



THE CENTER FOR

# **EPILEPSY & SEIZURE EDUCATION**

IN BRITISH COLUMBIA

## **Resource Guide**



## TABLE OF CONTENTS

<b>INTRODUCTION .....</b>	<b>4</b>
 <b>SECTION 1</b>	
<b>GENERAL INFORMATION ABOUT SEIZURE DISORDERS (EPILEPSY)</b>	
What Is a Seizure Disorder? .....	5
What Happens in a Seizure? .....	5
What Is an Aura? .....	5
Who Has Epilepsy? .....	5
How Do You Know if You Have a Seizure Disorder? .....	6
What Is a Seizure Trigger? .....	6
What Can You Do about Seizure Triggers?.....	6
How Are Seizures Classified? .....	7
Common Types of Seizures .....	7
First Aid for Seizures .....	9
Status Epilepticus .....	9
Recovery from a Seizure .....	10
Epilepsy and Safety .....	10
The Importance of Keeping Records .....	14
Seizure Record Template .....	15
Medication Form Template .....	16
 <b>SECTION 2</b>	
<b>TREATMENT OPTIONS</b>	
Diagnostic Tests for Epilepsy .....	17
How a Seizure Disorder is Treated .....	18
Important Points about Taking Anticonvulsants .....	18
Common Anticonvulsants and Their Characteristics .....	19
The Ketogenic Diet (a therapeutic diet for seizure control) .....	21
Vagus Nerve Stimulation (a surgical implant for seizure control).....	23
Surgery .....	23
Alternative and Complementary Therapies for Epilepsy .....	24

**SECTION 3****PSYCHOSOCIAL ISSUES**

Introduction .....	27
Issues Faced by Individuals and Families Living with Epilepsy .....	27

**APPENDIX A**

Services & Supports .....	29
---------------------------	----

**APPENDIX B**

Glossary .....	31
----------------	----

## When an Individual Is First Diagnosed with Epilepsy: A Personal Perspective

*"I remember a whirlwind of questions and emotions when my son was first diagnosed with epilepsy. I felt totally helpless and wanted a magic pill as I watched him deteriorate mentally due to uncontrolled seizures. It felt like he was someone's experiment. I didn't know what to do or where to get information, and it quickly became apparent that I needed to do some research on my own and not blindly follow every piece of advice I was given."*

Watch your child closely and make a note of every change, no matter how small. Investigate all the options available. There are many different treatments, including alternatives that the medical profession is not willing to promote. There are many different types of seizures, and the disorder affects everyone differently. What works for one person may not work for another. It often takes much trial and error to find the right medication, the right dose, the right alternative treatment, or all three. For some people, long-term seizure control is achieved with relative ease. For others, it can be more of a challenge, with difficult choices and some frustration. Keep accurate records of the symptoms and take this information and a notepad to your medical appointments. Always write the doctor's answers down.

One way to get the information you are looking for is to network with other families who also face the challenge of epilepsy. One-on-one conversations with those in the same situation may help to educate and help you explore a variety of treatment options. Our executive director can refer you to someone with whom you can talk. I also encourage you to bring your concerns and issues to us. Our goal is not only to educate the public, but also to advocate for families and individuals whose needs are not being met. Your ideas also help us develop new programs.

I feel strongly that the members of this board and the volunteers who help us are truly focused on finding excellent, up-to-date information. From the perspective of my own experience, finding the right support and education can make all the difference.

-

Arlene Martel



## GENERAL INFORMATION ABOUT SEIZURE DISORDERS (EPILEPSY)

### What Is a Seizure Disorder?

A seizure disorder is another name for epilepsy. Anyone can have a seizure if the brain is severely stressed. Epilepsy is a neurological disorder that is characterized by recurrent unprovoked seizures. Messages are sent within a person's brain by electrochemical signals. During a seizure, abnormal electrical activity occurs as a large number of brain cells send their messages rhythmically and at once, disrupting normal functioning. As this happens, the individual may experience uncontrollable changes in movement, breathing, behaviour, sensation and/or consciousness. Most seizures last less than five minutes. After a few seconds or minutes, the brain regains control and the individual returns to normal. A person is said to have a seizure disorder (or epilepsy) when he or she has repeated seizures.

Most persons with epilepsy are generally able to completely control their seizures with drug therapy and to lead active and full lives, but a percentage of cases are drug-resistant (or *intractable*) and can be more complicated to manage. However, these individuals can still live rewarding lives. Intractable epilepsy occurs more frequently in the more developmentally delayed individuals, but prolonged and uncontrolled seizures in others can lead to cognitive issues (Blume, Kwan).

### What Happens in a Seizure?

A seizure may consist of a brief stare, an unusual movement of the body, breathing difficulties, loss of bladder or bowel control, an odd sensation, a change in consciousness, or a convulsion (muscle contractions). Seizures may be either convulsive or non-convulsive. Non-convulsive seizures may be difficult to recognize. Seizures differ in form, strength and frequency from person to person, depending upon where in the brain abnormal electrical activity is found. There are many types of seizures and therefore many types of epilepsy (or epilepsies). Most seizures are self-limiting and do not last more than a few minutes.

### What Is an Aura?

An *aura* is a brief warning in the form of an unusual sensation that alerts a person that a major seizure is coming. The sensations may be an unpleasant taste or smell, tingling, a funny feeling in the stomach, or a visual sensation. An aura is a simple partial seizure that warns of a larger seizure to come.

A *prodrome* also alerts the individual that a seizure is coming, but it may last for hours or days. The individual's behaviour or mood may alter during this period.

### Who Has Epilepsy?

Epilepsy knows no geographical, racial, social or sexual boundaries. It can begin at any age but is most frequently diagnosed in infancy, childhood or adolescence. The epilepsy community may also include persons with developmental disabilities, head injuries, brain tumours, and neurological diseases and disorders. More people have epilepsy than cerebral palsy, multiple sclerosis, muscular dystrophy and cystic fibrosis combined. One in ten people will have a seizure in their lifetime, but people are not diagnosed with epilepsy unless they have repeated seizures. One percent of Canadians have epilepsy, ongoing seizures that require medical attention. Epilepsy is not a mental illness, and it is not contagious.

## How Do You Know if You Have a Seizure Disorder?

Some signs of a seizure disorder may go unrecognized, causing a delay in diagnosis and treatment. Consult your doctor if you or your child experience any of the following:

- Blackouts or unclear memory
- Fainting spells (accompanied by loss of bladder/bowel control and fatigue)
- Blank staring (unresponsive to questions or instructions)
- Inexplicable falls
- Periods of unusual blinking or chewing
- A convulsion (muscle rigidity or contractions)
- Repeated rapid, jerking movements in infants

## What Is a Seizure Trigger?

A seizure trigger is an event that sets off a seizure and is unique to each individual. Not all seizures have triggers, although they are common. Persons with epilepsy should try to identify and avoid their known triggers.

Some common triggers include:

- |  |  |
|--|--|
| <ul style="list-style-type: none"> <li>• a missed dose of medication</li> <li>• lack of sleep</li> <li>• stress (positive or negative)</li> <li>• running water</li> <li>• loud noises</li> <li>• fever, illness and pain</li> </ul> | <ul style="list-style-type: none"> <li>• bright or flashing lights</li> <li>• menstrual cycles</li> <li>• missed meals</li> <li>• excitement</li> <li>• depression</li> <li>• drugs</li> </ul> |
|--|--|

## What Can You Do About Seizure Triggers?

- Most importantly, take anticonvulsant medication regularly (use some type of reminder system).
- Keep a week's extra medication on hand so you do not run out (it is dangerous to suddenly stop taking anticonvulsants).
- Check with a pharmacist before taking any over-the-counter drugs, herbal remedies or prescription medications to avoid drug interactions with the AEDs (anti-epileptic drugs) that you are taking. (For example, Zyban™, an anti-smoking medication, and ginkgo biloba, an herbal remedy, have both been associated with increased seizures).
- Refrain from the use of alcohol or drugs.
- Stay well rested.
- Stay well hydrated (6-8 glasses of water a day).
- Avoid excessive heat (learn ways to stay cool on hot days).
- Eat healthy meals.
- Avoid loud noises.
- Maintain an active lifestyle, which includes regular physical activity.
- Use stress management techniques.
- Avoid blood sugar changes by eating regularly and avoiding alcohol, sweets and caffeine.
- Avoid flashing lights (for photosensitive seizures only).
  - Use a TV screen filter that blocks long-wavelength light and reduces brightness.
  - Adjust the blink rate on the computer cursor.
  - Wear polarized sunglasses to reduce the effects of natural light.
  - Use a new computer monitor/LCD screen.

## How Are Seizures Classified?

Seizures are classified into two main categories that describe where they originate in the brain: focal and generalized. Asterisks are used below to indicate older terms for seizure types.

### Focal (partial) \*

A focal seizure involves abnormal electrical discharges that occur on **one side** (hemisphere) **of the brain**, and the person remains conscious. There are two types: focal aware and focal impaired awareness (complex partial)\*.

### Generalized

In a generalized seizure, abnormal electrical activity is found along networks of brain cells in both hemispheres of the **brain**, and the person loses consciousness. The two most common types of generalized seizures are known as absence (petit-mal) \* and tonic-clonic (grand-mal) \* seizures.

## Types of Focal Seizures

### Focal Aware (focal non-dyscognitive or simple partial)\* (14%)

During a focal aware seizure, the person is conscious and may experience muscle jerking, which may remain localized to one part of the body or it may spread. It may become a generalized convulsive seizure. This is then called a secondarily generalized seizure. A focal aware seizure may also involve sensory disturbances—the person may hear, see or smell things that are not there. A person may experience emotions of joy, fear, anger, déjà vu, jamais vu, or a funny feeling in the stomach.

*May look like the person is acting out, has a mental or psychosomatic illness, or is having a mystical experience.*

---

### Focal Impaired Awareness (complex partial, psychomotor or temporal lobe) \* (36%)

During a focal impaired awareness seizure, there is a disturbance in the person's consciousness. It may start with a blank stare and involve chewing, lip smacking or other random movements called automatisms. Other automatisms may include taking off clothes, picking at clothing, picking up objects or random walking. The seizure may last a few minutes, during which time the person may be unaware, unresponsive, dazed, mumbling or clumsy. The person may run or struggle if frightened or restrained. The same set of actions will appear with each seizure. There may be confusion afterwards and no memory of the seizure. There are no convulsions with these seizures unless they become secondarily generalized.

*May look like the person is drunk or on drugs, mentally ill, disorderly or non-compliant.*

---

## Common Types of Generalized Seizures

### Tonic-Clonic (Grand Mal)\* (23%)

A tonic-clonic seizure may start with a sudden cry and fall and progress from muscle rigidity to jerking. There may be a change in breathing (breathing may be temporarily suspended, skin bluish), drooling, possible vomiting, and loss of bladder or bowel control. There is a loss of consciousness with a duration of 2-5 minutes. The person will experience fatigue and confusion before full recovery.

*May look like a heart attack.*

---

**Absence (Petit Mal) \* (6%)**

These occur most often in children and appear as 2-10 seconds of staring. There may be blinking, eyelid fluttering, eye rolling or chewing movements. The person is unaware during the seizure, followed by a return to full awareness. These seizures are fairly easy to control with medication.

*May look like daydreaming or noncompliance to adult instructions. May result in learning difficulties if not detected and treated.*

---

**Atonic (Drop Attack) \***

The person collapses and falls without warning. Seizures last 10 seconds with a quick recovery, then consciousness returns, and the person is able to function again. Seizures may be drug resistant and require a safety helmet.

*May look like clumsiness or poor gross motor skills in a child or drunkenness in an adult.*

---

**Myoclonic (3%)**

These appear as abrupt muscle jerks in one part or all of the body. They are seen in children and can be a single incident or a series of incidents. Individuals might fall off chairs or spill things, and the seizures may occur when going to sleep or upon awakening.

*May look like a nervous tic or startle response.*

---

**Tonic**

These rigid muscle contractions are similar to tonic-clonic but lack the clonic (jerking) portion.

---

**Clonic**

These appear as repetitive jerking. They may lead to a tonic-clonic seizure.

---

**Infantile Spasms (IS)**

Onset is usually before age one. If the child is sitting, the head may fall forward and arms flex forward. If the child is lying down, the knees may be drawn up with arms and head flexed forward, as if the child is reaching for support. Duration is 1-5 seconds, occurring in clusters. Many occur upon going to sleep or waking.

*May look like normal infant movements or colic.*

---



## First Aid Procedures for Seizures

For all seizures, your main job is to protect the person from injury. Time and carefully observe what happens before, during and after the seizure, and record all details as soon as possible. Follow up by updating the seizure management plan with the health care team or at the health unit. Not all seizures involve convulsions (muscle contractions), and some may be harder to recognize. Most seizures last under five minutes and are not medical emergencies except for *status epilepticus*.

**Status epilepticus is any seizure that lasts more than five minutes or repeats without full recovery in between. It is a life-threatening medical emergency: Call an ambulance!** Status epilepticus may occur with seizures other than tonic-clonic.

Status epilepticus may result when anticonvulsant drugs are suddenly stopped.

**Note:** Lengthy or repeated seizures can be treated at home with emergency medication, prescribed by a neurologist. Rectal gel (Diastat) or orally administered Lorazepam (Ativan) are commonly used for this purpose.

### First aid for tonic-clonic seizures

- Stay calm.
- Ease the person onto the floor.
- Check for a Medic Alert bracelet.
- Keep the airway clear by turning the person onto one side. If sitting, turn the head to the side. Do not try to move a person from a wheelchair.
- Do not put anything into the person's mouth.
- Loosen clothing around the neck; remove glasses.
- Place something soft under the person's head.
- Remove anything from the area that might cause injury.
- Do not try to restrain; this can cause a muscle tear or break a bone.
- Reassure the person and let him or her rest afterwards.
- Do not give fluids until the person is fully conscious.
- Offer assistance in getting home.

Do not use artificial respiration unless you have been trained.

### First aid for focal impaired awareness seizures

- Gently redirect the person away from danger.
- Speak calmly, quietly and reassuringly until consciousness is regained.
- Help the person get home.

Absence, atonic, focal aware, myoclonic and infantile spasms do not require first aid unless they are **over 5 minutes in duration**. A follow-up evaluation with a health care provider or at the health unit is advisable.

### An ambulance should be called in the following circumstances:

- The person experiences status epilepticus.
- It is the person's first seizure or the person's seizure history is unknown.
- Acute confusion lasts more than one hour after the seizure.
- The seizure takes place in the water.
- Normal breathing and consciousness are not restored after the seizure.
- The person is pregnant, diabetic or has sustained an injury.

### **Information for the ambulance attendant**

You should be able to answer questions about the following regarding the patient:

- Level of consciousness
- Changes in breathing
- Bleeding
- Duration of seizure
- What happened during the seizure
- Any injuries

### **Recovery**

Recovery time varies depending on the type of seizure. It might be almost immediate, take minutes or take hours. Sometimes it may even take days. After a major seizure in which there are muscle contractions (convulsions), it is normal for the person to feel confused, drowsy or unsteady, to have a headache or to have slurred speech.

#### **Other points to remember about seizures:**

- You cannot prevent a seizure.
- A person does not feel pain during a seizure, although muscles may be sore afterwards.
- You should notify the parents/guardians if a child has a seizure.
- Seizures are not dangerous to others.
- Seizures place seniors at increased risk due to extra strain on the heart, reduced oxygen and the possibility of injury.

## **Epilepsy and Safety**

### **Balancing life's risks against its rewards: some say it's the key to living well.**

Having epilepsy may increase life's risks, at least for some. Should you be taking special safety precautions? A lot depends on the kind of seizures you have, how often they happen, and the kinds of things that are important in your life.

Having seizures might require you to balance your personal freedom with your personal safety.

If you have very brief staring episodes or only have seizures while asleep, your chance of being injured is probably low. People with frequent seizures that affect consciousness and happen without warning (especially convulsions and drop seizures) are the most likely to be at risk of injury.

Studies show that only about 1% of seizures result in injuries. Accidents are not evenly distributed among epilepsy patients; those with accidents have usually had more than one. Overall, the annual chance that a person with epilepsy will visit an emergency room because of an injury due to a seizure is estimated to be 5%.

Activities taking place at heights or near water (or some other hazard) increase your risk of being hurt if you are prone to having seizures. You might consider whether the activity can be made safer or whether it is important enough to take the risks involved.

As we make decisions, each of us must weigh how much we value an activity against any risks of injury it may carry. Our choices depend on individual health, preferences and lifestyle.

People with epilepsy should not be overprotected since restrictions will not necessarily prevent accidents. When some risk is unavoidable, it is important not to overreact since unnecessary restrictions on one's independence (especially on children with epilepsy) may cause greater harm than the potential accident.

The information below will help you think about any risks you may face and offer ways to help you live a safe and active life. Take some time to set up those basic safety procedures that directly apply to your seizure pattern. Then concentrate on all the things you **can** do. The goal is to balance safety concerns with living your life well.

## Letting Others Know

- Make sure your family, friends, teachers and co-workers know seizure first aid. You and your family should know first aid for choking.
- Wear a medical identification bracelet or necklace (available from Medic Alert by phoning 1-866-679-3218, or online at [www.medicalert.ca](http://www.medicalert.ca)). Medic Alert keeps your file with pertinent health information and instructions, which is accessible to first responders. There is a monthly charge, but through its “No Child Without” program, the service is free to children in participating schools. This program is widespread, so check online so see if your child’s school is involved.
- Universal Medical ID also carries a line of medical identification jewelry, and the centralized medical registry is free with the purchase of the identification jewelry. Call 1-800-616-3400 or see [www.universalmedicalid.com/canada/](http://www.universalmedicalid.com/canada/).
- Universal Medical ID carries a USB flash drive that can be loaded with pertinent medical information. It is identifiable so that first responders know its purpose.
- Carry a small, portable, pre-programmed phone or beeper in case you have to call for help and you are away from a telephone.

## Safety Precautions for the Home

- Make specific changes around the home to significantly reduce injuries due to falling or burning.
- Carpet the floors, including entranceways and bathrooms, using dense-pile carpet with thick underpadding.
- Pad sharp edges of tables and other furniture. Don’t leave drawers open.
- Avoid freestanding or table lamps and glass decorations.
- Whenever possible, sit down when doing household chores or using tools.
- Place non-flammable secure barriers in front of hot radiators, heaters and fireplaces.
- Avoid smoking or lighting fires or candles when you’re by yourself.
- Keep floors clear of clutter and tie up dangling electrical cords.
- Avoid climbing up on chairs or ladders, especially when alone.
- Put safety gates at the top of steep stairs.
- Use “automatic shut off” appliances, power tools, etc. whenever possible.
- Be careful of irons, hair dryers, lawn mowers, saws, sewing machines, etc.
- Securely lock outside doors if you tend to wander during a seizure.
- Consider placing an alarm on an outside door to alert others.
- If your seizures are very frequent and sudden, consider wearing a helmet with a faceguard and/or knee or elbow pads, at least when you’re at home alone. Many styles of head protection can be found online.
- If you live alone, have a “buddy system” in case you need to be checked on. Pre-program your phone for emergency contact numbers. A subscription to a Lifeline® Medical Alert Service (1- 866-784-1992, [www.lifeline.ca](http://www.lifeline.ca)) gives you push-button contact with a responder from your home.
- A Lifeline product is available to detect falls and connect with the responder when the wearer is unable to push a help button.

## Safety While Bathing

- Take showers rather than baths.
- Routinely check that the bathroom drain works. Do not let face cloths or sponges block the drain and allow the tub to fill with water.
- Put non-skid strips or a rubber bathmat on the floor of the shower.
- Shower only when someone else is at home. (Singing in the shower will reassure others that you are doing fine.) Otherwise, take a sponge bath using the sink.
- Set water thermostat low to prevent scalding. Turn on the cold water first and turn off the hot water first.
- Avoid very hot showers—some people find heat to be a seizure trigger. Keep your bathroom well ventilated.
- If you fall frequently during seizures, use a shower/tub seat with a safety strap, a handheld shower nozzle, and/or a folded towel to pad around the edges of the tub.
- Avoid glass shower doors. Use shatterproof glass for mirrors.
- Leave the bathroom door unlocked; use an “Occupied” sign instead of locking.
- Hang your bathroom door so it opens outwards, instead of inwards, if you might fall against a closed door.
- Avoid using hair dryers, electric razors or other electrical appliances near water or when you’re alone.
- Consider using a padded toilet seat.

## Safety While Sleeping

- Avoid using hard-edged bed frames or sharp-cornered bedside tables.
- Avoid top bunks.
- Avoid potentially suffocating sleeping surfaces (e.g., waterbeds).
- If a pillow causes concern, discard it or use a smother-proof egg carton foam pillow.
- A monitor in your bedroom may alert others to the sound of a typical seizure.
- High-tech, seizure-specific mattress alarms (e.g., triggered by seizure movements in bed and wired to a telephone auto dialer) are now available (See, for example, The Stevens Company, 8188 Swenson Way, Delta, B.C., V4G 1J6, phone 604-634-3088). They also make protective helmets.
- Smartwatch by Smart Monitor monitors and detects tonic-clonic type movements and communicates with an android phone on or near the person, which in turn sends a message to a designated number. There is a one-time activation fee and a monthly subscription fee. See [www.smart-monitor.com](http://www.smart-monitor.com).
- SAMi™ is a sleep activity monitor that uses an infrared camera to capture seizure-like movements and alarm parents. Sensitivity is calibrated to minimize false alarms due to typical sleep movement (see [www.samialert.com](http://www.samialert.com)).

## Safety While Cooking

- Use a microwave oven for boiling water and cooking as much as possible.
- If using a stove, use the back burners.
- Saucepan handles should face the side or back of the stove.
- Use a stove guard that fits around the side or front of the stove.
- Use long, heavy-duty oven mitts when reaching into a hot oven.
- Cook when someone else is at home whenever possible.
- Buy a kettle and iron with an automatic shut off.

- Avoid knives, slicers, etc. Use a blender or food processor or buy foods that are pre-cut or already prepared.
- Consider a wall-mounted or tabletop ironing board.
- Use unbreakable dishes to prevent cuts and cups with lids to prevent burns.
- Avoid carrying hot food or liquids.
- When using a dishwasher, ensure that knives and other sharp utensils have their blades pointed downwards and are placed safely out of the way.
- Wear rubber gloves when washing glassware or handling knives.

## Safety during Sports and Recreation

Most sports and recreational activities are both safe and beneficial for people with epilepsy, promoting fitness and stress reduction, as well as maintaining bone mass. Before taking up sports that would put you in danger, think about if you were suddenly unaware of what you were doing and review the risks and benefits.

Here are some safety tips:

- Wear appropriate safety gear, such as helmets, flotation devices, elbow and kneepads.
- Exercise on soft surfaces like grass or mats whenever possible.
- Stay cool when exercising by taking frequent breaks.
- Keep hydrated.
- Swimming can be safe and enjoyable, but always go with a buddy who is an experienced swimmer. Inform a lifeguard about your seizures and consider wearing an easily identifiable bathing cap or flotation device.
- Consider avoiding or modifying sports that have a high risk of a head injury (i.e., play touch football instead of tackle football).
- When bicycling or rollerblading, wear a helmet, kneepads and elbow pads. If the helmet liner is damaged in an accident, the entire helmet must be replaced. Avoid busy roads and solo trips.
- Avoid boating, snowmobiling or skiing alone.
- Consider using a safety strap and hook when riding ski lifts.
- Avoid skydiving, deep-sea diving or hang-gliding.

## Safety While Travelling

- Do not drive a car unless you have a valid license and are not having seizures.
- If you can't drive because of epilepsy, explore local "dial-a-ride" services, paratransit and public transportation options. People with a disability are sometimes eligible for local discounts on transportation.
- If you have frequent seizures, the added safety of a taxicab may be worth the extra cost.
- If you wander during a seizure, consider taking a friend along when you travel.
- If you need to travel with an attendant for your seizures when taking a train, bus or airplane, you may be eligible for a discount. Contact the Canadian Epilepsy Alliance in your area for more information.
- If escalators or stairs are unusually steep, consider using an elevator instead if available.
- When flying, take all medications in a carry-on bag.
- Carry an extra copy of your prescription with you.
- Be aware of time zone changes when taking medications. If the time difference is large, speak with your doctor about how to adjust your schedule.

## Workplace Safety

Jobs can often be made safer with a few changes, and in most jurisdictions, employers are required to make reasonable accommodations for their employees with disabilities. Review any job-related risks to you. Can something be changed to improve safety? Helpful advice is available by phoning The Canadian Council on Rehabilitation and Work at 1-800-664-0925 or online at [www.ccrw.org](http://www.ccrw.org). Consider telling your co-workers that you have epilepsy and about correct seizure first aid. This often helps to calm fears and correct misconceptions. The Canadian Epilepsy Alliance in your area can help. Here are some useful tips:

- Try to keep consistent work hours so you don't go too long without sleep.
- Climb only as high as you can safely fall, especially on a concrete floor, unless you are protected by a reliable safety harness and wearing a secure hard hat or helmet.
- When working around machinery, check for safety features, such as automatic shut offs or safety guards.
- Depending on your job and the demands of your work site, consider wearing protective clothing.

## The Importance of Keeping Records

The importance of proper record keeping cannot be overstated. If you have a seizure disorder or have a child with one, you play an important role as a member of the overall health care team. Keeping accurate, consistent records provides the neurologist with critical information needed to offer effective medical treatment. Detailed descriptions about exactly what happened before, during and after the seizure will help your doctor assess the types of seizures present and to choose which medications and dosages to use. Your information may also help your neurologist decide when to try a new drug and whether side effects are present.

Effective record keeping is most easily done by keeping a seizure record sheet and an attached pen in a permanent and easily accessible place in your home and by having a portable record-keeping system in your car for seizures that occur when out.

Time the seizure and establish a habit of recording information as soon as possible afterwards. It may be difficult to remember exactly what happened if you leave it until later, or you may completely forget to record the data.

## Medication Record Information

A record of medication may also be useful to you. It will serve as a permanent record of drugs prescribed by the neurologist and their effects upon you or your child. Update the record every time there is a change in the type of medication, the amount prescribed or how often a drug is to be taken. Use the last page to record notes and reminders about special instructions given by your doctor, any changes you notice in your (or your child's) condition, or behaviour that you think may be related to a drug. Be sure to discuss this information with your doctor at your next medical appointment.

This record may be helpful when you travel or if your family moves to another area. A history of your child's medications will be important for a new physician, who will want to know what drugs have or haven't worked and the reactions to different dosages. The medication record may also be useful if official medical records cannot be obtained.

Take this record with you whenever you travel. If there is any change in your (or your child's) medical condition, the record will be on hand for the physician providing temporary care.

**SEIZURE RECORD** for \_\_\_\_\_

Date	Time seizure began	Length
What happened just before the seizure?		
Was the person asleep or had he/she just awakened?		
What was the first thing you noticed (a cry, a fall, a stare, etc.)?		
Were there any movements? Which parts of the body? Did they affect one side in particular?		
What was the progression of movement from one part of the body to another?		
Were there changes in breathing?		
Did the person speak or make any sounds?		
Were there skin changes (flushed, clammy, pale, blue)?		
Did the person lose consciousness, or was his/her awareness changed? For how long?		
Were any actions performed (e.g., picking at clothes or wandering)?		
Were there any seizure triggers (e.g., a missed dose of medication)?		
Was there a loss of bladder or bowel control?		
How long did the person take to <i>fully</i> recover? Did he/she remember the seizure or any unusual sensations before the seizure started?		
Did the person go rigid or limp? Was there any jerking or twitching? Were there any eye movements?		
Did the person vomit?		

# Medication Record

MEDICATION(S) PRESCRIBED	DATE PRESCRIBED	DOSE	DATE(S) CHANGED & DISCONTINUED	REASON FOR DISCONTINUANCE



**TREATMENT OPTIONS****An Overview of the Diagnostic Tests for Epilepsy****Computed Tomographic (CT) Scan**

A CT or CAT scan is a series of detailed x-rays, taken at different angles in the brain, that show abnormalities in the brain or skull that could indicate where a seizure originates.

**Electroencephalogram (EEG)**

An EEG is a primary diagnostic test that records brain waves and is used to detect epilepsy and the types of seizures present.

(See BC Children's Hospital website, <http://www.bcchildrens.ca/EEG-Department-site/Documents/2009EEGPHOTOBOOK.pdf>, for an excellent children's photobook about EEGs.)

**Magnetic Resonance Imaging (MRI)**

MRI uses magnetic fields instead of x-rays to produce two- and three-dimensional images of the brain. It can be used to detect brain tumours and other brain abnormalities.

**Magnetoencephalography/Magnetic Source Imaging (MEG/MSI)**

MEG/MSI records magnetic brain waves to assess brain function and structure.

**Positron Emission Tomography (PET) Scan**

A PET scan shows brain function, metabolism and how glucose is used in the brain through colour computer images.

**Functional Magnetic Resonance Imaging (fMRI)**

A functional MRI (fMRI) provides information about active brain tissue function and blood delivery and can find the exact location of a seizure area. It may be used to measure small metabolic changes in the active part of the brain and can be used to map the areas used for thought, speech, movement and sensation.

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

SPECT uses three-dimensional images to show blood flow in different areas of the brain. (Individuals with epilepsy often have changes in blood flow when a seizure begins.)

**Video EEG Monitoring**

The patient remains in a special hospital room where simultaneous video and EEG monitoring helps to determine and pinpoint seizure activity. It's referred to as the Intensive Monitoring Unit (Children's Hospital) or Seizure Investigation Unit (Vancouver General Hospital).

Note: Some of the above procedures are not generally available in British Columbia.

## How is a Seizure Disorder Treated?

The first step in the treatment of epilepsy involves making a correct diagnosis through taking a detailed history of the patient and performing a physical examination. **Often a person is unconscious or unaware of events just prior to or during the seizure. It is important to have the seizure symptoms and history provided to the physician by family or friends.** This information is supported by further diagnostic testing.

Epilepsy may be treated with anticonvulsant drugs (anti-epileptics or AEDs), a therapeutic diet, hormonal treatment, a surgical implant, surgery or alternate therapies.

The most common form of treatment is drug therapy. Different types of anticonvulsant drugs are used to treat different types of seizures. An individual with epilepsy is usually prescribed one drug for seizure control. **An accurate history of symptoms is critical in prescribing the correct medication.** If there are different types of seizures present, he or she may be required to take more than one drug. Reaction to anticonvulsants may vary among individuals, and it may take time to find the correct dosage and correct drug(s).

An anticonvulsant must reach a certain level in a person's bloodstream before it is effective in controlling seizures. The level must be maintained by taking the medication in the prescribed amounts and at the prescribed times. The amount of the drug given should be enough to prevent seizures without causing drowsiness or other side effects. Once drug therapy begins, drug levels and side effects are monitored through regular blood testing and through review of seizure records.

Anticonvulsants do not cure epilepsy but are generally able to control an individual's seizures, allowing those with epilepsy to lead lives with fewer restrictions.

### Some important points to remember about taking anticonvulsants

- Take the *exact* amount prescribed, neither more nor less.
- Take the medication at the same time every day.
- Do not stop taking an anticonvulsant suddenly; this may cause uncontrollable seizures.
- Do not drink alcohol or take street drugs with anticonvulsants.
- Check with your pharmacist before taking over-the-counter, herbal or other prescription medications, including birth control pills (the effectiveness of either medication may be affected).
- Check with your physician about what to do if you miss a dose.
- Keep medication locked up and in a dry place (humidity in the bathroom or kitchen may affect medication).
- Carry a copy of your prescription if traveling, and take more medication than is necessary for your stay.

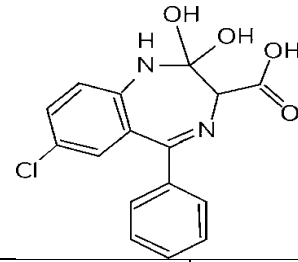
### Side effects

Minor side effects may be initially present when starting a new drug. They may include drowsiness, irritability, nausea, poor physical co-ordination, emotional changes and hyperactivity in children.

**Note: Side effects requiring immediate medical attention are fever, sore throat, mouth ulcers, easy bruising, pinpoint bleeding, allergic skin rash or jaundice.**

## Common Anticonvulsant Drugs

This chart contains the most commonly occurring side effects associated with these drugs. For more detailed information, see your doctor or pharmacist.



Trade Name	Generic Name	Common Use	Possible Side Effects	Unacceptable Side Effects	Notes
Aptiom	Eslicarbazepine	In combination with other AEDs for partial seizures	Dizziness, sleepiness, nausea, headache, double vision, vomiting, feeling tired, problems with coordination, blurred vision, shakiness	Severe skin rash, severe allergic reactions, suicidal thoughts, dangerous drop in blood sodium levels	
Banzel	Rufinamide	Used in addition to other AEDs for seizures associated with Lennox Gastaut	Headache, dizziness, fatigue, sleepiness, nausea	Heart rhythm irregularities	Should not be taken by people with condition known as short QT syndrome.
Brivlera	Brivaracetam	In combination with other AEDs for partial seizures that are not satisfactorily controlled with conventional therapy	Sleepiness, fatigue, dizziness, vertigo, coordination problems, anxiety, irritability, restlessness	Psychosis	
Depakene	Valproic acid	Atonic, myoclonic, infantile spasms, absence, tonic-clonic, partial (somewhat effective)	Nausea/vomiting, indigestion, sedation, dizziness, hair loss, tremor, weight gain, loss of coordination	Hypersensitivity, allergic reaction, impaired liver function, low blood platelet count, stupor, coma	
Depakote (Epival)	Divalproex Sodium (forms valproic acid in body)	Atonic, myoclonic, infantile spasms, absence, tonic-clonic, partial (somewhat effective)	Nausea/vomiting, indigestion, sedation, dizziness, hair loss, tremor, weight gain, loss of coordination	Hypersensitivity/allergic reaction, serious (possibly fatal) liver problems, low blood platelet count, stupor, coma	1-2% increased risk of spina bifida and birth problems; greater risk of liver problems in children under 2 yrs.

Trade Name	Generic Name	Common Use	Possible Side Effects	Unacceptable Side Effects	Notes
Dilantin	Phenytoin	Tonic-clonic, simple partial, complex partial	Body hair increase, gum overgrowth, tremor, anemia, loss of coordination, double vision, nausea/vomiting, confusion, slurred speech	Hypersensitivity/allergic reaction	Affects birth control pills: 5% risk of birth defects including cleft palate and congenital heart disease
Felbatol	Felbamate	Not recommended due to serious adverse side effects		Aplastic anemia and hepatic failure	There have been several deaths from this drug.
Frisium	Clobazam (Benzodiazepine)	Used in addition to other AED therapy in a broad range of seizures, including atonic, myoclonic, infantile spasms, absence	Sedation, tiredness, drowsiness, unsteadiness, irritability, muscle weakness, weight gain	Hypersensitivity/allergic reaction	
Fycompa	Perampanel	Used in addition to other AEDs for adults with partial onset seizures not satisfactorily controlled with conventional therapy	Dizziness, gait disturbance, falls, sedation	Serious psychiatric and behavioural reactions, including severe hostility and aggression	Contact a health care provider immediately if any of these reactions are observed. May be worsened by alcohol. May reduce potency of some birth control pills.
Gabitril	Tiagabine	Used in combination with other anticonvulsants to treat partial seizures in adults	Drowsiness, dizziness, fatigue, depression, impaired concentration, lack of energy, weakness, tremor, nervousness, stomach pain	Rash, changes in vision, bruising, increase in seizures	

## **The Ketogenic Diet – A Therapeutic Diet for Seizure Control**

The ketogenic diet is used in the treatment of hard-to-control seizures. It is carefully calculated to be high in fat, low in protein and almost free of carbohydrates. This diet is often chosen as a therapeutic strategy for children when anticonvulsant medication has failed to be effective or if undesirable side effects are present. It is a medical therapy that should only be administered under the careful supervision of a neurologist and a dietitian.

### **What is the history of the diet?**

As far back as biblical times, fasting was recognized as having a beneficial effect on seizure control. Wilder introduced the modern ketogenic diet in the 1920s in an attempt to reproduce the metabolic effects of fasting. With the invention of modern anticonvulsants in the 1950s, the diet was used less frequently. In recent years, further refinement of the therapy has taken place at Johns Hopkins University in the United States. It is now being used in many medical centers for the treatment of hard-to-control seizures.

### **Who might benefit from the diet?**

Traditionally, the diet has been used for young children between two and ten years of age. It appears to be effective for multiple types of seizures: atonic, myoclonic, tonic-clonic and Lennox-Gastaut syndrome.

Some studies indicate the diet is not as effective for partial and absence seizures. It works best for children between one and ten years of age because it is often difficult to maintain ketosis in children under one year of age, and older children often reject the food restrictions. There are currently few published studies on the effectiveness of this diet in adults.

Studies are being conducted at Johns Hopkins on a modified Adkins Diet that is less restrictive than the ketogenic diet and more acceptable for adults. Preliminary results have been positive.

### **How does the diet control seizures?**

The exact mechanism of the ketogenic diet is not understood. Originally, it was thought to be related to the state of ketosis produced during fat metabolism. Ketones are the end products of fat breakdown and circulate in the blood once the diet has been initiated. The human body normally burns glucose (sugar) for energy and can store up to one day's supply. After a one-day fast, most of the glucose in the blood is used up, which causes the body to burn stored fat for energy, resulting in ketosis.

Ketosis is produced by eating foods that are ketogenic (fats) and limiting foods that are anti-ketogenic (carbohydrates and proteins). A dietician will calculate how many calories the child needs for energy and minimal growth (approximately 75% of the recommended dietary allowance).

The diet may also limit fluids to promote a state of slight dehydration, which could also help to reduce seizures.

To maintain the patient in ketosis, a set ratio of fats to carbohydrates and protein is prescribed. For example, a 4:1 ratio means that for every gram of carbohydrate/protein, there are four grams of fat.

When a person is prescribed the ketogenic diet for seizure control, a dietician will develop meal plans that contain the correct ratio of fats, carbohydrates and protein. The meal plans give the exact number of grams for each food item in the meal and are weighed using a gram scale. The allowed foods on the diet are limited but often include small amounts of fruits and vegetables. Sugar, starch, grain and bread products are virtually eliminated. The ketogenic diet must be followed rigidly, since even small amounts of extra carbohydrate (like a bite of cookie or a cracker) may negate its beneficial effects.

### **Does the diet provide adequate nutrition?**

The diet significantly limits dairy products, grains, fruits and vegetables. Because it is not nutritionally adequate, daily vitamin and mineral supplements are necessary.

### **What are the risks and benefits?**

#### **Benefits**

The ketogenic diet is beneficial in that it provides some type of seizure control for two-thirds of the children who rigidly follow it. A small percentage will have complete seizure control and be able to gradually discontinue medication. Many children will have their medications reduced while they are on the diet. This helps to minimize drug side effects such as sedation, cognitive impairment, behavioural changes, liver function/blood abnormalities, and dental problems such as gum overgrowth. Many parents report improvements in their children's general levels of alertness, concentration and overall behaviour while their children are on the diet.

#### **Potential risks**

Blood tests are done at 3- and 6-month intervals, or upon the neurologist's or GP's request, to monitor for potential problems. These might include

- Added stress to the child and family because of difficulty in implementing and maintaining the diet
- Slowing of the child's physical growth
- Hypoglycemia (low blood sugar), or the child may become too ketotic
- Kidney stones (the individual may have to be taken off the diet if this problem cannot be controlled with oral citrates)
- Elevated blood cholesterol levels
- Poor bone mineralization
- Behavioural problems due to food restriction
- Risk of dehydration during illness
- Isolated reports of cardiac complications

### **How does the diet start?**

In the past, a child would be admitted to hospital for a 24- to 36-hour fasting period and then started on the diet at a 3.5:1 or 4:1 ratio. However, since 1998, the diet has been introduced on an outpatient basis. Children are still fasted, although usually for a shorter period, then the diet is gradually introduced over a period of a few days. During the introductory week, families generally spend 5-6 hours in the clinic each day for teaching and for the health care team to monitor the child's progress. Some families choose to stay near the hospital during this week. A nurse coordinator can help families arrange low-cost accommodations and manage other details related to their stay.

### **How long will my child be on the diet?**

Families should commit to a trial of at least 3 months. If a good response is achieved, the diet may be continued for another year or so. If not, the family and health care team might start to gradually wean the child off the diet. This decision depends on several factors, including how well the child's epilepsy has responded to the diet, how well the child is tolerating the diet, the EEG result, the natural history of the child's epilepsy syndrome, family coping and so on. The diet is weaned by decreasing the ratio of fat to carbohydrate/protein in the diet every 2-3 months until the child is on a regular diet again.

Adapted from: British Columbia Children's Hospital  
 Ketogenic Diet Program  
 Johns Hopkins Epilepsy Center  
 Ketogenic Diet Program  
 Eileen Vining, M.D., Millicent T. Kelly, R.D.



For more information about the ketogenic diet, including recipes, resources and stories, see the Charlie Foundation at [www.charlifoundation.org](http://www.charlifoundation.org).

For information about the ketogenic diet program at BC's Children's Hospital, contact the nurse coordinator at 604-875-2345, local 7133.

Variations of the ketogenic diet include the MCT Diet (medium-chain triglyceride), the Low Glycemic Index Treatment, and the Modified Atkins Diet, all of which severely limit carbohydrates and have helped to reduce or eliminate seizures in some people. More information is also available at the Charlie Foundation.

## **Vagus Nerve Stimulation: A Surgical Implant for Seizure Control**

Vagus nerve stimulation (VNS) involves periodic mild electrical stimulation of the vagus nerve in the neck by a surgically implanted device (similar to a heart pacemaker).

VNS has been found effective in reducing the number and severity of seizures in some epilepsies when anti-epileptic drugs have been inadequate, their side effects intolerable, or if neurosurgery has not been an option. In some cases, VNS has also been effective in completely stopping seizures.

Common side effects, which occur only during stimulation, may include a tingling sensation in the neck and/or mild hoarseness of the voice. Other possible side effects may include coughing, voice alteration, shortness of breath, transient sensations of choking, throat pain, ear or tooth pain, and skin irritation or infection at the implant site. Unlike with many medications, there seem to be no significant intellectual, cognitive, behavioural or emotional side effects with VNS therapy. The success rate is a one-third moderate improvement and a one-third major improvement in those who use this type of therapy.

VNS is approved in more than 20 countries and is now the second most common treatment for epilepsy in the United States.

## **Surgery**

Another treatment option for epilepsy involves surgical removal of the underlying abnormality in the brain that generates seizures. Surgery can be a safe but often underutilized procedure. Epileptologists urge physicians to refer patients for a surgical assessment if seizures are not controlled after maximizing their efforts with at least two medications. Surgery for seizure control is highly successful because of the very thorough neurological investigation that is conducted before a patient is considered a candidate for this procedure. Surgery is only performed if an abnormality can be found and removed without causing damage to neighbouring brain structures that are responsible for important functions.

A second, less-common type of surgery involves making a strategic cut in the brain tissue which interrupts the transmission of abnormal electric impulses from spreading throughout the brain. This is called a surgical disconnection. A procedure called a corpus callosotomy disconnects the two hemispheres of the brain. It does not eradicate seizures but reduces their frequency and severity, increasing the quality of life in people with severe cases of uncontrolled epilepsy.

A randomized study published in 2001, conducted by Canadian researchers, compared the use of surgery versus anticonvulsants for seizure control in persons with uncontrollable temporal lobe seizures. The results

published in *The New England Journal of Medicine* showed that at one-year post surgery, 58% of those who had received surgery were free of seizures that impaired awareness. Only 8% of the non-surgery group was seizure-free. Quality of life was also greater in the group that received surgery. A limitation of the study was that follow up was relatively short, only one year.

For more information about access to surgery call 1-866-EPILEPS(Y)

For more information about the study, see *The New England Journal of Medicine*, August 2, 2002, p.311-318, available online.

## **Alternative and Complementary Therapies for Epilepsy**

### **What do we mean by alternative and complementary therapies?**

Alternative therapies include such techniques as acupuncture, chiropractic, massage therapy, relaxation, guided imagery, biofeedback, aromatherapy, yoga, therapeutic touch, homeopathy, diet, etc. These are unconventional or non-medical therapies that focus on the integration of the body, mind and spirit and are sometimes referred to as the holistic model.

Most people with epilepsy need to take anti-epileptic medication to control their seizures, so the non-medical therapies are more often "complementary" to their conventional medical treatment and not truly "alternative."

### **How effective are alternative or complementary approaches to epilepsy?**

There has not been much research done into alternative therapies for epilepsy, and, as yet there is little scientific evidence of their effectiveness. However, many who have tried complementary treatments believe they have helped their epilepsy and improved their quality of life.

Certainly, reducing stress can reduce seizures in some people, and alternative therapies that include stress-reduction techniques can help some people better control their seizures. Furthermore, the greater involvement of the person with epilepsy in managing seizures through these therapies can be positive in itself.

### **Can relaxation, yoga and meditation control epilepsy?**

People with epilepsy who find that they have more seizures when under stress may benefit from learning stress management and relaxation techniques such as progressive muscle relaxation and deep diaphragmatic breathing. Some people have found that yoga or meditation helps them prevent stress-induced seizures and improves their quality of life.

### **Can epilepsy be controlled by acupuncture?**

Acupuncture, which is part of the traditional medicine of China, uses needles and sometimes heat to stimulate nerve endings. The goal is to bring the person's health into a better mental, physical and emotional balance. Acupuncture has been used in patients with epilepsy with mixed results.

### **Can epilepsy be controlled through behaviour therapy?**

In behavioural therapy, seizures are viewed as a kind of conditioned or learned (though not voluntary) response to environmental conditions. Behaviour modification strategies that have had some success in people with seizures involve rewards, reinforcement, auto suggestion, relaxation, desensitization and other conditioning strategies.



### **Can epilepsy be controlled using aromatherapy?**

Aromatherapy uses pure aromatic oils from plants for stimulation and relaxation and to aid the healing process. Dr. Tim Betts, a British researcher, has had some success using oils on patients with epilepsy who can predict an imminent seizure. The idea is that the neuronal excitement in the brain that produces seizures can be altered, aborted or prevented by teaching patients to change their states of arousal with the help of particular aromas.

The use of oils such as ylang ylang, chamomile and lavender appear to help relaxation; whereas oils like rosemary, sage, hyssop, sweet fennel and wormwood can have the opposite effect and should therefore be avoided by people with epilepsy.

### **Can epilepsy be controlled through biofeedback?**

Biofeedback for epilepsy uses EEG machines to help people identify and alter their own seizure-related brain activity. The person with epilepsy is trained over time to use relaxation or other biofeedback techniques to generate a more normalized brainwave pattern, which may in turn reduce their seizures. Neurofeedback uses EEG recordings and computerized exercises to attempt to normalize brain patterns.

### **Where can I find an alternative therapist?**

It is difficult to find an alternative therapist who specializes in epilepsy. Professional associations responsible for regulating alternative therapists are good places to make inquiries about therapists' specializations and credentials. The epilepsy association nearest you may be able to give you some guidance. It is important to let your alternative therapist know that you have epilepsy and what medications you are on.

### **Should I tell my doctor that I am trying an alternative treatment?**

Yes. Any chemicals, including herbs, can affect the way anti-epileptic drugs work, and your doctor, as your partner in managing your epilepsy, should know what you are using. Remember, it is not advisable to reduce or stop taking anti-epileptic medication without consulting your medical doctor.

### **Do people with epilepsy require a special diet?**

It is important that people with epilepsy follow a nutritious, well-balanced diet. Good nutritional habits and a healthy lifestyle are important in obtaining optimal seizure control. However, no special diet is prescribed for epilepsy itself.

To avoid dietary deficiencies, ensure proper intake of nutrients through a diet containing adequate folic acid (commonly found in raw and slightly cooked fruits and vegetables), calcium and magnesium (dairy products are the richest source), Vitamin B12 (animal and dairy sources), and vitamin K (leafy green vegetables and cereal grains). Vitamin D is found in fish oils/flesh and supplemented milk, and it is made in the body in response to sunlight. Rules for a healthy diet are outlined in Canada's Food Guide.

If you have some other condition in addition to epilepsy that requires a special diet (diabetes, for example), it is important that you follow the diet needed for that disorder.

### **Do anticonvulsant medications for epilepsy affect nutrients in the body?**

The medicines that control seizures may interfere with the body's ability to use certain nutrients including vitamin D, vitamin K, calcium, magnesium, manganese and folic acid. While this problem is present in most people who take medications, it is usually mild and causes no harm. Those most vulnerable to vitamin deficiencies include people on large doses of medication or multiple drugs, the elderly, growing children, pregnant women, alcohol abusers and those who follow poor dietary habits.

### **What about calcium and magnesium to control epilepsy?**

It is true that convulsions may occur if the body is depleted of calcium and magnesium. However, unless you have some other disease that affects these substances, you will not have problems with them if you eat a balanced diet.

### **What about other vitamins and minerals?**

As stated above, the use of anticonvulsants may have an adverse effect on vitamins. Problems can generally be avoided with a proper diet. However, in rare cases, more serious problems may arise. For example, anemia can result from severe folic acid deficiency. Weak bones are related to inadequate amounts of vitamin D.

A medical examination and laboratory screening can discover vitamin deficiencies. Vitamin supplements can be prescribed, as necessary. Please note that self-diagnosis is discouraged. Self-prescribed "megavitamin" therapy could be harmful. For example, excessive folic acid intake may actually decrease seizure control.

### **Is it important to eat regularly?**

Yes. Some individuals are sensitive to missing meals. If meals are missed or delayed, seizure frequency may increase. Therefore, regular meals and balanced diets are recommended.

### **Do food allergies cause epilepsy?**

Allergies do not cause epilepsy. However, they may aggravate a pre-existing seizure problem.



Suggested reading: *Treating Epilepsy Naturally: A Guide to Alternate and Adjunct Therapies*, by Patricia A. Murphy, forward by Russell L. Blaylock, MD, Assistant Clinical Professor of Neurosurgery, published by Keats/McGraw-Hill, 2001.

*Alternative Therapies for Epilepsy*, by Steven B. Pacia, Orrin Devinsky, and Steven C. Schachter, Demos Medical Publishing, 2012.

## PSYCHOSOCIAL ISSUES

Epilepsy is almost always a trying disorder. Reaction to a diagnosis of epilepsy may range from guilt, dismay, fear or embarrassment to regarding seizures as a routine matter. Many individuals with epilepsy, as well as their families, withdraw from social interaction and normal activity. However, research has shown that some persons with epilepsy have fewer seizures by maintaining an active lifestyle.

If an individual's seizures are infrequent or well controlled and the side effects of medication are minimal, then withdrawal from normal activity may indicate low self-esteem. Family members of individuals with epilepsy may also be vulnerable to these problems.

It may be important to seek help for depression, as research has shown that as many as 25% of those affected by epilepsy will experience depressive symptoms. Some risk factors for depression are a negative attitude towards seizures, poor family relations and an external locus of control. Emotional problems related to the disorder may be more likely to result if the individual has central nervous system damage, poor seizure control or family stress (marital, financial, poor social support or unresolved losses).

Support services may offer a variety of coping strategies through counseling, peer support and education about the disorder. These services may help to provide a pathway to acceptance and a better quality of life. If you or your family members are feeling lost, confused or overwhelmed, an initial consultation with your local epilepsy organization will help to identify available support services, information and referrals for professional help.

## Issues Faced by Individuals and Families Living with Epilepsy

### Children's issues

- Disclosure
- Frequency of seizures
- Fear of having a seizure in public
- Knowledge of anticonvulsant medications
- Schooling
- Medication tolerance/adherence/side effects
- Effects of the ketogenic diet
- Surgery
- Cognitive and developmental delays and/or impairments

### Adolescent issues

- Disclosure
- Fear of having a seizure in public
- Independence (e.g., driving)
- Negative feelings related to the diagnosis
- Psychological issues of living with epilepsy
- Side effects of anticonvulsants
- Medication adherence
- Transfer of responsibility from parent to teen
- Drug and alcohol interaction with anticonvulsants
- Impact of epilepsy on education
- Impact of seizures on potential career choices
- Impact of seizures on employment opportunities
- Safety issues and epilepsy

### Parental issues

- Negative feelings related to a child's diagnosis of epilepsy
- Appropriate seizure management
- Side effects of a child's anticonvulsants
- Dealing with medical emergencies related to seizures (i.e., recognizing status epilepticus and knowing procedures to use, including how to administer emergency medication)
- Education about medical tests and procedures (e.g., EEG), types of seizures
- Implementation of the ketogenic diet
- Long-term planning, effective transfer of responsibility
- Inability to gain seizure control
- Depression
- Breakdown of either parent
- Spousal stress (marital breakdown)
- Negative feelings (particularly when seizures are uncontrolled)
- Family stress
- Need for new parenting techniques (behavioural issues)
- Need for special educational planning
- Need to educate others
- Need to advocate for a child within the education, social service and medical system

### Adult issues

- Negative feelings after the initial diagnosis
- Side effects of anticonvulsants
- Surgery
- Employment issues
- Inability to gain seizure control
- Disclosure of disorder
- Driving
- Discrimination
- Pregnancy (danger of anticonvulsants to fetus)
- Negative feelings about having a seizure (alone or in public)
- Socialization anxieties (sexuality, alcohol intolerance)
- Maintaining independence
- Maintaining parental responsibilities

## Services & Support Links

- [Canadian Human Rights Commission – Make a Complaint](#) Everyone in the world is entitled to the same fundamental human rights. There are [30 of them](#), in fact. They are the universal human rights that we, as citizens of this world, have agreed we are all entitled to. They include the right to live free from torture, the right to live free from slavery, the right to own property, and the right to equality and dignity, and to live free from all forms of discrimination.
- [Human Rights Protection](#) – British Columbia has a law to protect and promote human rights. It is called the B.C. Human Rights Code or the Code. The Code helps to protect you from discrimination and harassment.

### Financial Assistance Links

- [Grants and Scholarships for Higher Education](#) – Scholarships and other non-repayable financial supports.
- [WorkBC Employment Services for People with Disabilities](#) – Discover job options and services designed to support people with disabilities.
- [Access the Registered Disability Services Plan \(RDSP\)](#) – Access RDSP is a partnership between BC Aboriginal Network on Disability Society (BCANDS), Disability Alliance BC (DABC), and Plan Institute, designed to help people become informed, become eligible, and open an RDSP.
- [Applying for Disability Assistance](#) – Disability assistance can help you if you need financial or health support. You must be designated as a Person with Disabilities (PWD) to receive this type of assistance.
- [Persons on Disability Assistance](#) – When you're on disability assistance the amount of financial support you receive depends on the size of your family. It also depends on whether another person in your family has the Persons with Disabilities designation.
- [Income Assistance](#) – If you are in need and have no other resources, you may be eligible for income assistance. This can help support your transition to employment.
- [Training Tax Credit](#) – The training tax credit is for employers and apprentices who take part in eligible apprenticeship programs administered through the Industry Training Authority (ITA).
- [CRA Disability Tax Credit](#) – The disability tax credit (DTC) is a non-refundable tax credit that helps persons with disabilities or their supporting persons reduce the amount of income tax they may have to pay. An individual may claim the disability amount once they are eligible for the DTC. This amount includes a supplement for persons under 18 years of age at the end of the year.
- [Child Disability Credit](#) – The child disability benefit is a tax-free monthly payment made to families who care for a child under age 18 with a severe and prolonged impairment in physical or mental functions.
- [Variety Children's Charity](#) – Variety – the Children's Charity steps in where health care ends, providing direct help to children with special needs in BC. For over 50 years, Variety has ensured that children have the support to reach their potential and thrive.
- [CRA Medical Expenses Tax Credit – Service Animals](#) – Currently, the METC provides tax relief in respect of certain expenses related to an animal specially trained to assist a patient in coping with the following impairments: blindness, profound deafness, severe autism, severe diabetes, severe epilepsy or a severe and prolonged impairment that markedly restricts the use of the patient's arms or legs. For the expenses to qualify for the METC, the animal must be provided by a person or organization one of whose main purposes is providing this special training.
- [BC Housing Assistance](#) – BC Housing works in partnership with the private and non-profit sectors, provincial health authorities and ministries, other levels of government and community groups to develop a range of housing options.
- [BC FoodBank](#)

## Health Links

- [HealthLink BC 811](#)– 8-1-1 is a free-of-charge provincial health information and advice phone line available in British Columbia. The 8-1-1 phone line is operated by HealthLink BC, which is part of the Ministry of Health. By calling 8-1-1, you can speak to a health service navigator, who can help you find health information and services; or connect you directly with a registered nurse, a registered dietitian, a qualified exercise professional, or a pharmacist. Any one of these healthcare professionals will help you get the information you need to manage your health concerns, or those of your family.
- [HealthLink BC Epilepsy](#) – An overview of Epilepsy by the Provincial Government of British Columbia.
- [HealthLink BC Epilepsy Diary](#)

## Other Support Links

- [Lions Foundation of Canada- Seizure Service Dogs](#) – Lions Foundation of Canada’s mission is to assist Canadians with a medical or physical disability by providing them Dog Guides at no cost. To do this, the Foundation operates Dog Guides Canada, a preeminent national training school and charity that assists individuals with disabilities through specialized Dog Guide programs. These Dog Guides are provided at no cost to eligible Canadians from coast to coast despite costing \$25,000 to train and place. The Foundation relies on donations from individuals, service clubs, foundations and corporations and does not receive any government funding.

## Driving and Transportation Links

- [TransLink – HandyDART](#)
- [Via Rail Pass – Epilepsy Canada](#)
- [BC Bus Pass Program](#)
- [Travel Assistance Program \(TAP\)](#)
- [Drivers with Epilepsy](#)

## Glossary

**Absence:** A type of seizure in which a child stares, blinks, flutters eyelids and is briefly unconscious, associated with learning problems if untreated.

**Anticonvulsant, antiepileptic drug (AED):** A type of drug used to control seizures.

**Atonic:** A type of seizure in which the individual abruptly falls and is briefly unconsciousness with quick recovery.

**Aura:** A warning sensation, feeling, smell or random activity that happens up to half an hour prior to a major seizure, allowing the person time to take safety precautions.

**Convulsion:** Epileptic muscle contractions which may be constant or jerking.

**Cryptogenic:** Cause suspected, but not proven.

**Drug Interaction:** When one drug changes the effect of another. A common problem when taking anticonvulsants with other drugs or over-the-counter medications or herbal remedies.

**Electroencephalograph (EEG):** A device used to measure electrical activity in the brain and used to diagnose epilepsy.

**Epilepsy:** Repeated abnormal electrical activity in the brain which may result in uncontrolled movement, unusual sensations, emotions and changes in breathing and consciousness.

**Focal Aware Seizure:** A type of seizure which involves only part of the brain and in which the person remains conscious.

**Focal Impaired Awareness Seizure:** A seizure in which a person may wander, engage in random behaviour, mumble, pick up objects, run or otherwise repeat the same behavioural pattern. The patient has no recollection of the seizure.

**Focus:** An area in the brain where abnormal electrical activity starts in a seizure.

**Generalized seizure:** Typically tonic-clonic or absence seizures. Abnormal electrical activity is found throughout the brain and involves loss of consciousness.

**Ketogenic diet:** A highly controlled, high-fat, low-carbohydrate diet used to treat hard to control seizures primarily in children since the 1920s. It requires consistency, high motivation and constant medical supervision.

**Idiopathic:** Cause unknown.

**Ictal:** Period of time during a seizure.

**Infantile Spasms (West Syndrome):** May look like head nods or stiffening of body. Brief, onset before age two.

**Interictal:** The time between seizures.

**Intractable:** Uncontrollable.

**Neurologist:** A medical specialist who is trained to treat seizure disorders.

**Partial seizure:** Two types, simple and complex.

**Photosensitive:** Seizures that are triggered by flashing lights (i.e., Christmas lights, computer screens, televisions). About 1% of epilepsies are photosensitive.

**Post ictal:** Period of time shortly after a seizure.

**Prodrome:** Feelings far beforehand, which indicate to the person that a seizure is coming (not an aura).

**Seizure disorder:** Another term for epilepsy.

**Seizure:** Uncontrolled movements, behaviour, sensations, feelings, changes in breathing or consciousness, caused by abnormal electrical activity in the brain.

**Symptomatic:** Cause is known.

**Status Epilepticus:** A life-threatening medical emergency that occurs when a seizure lasts for more than five minutes or repeats without full recovery. **Call 911.**

**Tonic seizure:** A type of seizure involving rigid muscle contractions.

**Tonic-clonic (grand mal) seizure:** A type of seizure in which the person loses consciousness.