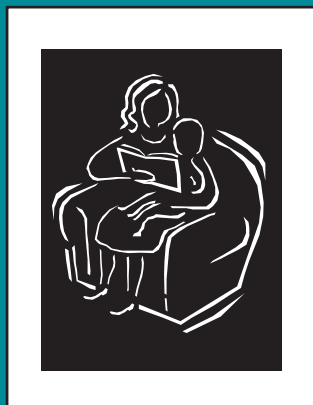


**A GUIDE FOR PARENTS**

# *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](mailto:info@edmontonepilepsy.org)   Website: [www.edmontonepilepsy.org](http://www.edmontonepilepsy.org)**

---

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

---

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

---

# Contents

---

<b>What is Epilepsy?</b>	<b>1</b>
<b>What are the Signs of Childhood Seizures?</b>	<b>2</b>
<b>What Causes Epilepsy and Seizures?</b>	<b>3</b>
<b>What are the Different Types of Seizures?</b>	<b>5</b>
<b>Epilepsy Syndromes?</b>	<b>11</b>
<b>How is Epilepsy Diagnosed?</b>	<b>17</b>
<b>What is the Treatment for Epilepsy?</b>	<b>23</b>
<b>How Can Parents Help?</b>	<b>32</b>
<b>Learn About Epilepsy</b>	<b>32</b>
<b>Encourage and Support Your Child</b>	<b>32</b>
<b>Develop a Positive Family Environment</b>	<b>35</b>
<b>Create a Safe Environment</b>	<b>36</b>
<b>Be Involved in Your Child's School Experience</b>	<b>38</b>
<b>Allow Participation</b>	<b>41</b>
<b>Help Teenagers to Make Wise Decisions</b>	<b>42</b>
<b>Teach Others About Epilepsy</b>	<b>49</b>
<b>First Aid for Seizures</b>	<b>50</b>
<b>When to Call an Ambulance</b>	<b>51</b>
<b>Epilepsy Terminology: Old and New</b>	<b>53</b>
<b>Epilepsy Associations</b>	<b>54</b>

# *Epilepsy: A Guide for Parents*

If your child has been diagnosed with epilepsy, you may have questions regarding the condition. What causes epilepsy? How is it diagnosed? What are the available treatments? How can I help my child?

It is not unusual for a parent to experience feelings of helplessness, fear, grief, or anger after a child has been diagnosed with epilepsy.

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

Often associations offer in-service training to schools which educate others about the condition. Associations may also be able to provide you with support groups, trained professionals, or other families who are facing similar challenges.

In some cases, a diagnosis of epilepsy may require little change in lifestyle. In other cases, there may be significant change for the child and the family.

In either situation, learning about epilepsy can empower you and help you make informed decisions regarding medical treatment, care, or safety.

Learning about epilepsy may also help to alleviate your own anxiety and allow you to focus on the needs of your child.

# W *What is Epilepsy?*

---

**Epilepsy is a condition of the brain that is characterized by recurrent seizures.** The brain is made up of approximately 100 billion nerve cells or neurons, which communicate through electrical and chemical signals. When there is a sudden excessive electrical discharge that disrupts the normal activity of the nerve cells, a change in the behaviour or function may result. This abnormal electrical activity in the brain is a seizure. Epilepsy **is** a seizure disorder. Epilepsy is **not** a disease, and it is **not** contagious. It is **not** a psychological disorder.

**Seizures are common in childhood and adolescence.** A seizure may occur as the result of a fever or illness that affects the brain. A single seizure is not epilepsy. Approximately 1 in 20 people (5%) will experience at least one seizure during a lifetime. Most do not have epilepsy. In children who have a single seizure, only a small percentage have a second one. Epilepsy is a condition that is defined by multiple unprovoked seizures.

**Seizures cause a change in function or behaviour.** A seizure may result in different symptoms such as 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 to many times per day. The condition may be controlled by anti-seizure medication. Most children become seizure-free.

**Epilepsy is one of the most common chronic neurological disorders.**

An estimated 1% of the general population has epilepsy. Epilepsy often begins in childhood.

**Childhood epilepsy is often outgrown.** The frequency of seizures in childhood may be partly due to the low seizure threshold of the child's brain. A seizure threshold is the level at which the brain will have a seizure, and the seizure threshold rises as the brain matures. This may also explain why about 50% of children with epilepsy outgrow the condition.

# W *What are the signs of childhood seizures?*

A seizure may last for a few seconds and involve a blank stare or a sudden fall. It may last for a few minutes and involve a convulsion or random, purposeless movements such as chewing motions or pulling at clothing.

Sometimes, it is difficult to distinguish between a seizure and unusual behaviour in a child. What is important to watch for is a pattern of behaviour that happens too often to be by chance.

## **Signs that may indicate a seizure include:**

### **In Babies**

- clusters of bowing or bending movements while a baby is sitting
- clusters of grabbing movements with both arms while a baby is lying down

### **In Children and Adolescents**

- a sudden loss of awareness that may appear like daydreaming
- a brief lack of response
- memory gaps
- rhythmic head-nodding
- rapid blinking
- repeated movements that appear unnatural
- repeated jerking movements of the body, arms, or legs
- unusual irritability and sleepiness when awakened
- sudden falls without an apparent reason
- sudden stomach pain followed by sleepiness and confusion
- frequent complaints that things taste, sound, smell, look, or feel strange
- sudden fear, panic, or anger without an apparent cause

# W What Causes Epilepsy and Seizures?

The cause of epilepsy is sometimes genetic and sometimes acquired. Often there are both genetic and acquired factors.

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

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 for the seizures is identified. In the remaining 25% - 40%, identifiable causes include:

- Genetic factors
- Birth injury (e.g., lack of oxygen or birth trauma)
- Developmental disorder (e.g., brain damage to the fetus during pregnancy; malnutrition, drugs, infections, and alcohol)
- Brain trauma (e.g., from car accidents, sports injuries)
- Infection (e.g., meningitis, encephalitis, AIDS )
- Brain tumour

## Q Is epilepsy hereditary?

A In certain epilepsies, 1 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 the seizures.

Susceptibility to seizures may be inherited. Each individual has a different 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 How does having repeated seizures result in a worsening of epilepsy?**

**A** The brain consists of a large network of nerve cells that generate 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 epileptic seizures occur.

This process is called "kindling." A seizure 'focus' results from the kindling process. Eventually, the electrical activity may spread from this focus throughout the brain, causing secondarily generalized seizures.

There is evidence that a similar process takes 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 "kindling." Somehow the nerve cell network has changed and has created a seizure.**



# W What are the Different Types of Seizures?

The different types begin in different areas of the brain and are grouped into two categories: focal and generalized.

## *Focal Seizures*

A focal seizure occurs when excessive electrical discharge is limited to one area of the brain. Sometimes seizures begin as focal and then spread and become generalized. These are referred to as **focal seizures secondarily generalized**.

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

### Focal Aware Seizure

During a focal aware seizure, sensory, motor, psychic, or autonomic symptoms may occur. These symptoms result in the child experiencing an unusual sensation, feeling, or movement called an **aura**. The aura may be a distortion in sight, sound, or smell where the child may see, hear, or smell things that aren't there. They may display sudden jerky movements of one part of the body such as the arms, legs, or face. For instance, the child may suddenly smell burning rubber, or a hand may twitch uncontrollably.

A child may experience an aura that involves a sudden overwhelming emotion such as joy, sadness, fear, or anger. Or there may be the experience of autonomic symptoms such as stomach upset, dizziness, a shiver, a tingling or burning sensation, pallor, or flushing. Occasionally there will be the experience of déjà vu or déjà écoutée during which the child has the sensation of having experienced something before.

A focal aware seizure usually begins suddenly and lasts from seconds to minutes. An aura is a focal aware seizure that may occur alone or may progress to a focal impaired awareness seizure or a generalized seizure.

The aura can sometimes be used as a warning signal to allow the child or parent to take precautions to avoid injury.

### **Focal Impaired Awareness Seizure**

During a focal impaired awareness seizure, the child may appear dazed and confused. A dreamlike experience may occur.

In some cases, the child is unable to respond or will do so incompletely or inaccurately. In some cases, the child is semi-aware, unable to respond fully.

The seizure often begins with an unusual sensation, feeling, or movement known as an aura. An aura may consist of a strange feeling in the upper abdomen, a feeling of fear, or a hallucination. The aura is a seizure that can occur by itself or as part of a focal impaired awareness seizure. As a rule, the aura occurs before awareness is altered, and may be used as a warning.

Purposeless movements over which the child 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 at inappropriate times.

Once the pattern has been established, the same set of actions often occur with each seizure. The seizure usually lasts between 1 and 2 minutes and is often followed by disorientation or confusion.

## Generalized seizures

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. There are 2 types of generalized seizures: absence (without convulsions) or tonic-clonic (with convulsions).

### Absence

This type of seizure results in a blank stare, usually lasting less than 10 seconds. Awareness is impaired, and the seizure starts and ends abruptly. A child may suddenly stop talking, stare blankly for a few seconds, and then continue talking without realizing that anything has occurred.

A child may experience as many as several hundred absence seizures in a day. These seizures are sometimes misinterpreted as daydreaming or inattentiveness. If absence seizures are not treated, they may interfere with learning. Rapid blinking may accompany the seizure and the eyes may roll upwards. Following the seizure, alertness is quickly regained.

Absence seizures most often begin in childhood and, in two-thirds of cases, stop during adolescence. There is a typical electroencephalogram (EEG) pattern associated with absence 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.**

If the onset of absence seizures is at adolescence, there is a greater chance of a person developing tonic-clonic seizures. In some cases, absence seizures go unnoticed until a person has a generalized tonic-clonic seizure. Absence seizures tend to run in families.

**Atypical absence** seizures are similar to absence seizures but involve more pronounced movement or automatisms. These seizures often occur with other types of seizures and are more common in children with additional neurological conditions.

### **Generalized Tonic-Clonic Seizures**

The tonic-clonic seizure is the most common type of seizure in children. The tonic phase of this seizure type typically involves a crying out or a groan, a loss of awareness, stiffening of the muscles, and a fall. The second phase or clonic phase of the seizure typically involves a convulsion with jerking and twitching of the muscles in all four limbs.

Urinary or bowel control may be lost, and there may be shallow breathing, a bluish or grey skin colour, and drooling. The bluish colour is partly the result of the change in available oxygen, caused by a difficulty in breathing as the chest muscles contract. The seizure usually lasts from 1-3 minutes. Awareness is regained slowly. Tongue or lip bite can be present.

A postictal state follows a tonic-clonic seizure. This may involve fatigue and confusion, and the child may experience a severe headache. Often the child will be sleepy.

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 (focal to bilateral tonic-clonic seizure).

Other types of generalized seizures include atonic and myoclonic seizures.

### **Atonic Seizures**

An atonic seizure is sometimes called a “drop attack” because it often results in a sudden fall. The seizure involves a sudden loss of muscle tone that may cause the child to fall or almost fall, drop an object, or nod the head involuntarily. Typically, an atonic seizure lasts for a few seconds.

As a “drop attack” happens suddenly and often with no warning, it can result in injury. Sometimes a child will have to wear a helmet for protection. These seizures usually begin in childhood and often occur in people with other seizure types. Often these seizures occur as part of Lennox-Gastaut syndrome.

### **Myoclonic Seizures**

A myoclonic seizure results in a sudden jerk of part of the body, such as the arm or leg. This startle response may result in a fall or a loss of posture if the child is sitting. Each seizure is very brief, although myoclonic seizures may occur singly or in clusters.

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. The seizures may be convulsive or nonconvulsive.

**Immediate medical care is necessary.**

Status epilepticus is more common in young children and in seniors.

If your child has experienced status epilepticus, you should obtain guidance from your doctor.



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

The cause of SUDEP, where death occurs suddenly for no discernible reason, is unknown. This is rare. This occurs more commonly in patients with uncontrolled (intractable) seizures, and in patients who are on several anti-seizure medications.

# Epilepsy Syndromes

---

Some types of epilepsy can be classified as syndromes based on patterns and/or features that they have in common.

For example, children with epilepsy sometimes experience similarities in terms of the age of onset, seizure type, EEG results, response to treatment, and prognosis. These children may be diagnosed as having an epilepsy syndrome.

The diagnosis of an epilepsy syndrome may help the doctor in outlining the likely prognosis and in finding the appropriate treatment. Epilepsy syndromes cannot always be identified. They are more commonly identified in children than in adults.

Some of the childhood epilepsy syndromes and epilepsies include:

## Benign Rolandic Epilepsy

In this type of epilepsy, the seizures generally start after the age of 3 and are usually outgrown at adolescence. The seizures tend to be infrequent and mild. Seizures often start with a sensation, as a tingling or twitching at the corner of the mouth. A jerking of that area may follow and may spread to one side of the face.

Occasionally, the seizure spreads to that side of the body or progresses to a tonic-clonic seizure. The seizures may result in excessive drooling or in an inability to speak. These seizures most often occur at night or upon awakening. This type of epilepsy is often treated with medication only if the seizures are frequent, or the parents or child are not able to cope with further seizures.

## **Infantile Spasms (West Syndrome Epilepsy)**

Infantile spasms are myoclonic jerks that usually occur in clusters in babies before the age of one. Spasms last only a few seconds but often repeat in a cluster or a series of 5-50 or more. The clusters may occur numerous times a day.



When the seizure occurs, the baby appears startled or in pain. If lying down, the baby will suddenly draw up the knees and raise both arms. If sitting, the baby's head and arms may suddenly flex forward, and the body flexes at the waist.

Typically, the spasms occur when the baby is waking up or going to sleep. Often the child experiences developmental delays and cognitive problems. A child with infantile spasms may later develop Lennox-Gastaut syndrome.

## **Juvenile Myoclonic Epilepsy (JME)**

JMEs account for 7% of all epilepsies. It is characterized by myoclonic jerks often in the arms, shoulders, neck, and sometimes the legs. The jerks usually occur as the child is awakening in the morning. Sometimes these jerks can be misinterpreted as clumsiness or nervousness.

Children with JME may also experience tonic-clonic or absence seizures.

JME typically begins in adolescence, often at the time of puberty. JME can generally be controlled with medication and is not likely to be outgrown. Most individuals will experience a relapse if medication is discontinued. JME can run in families. Conventional anticonvulsants (e.g., Dilantin and Carbamazepine) do not control JME, but Divalproex and Lamotrigine do.



## **Landau-Kleffner Syndrome**

This epilepsy syndrome is rare and generally begins in children under the age of 6. The syndrome is characterized by a language disorder that affects the child's ability to understand language and to speak. The syndrome is characterized by a regression in speech development. Convulsive and nonconvulsive seizures may occur although epilepsy-related seizures are infrequent and are not always experienced with the condition. Seizures may be controlled with hormonal therapy and may be outgrown. In some cases, speech may be recovered by adulthood.

## **Lennox-Gastaut Syndrome**

Children with this syndrome generally have several different types of seizures, including atonic seizures. Its onset is typically in early childhood before the age of six. The syndrome is most common in children who have acquired brain damage or a developmental problem of the brain.

Lennox-Gastaut syndrome can be difficult to treat and often involves mental impairment. The prognosis is poor for seizure remission.

## **Rasmussen's Syndrome**

This rare syndrome is associated with uncontrolled focal seizures, intellectual deterioration, and progressive weakness on one side of the body. Typically, the epilepsy begins before the age of 14 years. Medication does not appear to be effective, but a hemispherectomy may stabilize the condition (surgical removal of half of the brain).

## Reflex Epilepsy

In this type of epilepsy, seizures are triggered by a specific stimulus or event.

In **photosensitive epilepsy**, the most common type of reflex epilepsy, lights flickering at a certain frequency and brightness (e.g., from televisions, computer screens, strobe lights, video games, movies) can trigger a seizure. Sometimes natural light patterns such as sunlight reflecting off of water can trigger seizures. Seizures are most often tonic-clonic.



Treatment includes avoiding the stimulation or, if the child's epilepsy is severe, medication may be prescribed. Closing one eye reduces the light intensity and may prevent a seizure. Z1 Blue Glasses (Zeiss) are quite effective in preventing these seizures. Photosensitive epilepsy affects children more often than adults and is often outgrown in adulthood (late 20s or early 30s). In some children with photosensitive epilepsy, seizures can also be triggered by stimuli other than flashing lights. Striped patterns and certain wallpaper designs have been known to trigger seizures.

Rarely, reflex epilepsy will occur with other stimuli such as listening to certain music or reading.

## *Special Syndromes*

### Febrile Seizures

Seizures triggered by high fever are the most common seizures in children.

These seizures are usually outgrown by the age of 5. This may be partly due to the fact that the seizure threshold tends to rise as the brain matures. Over half of the children who have a single febrile seizure will not have a second. Febrile seizures tend to occur in families.

These seizures are tonic-clonic, any young child who has experienced a seizure with a fever should be seen by a doctor. Fever-lowering medication may prevent seizures. Long-term anti-seizure medication is not generally prescribed.

Factors that influence the occurrence of febrile seizures include:

- the lower seizure threshold of infants.
- how high the fever is and how quickly it develops.
- a genetic susceptibility to seizures.

The risk of a child developing epilepsy following a single febrile seizure is increased if:

- the first febrile seizure lasts longer than 15 minutes or is a focal seizure, or there is seizure recurrence in the first 24 hours.
- there is a family history of epilepsy.
- there is a preexisting neurologic disorder (e.g., cerebral palsy) or the child's development has been delayed before the seizure.

# 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 many people with epilepsy do not experience significant impairment in cognitive function, some do.

Factors that may have a negative impact on cognition and development are:

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

Certain epilepsies and epilepsy syndromes are associated with impairment of cognitive development. With Benign Rolandic Epilepsy, there is no cognitive impairment. Other syndromes such as West Syndrome and Lennox-Gastaut are known as progressive because seizures and/or the individual's motor or cognitive abilities may worsen over time.

Developmental delay means that the processes of physical growth and intellectual development are disrupted. If both seizures and developmental delays occur, there is usually an underlying problem in the brain. Although epilepsy is associated with other disorders such as cerebral palsy, epilepsy is just one of the conditions commonly found in people with developmental delays.

# H How is Epilepsy Diagnosed?

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*

The medical history is very 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 is important for accurate diagnosis and treatment.



## Seizure Record

*Carefully observing your child's seizures is important.*

*As your doctor may not view one of your child's seizures personally, providing detailed descriptions of the seizures will be helpful. Asking other witnesses (teachers and caregivers) for further details is useful. Often a person who has had a seizure does not remember the seizure.*

*Seizure record charts are available from most epilepsy associations, or you could create your own chart.*

*In addition to 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 seizure triggers.*



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 a generalized seizure. The aura may sometimes be used as a warning signal to allow necessary precautions to avoid injury.

The **ictus** (from Latin meaning "stroke" or "attack") refers to the seizure itself.

The **postictal** period follows the seizure. A child may temporarily experience confusion (**postictal confusion**), weakness (**postictal paralysis**), or sleepiness (**postictal state**).

**In the 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 child's behaviour before, during, or after the seizure.

### Before the seizure:

- What was your child 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 your child 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 your child experience an aura?
- Was there unusual or involuntary body movement? What part of the body moved first? Next?
- Was your child responsive during the seizure?
- Did your child experience automatisms (e.g., lip-smacking, chewing movements, rapid blinking,

head-turning, pulling at clothing, random wandering)?

- Did your child appear to be daydreaming?
- Did your child stare blankly?
- Did your child's eyelids flutter or eyes roll?
- Did your child's body become rigid?
- Did your child cry out or yell?
- Was there jerking, and if so, did it occur more on one side?
- Did your child's skin change colour?
- Did your child's breathing change?
- Did your child fall?
- Did your child bite his or her tongue or lip?
- Did your child lose bowel or bladder control?

### After the seizure:

- Did your child 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

As diagnostic tests can be frightening; parents should prepare a child by providing information such as why the test is necessary, where it will take place, what will happen, and who will be involved. Children should be aware that sometimes the machinery used in taking x-rays or scans makes unfamiliar sounds such as the loud knocking heard during a magnetic resonance imaging (MRI) test. Bringing a favourite toy or book to the appointment may be helpful.

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

Neuroimaging tests are often used to provide pictures of the brain. Computed tomography (CT) and 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 may be 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 located too deeply in the brain to be recorded.

Diagnostic tests used in the diagnosis of epilepsy may include:

### **EEG (Electroencephalogram)**

An EEG is a painless, noninvasive test used to measure a person's brain wave pattern. The brain's electrical impulses 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, sleep deprivation, and photic stimulation are routinely used to reveal abnormalities in brain activity.

**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, school, or during sleep.

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

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

A CT scan is used to detect physical conditions in the brain that may be causing 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 is sometimes 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, abnormal blood vessels, or abnormal development. Magnetic fields instead of x-rays are used to produce precise two-dimensional 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 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 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 given to the patient. 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 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 2 separate injections. One is given during a seizure and 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)**

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 is the Treatment for Epilepsy?

In well over 50% of those with epilepsy, seizures are controlled with **monotherapy** (a single medication). In others, **polytherapy** is effective in controlling seizures.

Surgery is considered in up to 15% of individuals with intractable epilepsy.

Depending on the type of epilepsy, most children will outgrow their epilepsy and will be able to discontinue their anti-seizure medication under medical supervision. For others, excellent control of seizures may continue for years with regular use of anti-seizure medication. Other children will benefit from surgery or from a specialized approach combining medication with surgery to obtain optimal seizure control.

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

## *Anti-Seizure Medication*

Anti-seizure medication is the primary treatment for epilepsy. In most children with epilepsy, anti-seizure medication is effective in controlling seizures. Medication does not cure epilepsy, but it often reduces or even stops seizures from occurring by altering the activity of neurons in the brain. As many children who have a seizure do not have a second one, medication is not typically prescribed after one seizure.



## **Dosages**

Due to the way the bodies of children and adults process medications, it often takes a larger dose to control seizures in the average child than in the average adult. As children grow, changes in dosage may be required. Sometimes a doctor has to adjust dosages to establish optimum seizure control. Regular checkups are necessary.

## **Blood Levels of Anti-Seizure Medication**

Sometimes the doctor will order tests to measure the amount of anti-seizure medication in the blood. This is referred to as the blood level of the anti-seizure medication. Effective blood levels differ from person to person. Correct blood level is the one that controls the seizures without causing toxicity and adverse side effects.

## **Types of Anti-Seizure Medication**

Anti-seizure medication comes in the form of tablets, capsules, sprinkles, and syrups. In the treatment of status epilepticus, a rectal gel, a sublingual (under the tongue), or nasal preparation may be prescribed. There have been significant improvements in recent years, especially with respect to side effects.

## **Side Effects**

Some anti-seizure medication may produce mild or severe side effects. Side effects tend to be 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 (dose-related). They can include, drowsiness, loss of coordination, fatigue, headache, decreased appetite, nausea, drooling, tremor, weight gain or loss, double or blurred vision, dizziness, depression, and learning and behaviour problems; including hyperactivity, and impaired attention and memory. Sometimes dose-related side effects are cosmetic and include overgrowth of the gums, hair loss, or excessive hair growth.

## Anti-Seizure Medications

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

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

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

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

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

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

**Allergy-related** side effects are less common and may include skin rash or, in rare cases, reactions that affect the liver or bone marrow. A rash may be the first sign of an allergic reaction to a medication and should be reported promptly.

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

**Your physician or pharmacist should be consulted regarding ALL side effects.**

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

### Discontinuing Medication

Discontinuing anti-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 is a life threatening condition. Seizures are prolonged or occur one after another without full recovery between seizures).

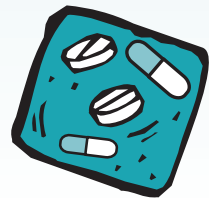
Reducing the prescribed dosage of anti-seizure medication can also result in problems such as diminished seizure control.

In most cases, if a child has been seizure-free for two years on anti-seizure medication, a doctor will recommend weaning the child off of the medication slowly. In well over 50% those children, medication can be discontinued and the child will have outgrown his or her epilepsy.

Some parents worry that children who take ongoing medication will become addicted or may have a greater chance of becoming drug abusers. There is no evidence of this.

## Anti-Seizure Medication Tips

- 1 Ensure that your child always takes anti-seizure medication as prescribed.** Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus.
- 2** It is sometimes recommended that if a single dose of anti-seizure medication is missed, the dose should be taken as soon as it is remembered. It is important to ask your doctor what you should do if your child forgets to take a single prescribed dose of medication.
- 3** Discuss the use of any other medications or vitamins with your doctor or pharmacist. Decongestants, acetylsalicylic acid products (ASA) such as Aspirin, and herbal medications can all interact with anti-seizure medication. Even some therapeutic drugs such as antidepressants and antibiotics could interact with your child's anti-seizure medication.
- 4** Avoid running out of medication by keeping a two-week supply.
- 5** Don't change from a brand name drug to a generic drug without first consulting your doctor or pharmacist. The use of different fillers, dyes, etc., can result in differences in processing by the body.
- 6** Children should wear a medical identification bracelet.
- 7** If medication must be taken during the day, contact the school regarding the handling of medication.
- 8** Keep medication out of reach of young children.
- 9** For older children, an alarm or a pill organizer may be helpful.
- 10** Some pharmacies will bubble pack medications, dividing them into doses for usage at the appropriate times of day. This may be helpful when the child is at a camp or sleepover.



## *Surgery*

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

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.

### **Focal Brain Resection**

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 and focal to bilaterally tonic-clonic seizures.

The removal of part of the temporal lobe is the most successful and most common type of epilepsy surgery and is called a **temporal lobectomy**. A temporal lobectomy offers the chance of a cure or a reduction in seizure frequency.

### **Hemispherectomy**

In rare cases, when severe brain disease results in one side of the brain no longer functioning, a hemispherectomy may be considered. This procedure removes half of the brain (a hemisphere) and is sometimes used for children with Rasmussen's Syndrome or other severe damage.

### **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 to 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. An advantage of this procedure is that it may be repeated if necessary. There are no serious adverse effects associated with this technique.



## Corpus Callosotomy

Corpus callosotomy is a surgical technique that involves disconnecting the two hemispheres of the brain. The corpus callosum is the tissue band that connects the two halves of the brain. The procedure is sometimes performed in children to prevent seizures from spreading from one hemisphere to the other. The surgery does not cure epilepsy, but the severing of the connections in the brain has been successful in reducing the frequency and severity of seizures in some children. For example, although a child will continue to experience focal seizures following the surgery, the procedure will stop the seizures from generalizing.

## Multiple Subpial Transection

Multiple subpial transections involve a series of cuts underneath the cerebral cortex to disconnect the neuronal pathways. The surgery has been used in treating focal seizures and Landau-Kleffner syndrome and has been successful in improving seizure control.

## Considering Surgery

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, cognitive abilities, disturbances in sensation, vision, or speech may result. With the arrival of stereotactic MRI guided laser ablation methods, complications are becoming much less.

When successful, however, surgery can be very effective in improving seizure control.

### *Questions to Ask Before Your Child Has Surgery...*

- Why is surgery being considered?
- What are the alternatives?
- What are the risks?
- What are the benefits?

## *Vagus Nerve Stimulation*

Vagus Nerve Stimulation (VNS) is a surgical therapy that involves the implanting 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 being used in patients who do not respond to medication and are not suitable for epilepsy-related surgery.

## *Ketogenic Diet*

A ketogenic diet has been used in the treatment of difficult-to-control epilepsy in children. The diet is high in fats, low in carbohydrates, with controlled proteins, and may be used in the treatment of various seizure types. It is used in conjunction with anti-seizure medication. The ketogenic diet is used most often in children.

The diet can be difficult for some children to maintain as only a limited range of foods is acceptable, and slight variations can result in changes in seizure control. Teenagers may find the diet particularly difficult to maintain due to peer pressure, lifestyle, food preferences, etc.

In general, any diet management should be discussed with caregivers and health care providers.

## Complementary Therapies

There is little scientific support for complementary therapies, but there are people who have found them helpful.

For example, some people have found that tools such as mental imagery, aromatherapy, or relaxation techniques have enabled them to prevent or delay seizures. Other individuals have found yoga, massage therapy, biofeedback, magnetic stimulation, or art, music or pet therapy to be helpful. Some have found herbal remedies and vitamin therapy effective.

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

For more information on these therapies, contact your local epilepsy association.

## Choosing A Doctor

**Developing a positive relationship with your child's doctor is an important part of your child's treatment.** Both you and your child should have confidence in the doctor.

Often a family doctor or pediatrician will refer a child to a neurologist or pediatric neurologist. The neurologist may refer the child back to the family doctor or pediatrician for ongoing therapy. In some centers, a patient may be referred to an epileptologist who is a neurologist with specialized training in epilepsy.



Prepare for medical appointments by taking a list of questions to ensure your concerns will be addressed. Taking a record of your child's seizures is also important.

# H How Can Parents Help?

## *Learn About Epilepsy*

When a child is diagnosed with epilepsy, parents react with a range of emotions, including anger, fear, grief, and denial. Parents may know very little about the condition and may feel confused and helpless. Learning about epilepsy can empower you and help you to make decisions with respect to care and safety.



Your local epilepsy association is a valuable resource. Associations often have libraries with resource material on epilepsy, and a staff committed to answering questions and providing helpful information. Associations may also assist in linking you with counselling services, support groups, or other parents experiencing similar challenges.

## *Encourage and Support Your Child*

### Feelings

Be straightforward about epilepsy with your child. A diagnosis of epilepsy may result in your child experiencing low self-esteem, anxiety, anger, or a feeling of powerlessness. Encourage openness and discuss these reactions with your child to build your child's self esteem.

Depression may occur in people with epilepsy. Depression may be a side effect of medication, or it may form part of the epilepsy itself. Depression may also be a reaction to the insensitivity of others or of living with the constant fear of having an unprovoked seizure.

Even if seizures are controlled by medication, children may be concerned about having a seizure when in front of others. They may be reluctant to take medication in public. It is difficult for some children (and some parents) to accept the diagnosis.

Talking with your child about his or her feelings is important. If the depression persists, medical advice may be necessary.

### **Developing Independence**

Being overprotective can hinder your child's emotional development. If a child learns to be fearful or is continually restricted, he or she may develop a dependency that will continue into adulthood. By encouraging your child to view seizures as a temporary inconvenience and encouraging participation in activities, you help your child to develop the confidence to become an independent adult.

### **Sharing with Others**

Depending on the type and frequency of your child's seizures, it may be important to inform others about your child's condition.

Informing caregivers, teachers, or neighbours who are responsible for your child is recommended, as it is essential that they know how to help should your child have a seizure.

Other people who often spend time with your child should also be told.

## Tips on Sharing

If your child has uncontrolled seizures, providing information to others may be important. You may want to:

- Describe any seizure triggers and/or indicators that a child may soon have a seizure.
- Describe a typical seizure, including its usual length.
- Explain what behaviour or symptoms would be considered a medical emergency and how to respond.
- Ask the individual to provide you with a detailed description of any seizures which do not follow the typical pattern which is typical for that child.

## *Develop A Positive Family Environment*

Discuss epilepsy with members of the family. Siblings may have fears such as whether or not they will get epilepsy, or they may feel jealous or resentful because of the extra time or attention given to the child with epilepsy. These concerns should be addressed and discussed openly.

Treating the child with epilepsy the same as other members of the family with respect to responsibilities, may be helpful in creating a positive family environment. Siblings should not be expected to be constant caregivers of a child with epilepsy, but they should know what to do should a seizure occur.

## *I Is There Financial Support Available for Families of a Child with Epilepsy?*

Funding for family support and disability-related services may be available through provincial programs. Many provinces provide information and referrals as well as a range of individualized supports and services to assist families with some of the extraordinary costs and care related to their child's disability.

If eligible for the program, a child with a disability and his or her family may receive family support services and/or funding for other individualized services, based on the family's unique needs. For information on available financial support, contact your local epilepsy association.

## *Create A Safe Environment*

### Your Home

Adapting the child's environment to make it safe is important. There is an increased risk of injury in people with epilepsy.

Depending on the type of seizures experienced by your child, carpeting the floors, padding sharp corners on tables and other furniture may be helpful.

Safety in the child's bedroom could include avoiding top bunks and placing a monitor in the child's room.

Discuss household safety with your child. For example, baths can be hazardous for anyone with epilepsy. Showers are safer than baths for those with epilepsy, but injuries can still occur. Special safety taps are available.

Young children should be supervised while bathing. Older children should not lock bathroom doors and should never bathe or shower when home alone. If your child experiences falls during a seizure, a shower seat with a safety strap should be considered.

Stoves and other hot surfaces can also be hazardous for those with epilepsy. It may be necessary to encourage your child to use a microwave oven while cooking alone.

Detailed lists of safety tips and information on safety devices are available from most epilepsy associations.

### Safety Aids and Tips

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 just a few examples.



Everybody who spends time with the child should be familiar with the first aid procedures in case of a seizure.

## **Seizure Triggers**

Monitoring and identifying seizure triggers is an important part of creating a safe environment for your child. Assuring that your child takes anti-seizure medication as prescribed, gets plenty of sleep, and manages stress levels may all help in controlling seizures. Eating regularly and maintaining a well-balanced and nutritious diet are also important. A poor and irregular diet can affect medication levels.

### **Common Seizure Triggers in Children**

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 child's seizure triggers so that seizures can be avoided. Some common seizure triggers in children include:

- Forgetting to take prescribed anti-seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Illness or fever
- Low anti-seizure medication blood levels
- Flickering lights or strobing lights

# *Be Involved In Your Child's School Experience*

## **Learning**

Children with epilepsy have the same range of intelligence as other children.

Children with epilepsy do, however, have a higher rate of learning problems and difficulty in school than others. This may be influenced by many factors, including the side effects of medication, the child's anxiety, teacher's attitudes, the underlying neurological cause of the epilepsy, and the seizures themselves.

- **Medication**

Anti-seizure medication can affect learning. Some medications have side effects that result in hyperactivity or interfere with concentration or memory.

- **Anxiety**

The unpredictability of seizures could result in anxiety and insecurity in children. This may affect initiative and independence in the classroom.

- **Teachers' attitudes**

While effective teachers may employ strategies to accommodate and encourage your child in the classroom; there are occasionally teachers who assume that a child with epilepsy has lower potential than other students. As a result, the teacher may influence the child's academic development because of reduced expectations.

- **Neurological causes**

In some cases, the underlying neurologic problem causing epilepsy may also result in learning problems.

- **Seizures**

Seizures may affect learning. For example, children experiencing absence seizures throughout the day will have their learning experience continually disrupted. Memory can also be affected by seizures.

## **Communicating With the School**

Open communication is important. If necessary, the school should have the relevant medical and treatment information in case of a seizure.

## **Social Interaction**

Sometimes children face ridicule, teasing, or prejudice from schoolmates. Peers may not understand the condition, and can be unkind. There are excellent Kids on the Block presentations available to students and staff. Talk to your local association for more information about this resource.

## **Helping Others to Understand**

Consider arranging in-service training for your school through your epilepsy association. This will provide staff and students with information regarding the condition. Many epilepsy associations have trained staff members who will visit schools and talk about epilepsy in order to educate others.

Some epilepsy associations offer an educational puppet program called **The Kids on the Block (KOB)**, which uses colourful puppets to teach about epilepsy. A puppet troupe may be available to visit your child's school and present an entertaining production.

## **School Accommodations**

In many cases, a regular classroom is considered the appropriate placement for a child with special needs because of the increased opportunities to participate with peers. In cases where a student has complex or severe learning and/or behavioural needs, other placements may be considered.

A student is entitled to have access to a special education program when necessary.

In finding the best placement, parents should consider what environment best meets the overall educational needs of their child as well as what is best for the other students.

If a parent disagrees with a decision by educators or the local school board on issues such as identification, evaluation, placement, or programs, a dispute resolution process and formal appeal procedure may be necessary. For information regarding children with special education needs, contact your local epilepsy association or special education branch.

## **Your Expectations**

If your child does experience learning setbacks or problems, try not to allow your expectations to create stress or feelings of failure in your child. Your child's self-esteem and motivation could be negatively affected by unrealistic expectations. Try to focus on your child's potential rather than on his or her limitations.

## *Allow Participation in Social Activities, Recreation, and Sports*

Children with epilepsy should be encouraged to participate in social and recreational activities and sports. Socializing with other children builds self-esteem. Recreational activities and sports enhance well-being and maintain health. There is some evidence that regular exercise may improve seizure control.

Tennis, basketball, volleyball, track and field, baseball, jogging, hiking, golfing, and cross-country skiing are just a few of the activities children enjoy. It is uncommon for children with epilepsy to have seizures during physical activity. Summer day camps or overnight camps may offer your child the opportunity to develop confidence and self-esteem.

Some forms of recreation require extra caution. For instance, if a child has uncontrolled seizures, 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.



Some sports or recreational activities pose risks for those with epilepsy and participation should be dependent on a doctor's recommendation.

Sports that involve body contact, such as hockey, soccer, and football or impact sports such as boxing and karate pose extra risks due to the potential for head injury. Some activities, such as scuba diving, rock climbing, and parachuting, are not advised for people with epilepsy. The use of appropriate safety gear (e.g. helmets, flotation devices, etc.) is important. Anybody with epilepsy should avoid low blood sugar, dehydration, or overexertion, which increases the risk of seizures.

Lifeguards, coaches, counsellors, etc. should be informed about your child's condition, anti-seizure medications, and how to respond should a seizure occur.

## *Help Teenagers to Make Wise Decisions*

### Support

The teenage years are times of dramatic change in a young person's life. As teenagers undergo physical changes and become increasingly independent, they face new challenges, including those associated with added responsibility, peer pressure, dating, driving, and plans for the future. A teenager with epilepsy has the additional stress of medication side effects and the unpredictability of seizures.

Offering your teenager continual emotional support and trying to keep the doors of communication open will help your teenager through a typically emotional stage of life. Continuing to focus on your child's achievements and potential rather than on his or her limitations will encourage confidence.

It is particularly important for teenagers with epilepsy to accept their condition as a reality in their daily lives. As they become more independent, they should be encouraged to take responsibility for their medications and other factors, such as monitoring seizure triggers.

## Relationships

Sometimes people treat those with epilepsy with unkindness or avoidance out of ignorance. It is important for parents to recognize how difficult this can be for teenagers who typically want to be accepted by their peers.

The decision involving who should be told about the condition is one you should make together with your teenaged son or daughter. While it may not be necessary for a teenager to discuss his or her condition with everyone, it is important for individuals who are with your son or daughter often to know how to help them if a seizure occurs.

## Sexual Activity and Pregnancy

Your teenager may also be concerned if having epilepsy affects sexual activity. Only in rare cases does sex 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. A teenager may want to discuss this with the doctor. A change in medication or other treatments may help.

Some medications 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 higher risk that having epilepsy or taking anti-seizure medication will affect the fetus.

If your daughter is taking birth control pills, and planning to become pregnant, or is pregnant, it is essential that she consult her doctor. Changes in medication levels of prescribed drugs may be required. Folic acid prevents some birth defects and is recommended for all women of childbearing age.

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

## Driving

If a person has uncontrolled seizures, there are restrictions to driving. Driving is generally not allowed until a person has been seizure-free for at least 6 to 12 months and is under a doctor's care. A shorter period may be considered upon a favourable recommendation from a neurologist. If seizures reoccur, the doctor should be contacted.

Each province and territory has its own regulations. For detailed information on driving standards in each province or territory contact the appropriate provincial or territorial regulatory agency.

There are standards that apply specifically to epilepsy surgery, nocturnal epilepsy, withdrawal from or changes in medication in collaboration with a physician, auras, etc.

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

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



## Employment

Jobs available to teenagers often involve schedules that can lead to a lack of sleep. A job can also add stress to an already demanding school schedule. Lack of sleep and too much stress are both recognized seizure triggers.

When a teenager is considering long-term career options, choices should be researched. Although the options are many, there are restrictions in certain careers (e.g., bus drivers, pilots) for safety reasons.

In many cases, having epilepsy has little or no effect on pursuing a rewarding career. In other 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.

## *Discrimination*

People are becoming more knowledgeable about epilepsy, but teenagers with epilepsy may face discrimination based on a lack of knowledge about the condition by an employer.

An employer may be biased because of a lack of knowledge about the condition or may have concerns over safety, reliability, or liability. Persons with physical disabilities are protected under human rights legislation. The Canadian Human Rights Act does not allow discrimination by an employer due to a disability such as epilepsy. Each province and territory has its own legislation. Under Canadian human rights law, however, it is not considered discriminatory if an act taken by an employer is considered to be reasonable and justifiable under the circumstances. For example, employers are not expected to hire or continue to employ a person whose disability notably increases the probability of health or safety hazards.

It is the responsibility of the employer to demonstrate that the person's disability would threaten his or her safety or the safety of others.

If your son or daughter has experienced discrimination in the workplace because of epilepsy, a complaint can be filed with the Human Rights Commission in the appropriate province or territory.

### *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 some provincial codes, it is the employer's duty 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, working in pairs, or trading work duties with another employee.

### *Applying for a Job*

In some provinces, legislation restricts pre-employment inquiries. How, when or whether you disclose your epilepsy to an employer is a personal choice. 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.

To find out more about the advantages and disadvantages of disclosure employment, contact your local epilepsy association.



## *Alcohol and Drugs*

Alcohol can lower the seizure threshold and the blood levels of anti-seizure medication. Some doctors recommend that people whose seizures are not fully controlled should abstain from alcohol consumption. If a person chooses to consume alcohol, it is essential that he or she continues to take anti-seizure medication as prescribed.

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

## **Smoking**

Smoking can be very hazardous when a person's seizures are not controlled.

## Seizure Triggers in Teenagers

Some seizure triggers in teenagers include:

- **Forgetting to take prescribed anti-seizure medication**
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Menstrual cycle/hormonal changes
- Illness or fever
- Low anti-seizure medication levels
- Medications other than prescribed anti-seizure medication
- Flickering lights or strobing lighting (e.g., in bars and nightclubs) in those with photosensitive epilepsy (e.g., screens, light reflecting off of water)
- Excessive alcohol consumption and subsequent withdrawal
- Street drugs

### Menstruation

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

Your daughter can track her periods on a seizure record chart. This will help the doctor to determine if menstruation is a seizure trigger.

## *Teach Others About Epilepsy*

The public is not well informed about epilepsy in general. A lack of public awareness and inaccurate depictions in public media result in incorrect generalizations and assumptions.

Sometimes seizures are mistaken for intentional behaviour. Attitudes are changing through public education, but slowly.

Epilepsy organizations worldwide are working hard to educate the public and to take epilepsy out of the shadows.

Medical diagnosis and the treatment of childhood epilepsy continues to undergo significant advances. Research is continuing to develop a better understanding of epilepsy.

By sharing information on epilepsy, you will both help people to better understand the condition and increase awareness on how to help in case of a seizure.

# First Aid for Seizures

## What to Do if Someone has a NonConvulsive Seizure (staring blankly, confused, not responding, movements are purposeless)

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

## What to do if Someone has a Convulsive Seizure (characterized by stiffening, falling, jerking)

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



## Status Epilepticus

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

## Calling An Ambulance

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



### CALL AN AMBULANCE:

- If a convulsive seizure lasts longer than 5 minutes.
- If consciousness or regular breathing does not return after the seizure has ended.
- If seizure repeats without full recovery between seizures.
- If confusion after a seizure persists for more than 1 hour.
- If a seizure occurs in water and there is any chance that the person has inhaled water. Inhaling water can cause heart or lung complications.
- If it is a first-time seizure, or the person is injured, pregnant, or has diabetes. A person with diabetes may experience a seizure as a result of extremely high or low blood sugar levels.

# E *Epilepsy Education Series*

---

## A BRIEF GUIDE INTRODUCING THE NEW CLASSIFICATION OF EPILEPSY

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

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

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

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

The most recent classification with which most of us are familiar was drawn up 28 years 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

---

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.

## 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)

© Edmonton Epilepsy Association, 2020

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

Canadian  
**epilepsy**  
Alliance

Alliance  
canadienne de  
**l'épilepsie**

Canadian League  
Against Epilepsy



La Ligue  
Canadienne  
Contre l'Épilepsie

**1-866-EPILEPSY**

[info@canadianepilepsyalliance.org](mailto:info@canadianepilepsyalliance.org)

[www.canadianepilepsyalliance.org](http://www.canadianepilepsyalliance.org)

**905-415-3917**

[info@claegroup.org](mailto:info@claegroup.org)

[www.claegroup.org](http://www.claegroup.org)



This Epilepsy Booklet Series is a project by the  
**Edmonton Epilepsy Association**

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

11215 Groat Road Edmonton, Alberta T5M 3K2

Phone: 780-488-9600

Toll Free: 1-866-374-5377 Fax: 780-447-5486

[info@edmontonepilepsy.org](mailto:info@edmontonepilepsy.org)



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

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