

**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, 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.

---



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

*Inspirés par les **patients**. Guidés par la **science**.*

**Free Canada-wide distribution of this publication  
was made possible by an unrestricted Grant from  
UCB Canada Inc.**

# *Index*

---

<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>What are Epilepsies and 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>34</b>
<b>Learn About Epilepsy</b>	<b>34</b>
<b>Encourage and Support Your Child</b>	<b>34</b>
<b>Develop a Positive Family Environment</b>	<b>37</b>
<b>Create a Safe Environment</b>	<b>38</b>
<b>Be Involved in Your Child's School Experience</b>	<b>40</b>
<b>Allow Participation</b>	<b>43</b>
<b>Help Teenagers to Make Wise Decisions</b>	<b>44</b>
<b>Teach Others About Epilepsy</b>	<b>51</b>
<b>First Aid for Seizures</b>	<b>52</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-services to schools in order to teach others about the condition. Associations may also be able to link you with support groups, trained professionals, or other parents 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 both the child and the family.

In either situation, learning about epilepsy can empower you and help you to make informed decisions regarding issues such as 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.

# What is Epilepsy?

---

***Epilepsy is a condition of the brain that is characterized by recurrent seizures.*** The brain is made up of billions of nerve cells or neurons that communicate through electrical and chemical signals. When there is a sudden excessive electrical discharge that disrupts the normal activity of the nerve cells, a change in the person's behavior or function may result. This abnormal activity in the brain that results in a change in the person's behavior or function is a seizure. 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.*** They happen for a variety of reasons. A seizure may occur as the result of a high fever or of an illness that affects the brain. A single seizure is not epilepsy. Approximately one in ten Canadians will experience at least one seizure during a lifetime. Many do not have epilepsy. In those children who have a single seizure, only a small percentage have a second one. Epilepsy is a condition that is defined by multiple seizures.

***Seizures involve 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 child may be seizure free. In well over half of those with epilepsy, seizures can be well controlled with seizure medication.

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

***Epilepsy that begins in childhood is often outgrown.*** The frequency of seizures in childhood may be partly due to the low seizure threshold of some children. A seizure threshold is the level at which the brain will have a seizure and the seizure threshold generally rises as the brain matures. This may partly explain why children with epilepsy often outgrow the condition.

# What are the signs of Childhood Seizures?

Seizures take many different forms. 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 behavior in a child. What is important to watch for is a pattern of behavior that happens too often to be by chance.

## Signs that may indicate that a child is having 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 from a sleep
- 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 reason

# What Causes Epilepsy and 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 defined 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 identifiable 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

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

## **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.

**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**

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.



# 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. 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, a child remains aware. A simple partial seizure may involve sensory, motor, psychic, or autonomic symptoms. 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, or it may be sudden jerky movements of one area of the body such as the arm, leg, or face. For instance, the child may suddenly smell burning rubber when it is nonexistent 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 during which the child has the sensation of having experienced something before.

A simple partial 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. The aura can sometimes be used as a warning signal to allow the child to take the necessary precautions to avoid injury.

### **Complex Partial**

(formerly called psychomotor or temporal lobe)

During a complex partial seizure, the child experiences altered awareness and 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 other cases, the child will lose contact.

The seizure often begins with an unusual sensation, feeling, or movement known as an aura. An aura can take many different 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 child 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 at inappropriate times.

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

This type of seizure results in a blank stare usually lasting less than 10 seconds. There is impaired awareness 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.

Although an absence seizure lasts for seconds, 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 could interfere with learning. Rapid blinking or chewing movements 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 many 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.**

Although absence seizures are often outgrown, some people with absence seizures develop tonic clonic seizures. 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 may involve more pronounced movement or automatisms such as falls or movement. These seizures often occur with other types of seizures and they occur more commonly in children who have damage to the nervous system.

## Tonic Clonic

(formerly called grand mal)

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 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 bluish color 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 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 child may experience a severe headache. Often the child 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).

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

## **Atonic**

An atonic seizure is sometimes called a “drop attack” because it often results in a child suddenly falling to the ground. The seizure involves a sudden loss of muscle tone that may cause the child to fall or almost fall, to drop an object he or she is holding, or to 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 with Lennox-Gastaut syndrome.

## **Myoclonic**

A myoclonic seizure results in a sudden jerk of part of the body such as the arm or leg. The abrupt jerk of a muscle group may result in a foot suddenly kicking or in a child being thrown to the ground. 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 non-convulsive. **Immediate medical care is necessary.**



Status epilepticus is more common in young children and in seniors than in others with epilepsy. If your child has experienced a state of status epilepticus, get medical advice regarding the necessary procedure should another episode occur.

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

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

# W What are Epilepsies and Epilepsy Syndromes?

As well as the different types of seizures, there are also different types of epilepsy. Types of epilepsy are classified as epilepsies and epilepsy syndromes. This classification system is based on patterns of features common to a type of epilepsy.

For example, children with epilepsy sometimes experience similarities in terms of the age of onset, seizure type, EEG results, response to treatment, and future 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 (or probable outcome of the condition) and in finding the appropriate treatment. While in many cases epilepsy syndromes cannot be identified, epilepsy syndromes 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 three and are usually outgrown at adolescence. The seizures tend to be infrequent and mild. Seizures often start with a sensation such as tingling or twitching at the corner of the mouth. A jerking of that corner may follow and that 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 an inability to speak or in drooling. The seizures most often occur at night or upon awakening. This type of epilepsy is often not treated with medication.

## 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 five to fifty 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 awakening, is sleepy, or is going to sleep. Often the child experiences developmental delay and cognitive problems. A child with infantile spasms may later develop Lennox-Gastaut syndrome.

## Juvenile Myoclonic Epilepsy (JME)

Juvenile myoclonic epilepsy 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. Although JME can generally be controlled with medication, it is not likely to be outgrown. If medication is discontinued, most individuals experience a relapse. JME is an inherited condition.



## **Landau-Kleffner Syndrome**

This epilepsy syndrome is rare and generally begins in young children under the age of six. 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 relapse in speech development. Convulsive and non-convulsive seizures may occur although epilepsy-related seizures are often 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 partial 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 hemispherectomy surgery may stabilize the condition.

## 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 speed and brightness (e.g. from televisions, computer screens, strobe lights, video games, movies) can trigger a seizure. Sometimes natural light patterns such as sunlight reflecting off of water can trigger seizures. Seizures are most often tonic clonic.



Treatment includes avoiding the stimulation or, if the child's epilepsy is severe, medication may be prescribed. 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 such as those in escalators or certain wallpaper designs have been known to trigger seizures.

Rarely, reflex epilepsy will occur with non-visual 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 five. 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 one. Febrile seizures tend to occur in families.

These seizures are tonic clonic and a young child who has experienced a seizure with a fever should be seen by a doctor. Long-term 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 an abnormal preexisting neurologic disorder (e.g. cerebral palsy) or the child's development has been delayed before the seizure.

## *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 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.

Certain epilepsies and epilepsy syndromes are associated with impairment of cognitive development. Some epilepsy syndromes such as Benign Rolandic Epilepsy are referred to as benign. This means that impairment of development or cognitive function is not associated with these types of epilepsy. Other syndromes such as West Syndrome and Lennox-Gastaut are known as progressive because seizures and/or the individual's motor or cognitive abilities can worsen over time.

Developmental delay means that the process of physical growth and the development of intelligence and the ability to problem solve are interrupted. If both seizures and developmental delay occur, there is an underlying problem in the brain contributing to both. Although epilepsy is associated with other disorders such as cerebral palsy, epilepsy is just one of a set of symptoms commonly found in people with this disorder.

# 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.

For example, a high fever resulting in a febrile seizure or very low blood sugar could result in a seizure.

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 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 a child is having is valuable in both the diagnosis and the prescribing of the appropriate 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 assist the doctor. Asking others who were with your child during a seizure (e.g. teachers or caregivers) for detailed descriptions 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 use a notebook or create your own chart.*

*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.*



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

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

The **ictus** 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 behavior before, during, or after the seizure such as:

### **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, strobe lights, etc., recent illness, drug or alcohol abuse, missed medication, missed meals)?
- Did your child 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 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 walking)?

- 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 on one side of your child's body more than on the other?
- Did your child's skin change color?
- 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 for a child, 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 quiet toys and favorite books 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 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 school, 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, abnormal blood vessels, or abnormal development. 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 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 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.

# 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, most children 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 children 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. In most children with epilepsy, seizure medication is effective in controlling seizures. Medicine 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 had a first 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 medicines, it often takes a larger dose to control seizures in the average child than it does in the average adult. As children grow, changes in medication dosages may be required. Sometimes a doctor has to adjust dosages to establish optimum seizure control. Regular checkups are necessary.

## Blood Levels of Seizure Medication

Sometimes the doctor will order tests to measure the amount of seizure medication in the blood. This is referred to as the blood level of the seizure medication. As correct blood levels differ from person to person, the correct blood level is considered to be one that controls the seizures without causing toxicity and adverse side effects.

## Types of Seizure Medication

There are many different seizure medications due to the many types of epilepsy and seizures. Seizure medication comes in the form of tablets, capsules, sprinkles, and syrups. In the treatment of status epilepticus, a rectal gel or a sublingual (under the tongue) preparation may be prescribed. There have been significant improvements in seizure medication in recent years.

## Side Effects

Some seizure medicine 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, depression, and even learning and behavior problems including hyperactivity and impaired

## 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 (Diastat) as a rectal gel
- diazepam (Valium) in a rectal injectable solution
- midazolam
- phenobarbital
- phenytoin (Dilantin)

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, in rare cases, reactions that may affect the liver or bone marrow. Skin rash may often be the first sign of an allergic reaction to a drug. If a child develops skin rash while taking seizure medication, a doctor should be consulted 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.

*Physicians should be consulted regarding side effects.* Even if the side effects are cosmetic and are causing the child unhappiness, discuss the changes with your child's doctor.

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

## Discontinuing Medication

Discontinuing 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.

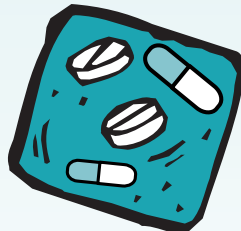
In most cases, if a child has been seizure free for two years on seizure medication, a doctor will recommend weaning the child off of the medication slowly. In well over half of those children, medication can be discontinued and the child will have outgrown his or her epilepsy.

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.

## Seizure Medication Tips

- 1 Assure that your child always takes 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 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 seizure medication. Even some therapeutic drugs such as antidepressants and antibiotics could interact with your child's 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. 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, a watch with a timer and a weekly pillbox 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*. This means that they do not respond to medical treatment such as the use of seizure medicine. 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 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.

### Hemispherectomy

In rare cases in which 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 to one brain hemisphere.

More recently this procedure has involved removing only a small portion of the brain or disconnecting one hemisphere from the rest of the brain. This surgery may improve seizure control.

In some cases, a child may become seizure free and development may improve. This surgery is rarely performed in children over 12 years of age, as chance of a full recovery is best in young children.



## Corpus Callosotomy

Corpus callosotomy is a surgical technique that involves cutting the corpus callosum to disconnect the two hemispheres in the brain. The corpus callosum is the tissue band that connects the two sides of the brain. The procedure is sometimes performed in children to prevent seizures from spreading from one hemisphere to the other and becoming generalized. 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 partial seizures following the surgery, the procedure will stop the seizures from generalizing and becoming atonic or tonic clonic seizures.

## 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 partial 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 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.

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

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

## *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.

The VNS has proven effective in both adults and children. In some cases, the device has been used successfully even in children as young as one year of age.

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 child 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 try to stop the seizure or reduce its intensity or how long it continues.

Individuals using the device should ask their doctor how long the battery lasts 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.

## *Ketogenic Diet*

A ketogenic diet has been used in the treatment of difficult-to-control epilepsy in children. The diet is high in fats and low in protein and carbohydrates and may be used in the treatment of various seizure types including myoclonic and atonic seizures. It is used in conjunction with seizure medication. The ketogenic diet is used most often in children but it has also been used to treat teenagers and adults.

The diet consists of a high intake of foods rich in fat such as butter, cream, and mayonnaise, and a strictly reduced intake of foods high in protein and in carbohydrates. The ratio is usually four parts fat to one part protein and carbohydrate. A chemical change called ketosis is created in the body. Ketosis results in a breaking down of fats instead of carbohydrates. This creates a metabolic state that inhibits seizures in some children.

The diet requires medical supervision and strict adherence. The diet could be dangerous for a child if it is not managed properly. As the diet does not provide all of the necessary vitamins and minerals for health, nutritional supplements are generally required. Use of these supplements must be monitored by a doctor.

The diet can be difficult for some children to maintain as only a limited range of foods is acceptable and even 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.

Side effects may include low blood sugar, kidney stones, and calcium loss. 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.

Often if a child has responded positively to the diet, a doctor will try gradually taking the child off the diet after two years.

## *Complementary Therapies*

Some people have found complementary therapies to be helpful in seizure control. Although there are generally not scientific studies to prove that these methods are effective, 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.

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 who specializes in the area of medicine relating to the nervous system and its disorders. The neurologist may refer the child back to the family doctor or pediatrician for ongoing therapy. In cases involving teenagers, parents may want to consider working with a neurologist who treats adults. In some centers, a patient may be referred to an epileptologist who is a neurologist with specialized training in epilepsy.



Being prepared for medical appointments and taking a list of questions will help in assuring that your concerns are addressed. Taking a record of your child's seizures is also important.

Occasionally, parents feel that they are not getting the treatment they would like for their child. In these cases, requesting a second opinion may be valuable.

# H How Can Parents Help?

## *Learn About Epilepsy*

When a child is diagnosed with epilepsy, parents sometimes react with a range of emotions including anger, fear, or grief. 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 regarding issues such as medical treatment, care, and safety.



Your local epilepsy association is an invaluable resource. Associations often have libraries with resource material on epilepsy and a staff committed to answering questions and providing helpful information. Associations may also be able to assist in linking you with counseling services, support groups, or with 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. In some cases, a child may even develop a fear of dying. Encouraging openness and discussing these reactions with your child may help to build your child's self-esteem. By assuring that your child knows that the seizures are not anyone's fault and that it is extremely rare for a child to die of epilepsy, parents may also help to alleviate some of the child's concerns.

There is an increased risk of depression in people with epilepsy. Depression may be a side effect of medication, or it may occur just before, just after, or between seizures. Depression may also be a reaction to the insensitivity of others or of living with the constant fear of having a seizure.

Even if seizures are being effectively controlled by medication, children may be concerned about having a seizure in public. Children are often afraid of being different. They may be reluctant to take medication while with others.

Explaining to your child that other children may also have conditions (e.g. food allergies or asthma) that could require medication and/or lifestyle changes may help your child to understand.

Talking with your child about his or her feelings is important. If depression is ongoing, or is hindering your child's enjoyment of life, discuss this with your child's doctor.

### **Developing Independence**

Being too overprotective can hinder your child's emotional development. If a child learns to be fearful or is continually being restricted, he or she may develop a dependency that will continue into adulthood. By encouraging a child to view seizures as a temporary inconvenience and, by encouraging participation in activities, you may 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 neighbors who are responsible for your child is advised, as it is essential that they know how to help should your child have a seizure.

People who are often with your child such as relatives, good friends, and their parents should also be told.

Sharing with others should be discussed with older children and adolescents and they should be allowed to be involved in decisions regarding who should be told and how.

As with any child, try not to use labels when talking about your child (e.g. epileptic). Your child has epilepsy but the condition is only one facet of your child's life.

### Tips on Sharing

If your child has uncontrolled seizures, then 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 behavior or symptoms would be considered a medical emergency and how to respond.
- Ask the individual to provide you with a detailed description of the seizure especially if the seizure does not take its regular form.



## *Develop A Positive Family Environment*

Discuss epilepsy with the members of your 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.

Treating the child with epilepsy like 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.

In some families, older relatives misunderstand the condition partly due to historical misconceptions. Sharing information on the condition with family members will help them to better understand epilepsy.

### *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 referral 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 and positive 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 and 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.

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 irons can also be hazardous for those with epilepsy. Encouraging your child to use a microwave oven if cooking while alone may be necessary.

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 a few.

First aid procedures should be readily accessible in your home and at the child's school. Always provide information to babysitters and others who will be caring for your child, so they know how to help should your child have a seizure.

## **Seizure Triggers**

Monitoring seizure triggers is an important part of creating a safe environment for your child. Assuring that your child takes 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 seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, emotional upset
- Illness or fever
- Low seizure medication levels
- Flickering lights of computers, television, videos, etc. in those with photosensitive epilepsy

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

## Learning

Children with epilepsy have the same range of intelligence as other children and often epilepsy itself has no effect on intelligence or ability.

Children with epilepsy do, however, have a higher rate of learning problems and difficulty in school than those without the condition. This may be influenced by many factors including the side effects of medication, the child's anxiety, the teacher's attitude, the underlying neurological cause of the epilepsy, and/or the seizures themselves.

- **Medication**

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 a 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. For example, if the condition results in problems in the association areas of the brain, letter recognition or the recollection of word meaning could be affected resulting in poor school performance.

- **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 following complex partial seizures or tonic clonic seizures. This could result in learning challenges.

### **Communicating with Teachers and Staff**

Each year meet with your child's teachers. Discuss the academic and social impact that epilepsy may have on your child and inform the teachers on how to help your child should he or she have a seizure. Assure that the school has a medical record on file with important information regarding doctors, medications, seizure descriptions, allergies, other medical conditions, and first aid instructions.

### **Social Interaction**

Sometimes children face ridicule, teasing, or prejudice from schoolmates. Peers may not understand the condition and children can sometimes be unkind. If your child is having this experience, then discuss his or her concerns and talk about options on how your child could cope with the reactions of others.

### **Helping Others to Understand**

Consider arranging an in-service for your local 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 life-sized colorful puppets to teach the students and staff about epilepsy. A puppet troupe may be available to visit your child's school and present an entertaining production.

## **School Act**

Find out about the education policies in your area in order to find the best school placement for your child.

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 of the same age. In cases where a student has complex or severe learning and/or behavioral needs, other placements may be considered.

In most provinces, a student is entitled to have access to a special education program if it is considered 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 all of the students in the classroom and the school.

If a parent disagrees with a decision by school staff 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 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.

When deciding which recreational activities and sports are appropriate for your child, parents may want to match activities with their child's degree of seizure control.

Tennis, basketball, volleyball, track and field, baseball, jogging, hiking, golfing, and cross-country skiing are just a few of the activities for children with epilepsy to enjoy. 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. Bicycling and horse back riding could pose risks. Some activities such as scuba diving, rock climbing, and parachuting are not advised for people with epilepsy as they are considered to be too dangerous. Use of appropriate safety gear (e.g. helmets, flotation devices, etc.) and avoidance of related problems such as low blood sugar, dehydration, or overexertion which could increase the risk of seizures, are also important.

Lifeguards, coaches, counselors, etc. should be informed about your child's condition, 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. This may lead to an increased risk of poor self-esteem and depression.

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.

As with any teenager, maintaining appropriate restrictions and discipline are also important to effective parenting.

Overcompensating for your teenager or becoming too permissive because of his or her condition could lead to other issues.



As teenagers begin to seek control in their lives, encourage them to take more responsibility for behavior, for taking their medication, and for monitoring seizure triggers. This may help them to develop greater self-esteem and independence.

## **Relationships**

Sometimes people treat those with epilepsy with unkindness or avoidance out of a lack of knowledge about the condition. 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 may depend partially on the type and frequency of the seizures experienced by your son or daughter. While it may not be necessary for a teenager to discuss his or her condition with everyone, it may be important for individuals who are with your son or daughter often or who may be with them when they have a seizure, to know how to help them if a seizure occurs. Sometimes the decision on whom to tell may also be based on how close the teenager feels to the person.

## **Sexual Activity and Pregnancy**

Your teenager may also be concerned over whether having epilepsy affects sexual activity. 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. A teenager may want to discuss this with the 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 higher risk that having epilepsy or taking seizure medication will affect the fetus.

If your daughter is planning to use or is taking birth control pills, is planning to become pregnant, or is pregnant, it is essential that she consult her 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 overall risk of a child having unprovoked seizures is one to two percent in the general population and approximately six percent if a parent has epilepsy.

## Driving

Learning to drive is often a highlight for a teenager. 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 favorable neurologist's recommendation. 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, and auras, etc.

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

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

## Employment

Part-time jobs and consideration of future career options are also issues affecting teenagers.

Jobs available to teenagers often involve work hours that can lead to lack of sleep. A job can also add stress to an already demanding school schedule. A lack of sleep and too much stress are both recognized seizure triggers so jobs should be considered carefully.

When a teenager is considering long-term career options, choices should be researched. Although the options are many, there may be 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 on the part of 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 yet studies involving people with epilepsy in the workplace do not support those concerns.

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

part of an employer if an act taken by an employer is considered to be reasonable and justifiable under the circumstances. For example, employers are not expected to hire or continue to employ a person whose disability notably increases the probability of health or safety hazards to himself or herself, other employees, and/or the public.

For instance, people who have seizures may not be suited to safely working on heights or driving a truck. It is the responsibility of the employer to demonstrate that the person's disability would threaten his or her safety or the safety of others.

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 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 or trading work with another employee.

### *Applying for a Job*

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



Consideration should be given to the advantages and disadvantages regarding disclosure. To find out more about the advantages and disadvantages of disclosure regarding employment, contact your local epilepsy association.

## **Alcohol and Drugs**

While excessive use of alcohol and subsequent withdrawal can trigger seizures, modest occasional alcohol consumption does not seem to increase seizure activity in those 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 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 seizure medication as prescribed.

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.

## **Smoking**

Smoking can be hazardous in that burns or a fire could result should a seizure occur while a person is smoking.

## Seizure Triggers in Teenagers

Some seizure triggers in teenagers 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 medication
- Flickering lights of computers, televisions, videos, etc. in those with photosensitive epilepsy
- Excessive alcohol consumption and subsequent withdrawal
- Street drugs (e.g. cocaine, amphetamines, ecstasy, LSD, withdrawal from marijuana)

### Menstruation

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

Noting the dates of your daughter's periods on a seizure record chart will help the doctor to determine whether menstruation is a seizure trigger.

## *Teach Others About Epilepsy*

One of the challenges facing those with epilepsy is the public's lack of knowledge about the condition. Misconceptions based on historical perceptions, a lack of public awareness, and inaccurate television and movie depictions 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.

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.

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

At the same time, the tools used in the medical diagnosis and the treatment of childhood epilepsy continue to undergo significant advances and research is continuing to develop a better understanding and a means of prevention of 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.

# F 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 regarding your child's epilepsy. 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 an unrestricted grant from UCB Canada Inc.

© Edmonton Epilepsy Association, 2015-2016

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

Canadian  
**EPILEPSY**  
Alliance



Alliance  
canadienne de  
**L'ÉPILEPSIE**

**1-866-EPILEPSY**

Email: [info@epilepsymatters.com](mailto:info@epilepsymatters.com)

**Website: [www.epilepsymatters.com](http://www.epilepsymatters.com)**

Canadian League  
Against Epilepsy



La Ligue  
Canadienne  
Contre l'Épilepsie

**1-905-415-3917**

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

**Website: [www.clae.org](http://www.clae.org)**

## Your Local Contact Information:



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

*Inspirés par les **patients**. Guidés par la **science**.*

**Free Canada-wide distribution of this publication  
was made possible by an unrestricted Grant from  
UCB Canada Inc.**