



Big Brothers Big Sisters
of the Fraser Valley

Chapter 1: Healthy Bodies

Epilepsy

Learning More to Reduce The Stigma

Call 9-1-1 or your doctor
in emergency situations

Kids Help Phone
1-800-668-6868

National Toll-Free
Number for Epilepsy
Support in BC
1-866-Epilepsy

The Center for Seizure
and Epilepsy Education
in BC (Abbotsford)

www.epilepsy.cc

Canadian Epilepsy
Alliance

www.epilepsymatters.com

British Columbia
Epilepsy Society

www.bcepilepsy.com

Victoria Epilepsy and
Parkinson's Centre

www.vepc.bc.ca

Epilepsy.com—Kids Page

Epilepsy.com/kids/kids

AboutKidsHealth:
Epilepsy

[www.aboutkidshealth.ca/
epilepsy](http://www.aboutkidshealth.ca/epilepsy)



What are Seizures?

A seizure is an involuntary behavior that results from an abnormal electrical signal in the brain. It can affect how you think and feel, and can make your body do things you can't control. There are several different types of seizures. **Partial seizures** may not cause a change in consciousness, but can cause you to feel unusual smells or tastes, weakness, numbness, twitching, paralysis, vision changes, or dizziness. These seizures happen when electrical activity becomes focused in only a *part* of the brain. In a **Simple-Partial seizure** a person is still aware of their surroundings, while a **Complex-Partial seizure** does impair consciousness, and can disorient and confuse a person. Sometimes seizures begin as partial then become generalized. **Generalized seizures** involve the entire brain and will cause loss of consciousness with or without muscular irregularities that can include movements of the legs, arms, and face. In a **Tonic-Clonic seizure**, the person may fall to the ground and begin to shake, sometimes becoming incontinent (losing control of their bladder), drooling, or biting their tongue. **Absence seizures** involve a brief loss of awareness that does not affect the muscles. Every now and then, a person will stop what they are doing and blank out for a moment (stare blankly, roll eyes upward, blink rapidly, etc.) before continuing with their activity. They will have no memory of the event and will not know it happened. This is one of the most common seizures in children. Some seizures are brought on by things other than epilepsy. Seizures can be caused by high fever, a head injury, a drug or medication, or a medical condition like diabetes. A doctor can determine whether or not a person has epilepsy.

What is Epilepsy?

Epilepsy is a disorder where there is a disturbance in the brain's electrical firing, which can cause seizures with or without a loss of consciousness. Epilepsy affects about 1% of Canadians. Up to 10% of people will experience a seizure at some point in their life that is not related to epilepsy. Anyone can have a seizure if the brain is experiencing severe stress (like a very high fever in young children).

How Does Epilepsy Happen?

Doctors don't always know why a person has epilepsy. Sometimes epilepsy is caused by a serious illness or an injury to the head. In 65% of people, it's impossible to determine what caused the condition. Epilepsy is not contagious, the way a cold or flu is. You can't catch epilepsy from a friend, or give it to somebody. If someone finds out they also have epilepsy, it is purely a coincidence and was not caused by anyone they know. Current research (eg. at McGill University Health Centre) suggests that epilepsy might be inherited (it might be in your genes, so you might be slightly more likely to get the disorder if you have a family member with epilepsy) but you can't "catch" it from another person—family member or not.

Big Brothers Big Sisters of the Fraser Valley:

www.mentoringworks.ca



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What Should I Do if I Have Epilepsy?

Not everyone needs to know about your epilepsy. Who you tell should depend on how often you have seizures and how you feel about telling people. If you might have seizures during the time you are with your friends, they should know what's going on so they know how to help you rather than panic. Even if your seizure medicine stops all your seizures, you might find that it feels good to share information about your epilepsy with your close friends rather than keeping it a secret. It's really up to you. If you are nervous about having a seizure at school, ask your teacher to speak to the class about epilepsy, refer her to the resources in this article, or consider offering your personal story to your classmates to help them understand you better. Explain what happens when you have a seizure, and how your classmates can help support you. Learn about important safety restrictions specific to your type of seizures (For example, some activities like swimming or driving aren't always recommended for those with uncontrollable seizures. In fact, citizens of BC must be seizure-free for one year before driving a car.) With a few minor lifestyle precautions like eating differently and getting enough rest, people with epilepsy lead totally normal lives!

How Can I Control My Seizures?

Most people with epilepsy can have their seizures totally and perfectly controlled. Stay well rested, take prescribed medication on time, and maintain an active and healthy lifestyle. Eat healthy meals (additive and Aspartame-free), stay well hydrated, use stress management techniques to control the amount of stress in your life, and avoid drug interactions by asking your doctor or pharmacist before trying new medications, herbal supplements, or other drugs that may interact with your seizure medication.

Some Common Seizure Triggers:

- ◆ MISSING, STOPPING OR MISUSING ANTI-CONVULSANT MEDICATION
- ◆ LACK OF REST; INCREASED STRESS
- ◆ BLOOD SUGAR CHANGES (EG. MISSING MEALS OR BINGING)
- ◆ DRUG OR ALCOHOL USE

Auras Help Me Know...

An *Aura* is a type of partial seizure experienced by many people with epilepsy. This serves as a warning that a Generalized-Tonic-Clonic seizure may occur. An Aura is usually felt as an unusual sensation that may include a funny taste or smell, a tingling or unusual feeling somewhere in the body, or a visual sensation. It could also be an unusual or confusing thought, like déjà vu, or sudden fear. This funny feeling can serve as a handy warning that a seizure is about to happen and give a person time to make sure they are in a safe location! When the funny feeling lasts for hours or days, it is called a *Prodrome*. Prodromes are also useful ways to alert someone that a seizure is coming. Other warning signs can include nausea, headache, depression, irritability, and sleep disruption. It's important to tell your doctor about your auras, since they can help him pinpoint where your seizures begin. It can also be handy to tell friends, mentors and family about your warning signs so they can notice when they occur and can help.

WHAT DO I DO IF MY FRIEND HAS A CONVULSIVE SEIZURE?



- First thing first—take a deep breath. As scary as a seizure looks, they typically last 1-3 minutes and usually aren't dangerous. Your friend will be fine.
- Don't try to stop the seizure. If your friend is standing up, try to guide them away from potentially dangerous areas (eg. stairs or a road) and help them lie down. Move objects out of the way that may injure your friend. Do NOT put anything in your friend's mouth or give them anything to eat or drink. Remove objects from your friend's mouth (eg. If they were in the middle of eating), loosen clothing around their neck, remove glasses, remove anything from the area that could cause injury, and place something soft under their head. Do not try to restrain them.
- If there is a crowd, ask them to step back and carry on with their normal business to give your friend some space and privacy.
- If you are able, after the seizure, you can gently turn your friend from their back to their side to prevent choking. Speak calmly to your friend and reassure them that everything will be alright. Stay with them until they are fully awake and with a parent or doctor. Note that people are often confused after a seizure and can become combative (fight back) if restrained.
- If possible, note how long the seizure lasted and any injuries so you can tell emergency personnel or your friend's parents.
- For Non-Convulsive Seizures, gently redirect your friend away from danger, speak reassuringly until consciousness is regained, and help them get home safely.
- Be a Friend.

Most seizures last under five minutes and are not medical emergencies, however, **Call 9-1-1 immediately if:**

- ◆ This is the person's first seizure
- ◆ A seizure lasts more than five minutes or a second seizure follows before full recovery from the first
- ◆ Normal breathing and consciousness are not restored after the seizure or skin/lips/tongue/nailbeds get a blue or green tinge (cyanosis caused by lack of oxygen in blood).
- ◆ Confusion lasts more than one hour after the seizure
- ◆ The seizure takes place in the water
- ◆ The person is pregnant, diabetic, or has been injured



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Ways to Cope with Epilepsy

From *The Center for Epilepsy & Seizure Education*

(www.epilepsy.cc)

Some ideas to encourage the coping or healing process:

- Find a safe place to vent, cry and talk.
- Keep a journal of your feelings and dilemmas - it can often help put things into perspective and contribute both in the moment and on later reflection.
- Identify what you enjoy doing and making it a priority to fit these into your routines.
- Communicate your needs to others in an assertive and effective manner. Family and friends will be willing to support you, but might not know how to - so let them know.
- Do not repress your happiness; seek social outlets with people who have had similar experiences. Look for friends who don't make an issue of your epilepsy.
- When words are inadequate to express feelings - explore your creativity (through music, art, poetry, photography). It is important to remember that expressing thoughts and feelings is what helps us move from hurt to healing and helps us understand what needs to change in our attitudes or behaviour, in order to integrate the "unwanted" in our lives in a meaningful way.
- Explore your faith - finding the spiritual significance for whatever is going on in your life is crucial in coping with distress.
- Advocate for yourself or your loved one, help others who are struggling with similar issues.
- Acknowledge that acceptance is a continuum and that you may waver on this continuum from time to time and that it involves a period of acute grief, before reorganization occurs.
- Pay attention to your physical needs - nutrition, exercise, sleep and rest. Learn and practice relaxation techniques. There is a lot of research evidence showing how a relaxed body contributes to the health and well-being of individuals with epilepsy and their families.
- Being part of a **support group** often helps people cope with epilepsy. Whether you are a parent, friend or mentor of a child with epilepsy, or an individual who lives with epilepsy, it is helpful to find people in a similar situation and form a support group to share your experiences. Listening to others in a similar situation breaks the isolation. It helps you see "you are not alone" and that your issues are common and surmountable. It provides an opportunity to learn from others and support others. You may gain an insight into your own ways of coping, when you listen to others deal with similar situations. If there is not a support group in your area, you may want to start one. You will be amazed how many people are interested. Many people have also found lasting friendships through support groups.

HAVE YOU HEARD?

Lavender is the colour of Epilepsy Awareness because lavender has traditionally been the symbol for things that are hidden or isolated, much like epilepsy. Lots of Canadians are wearing lavender wristbands (available at Epilepsy Centres or online) to raise money for Epilepsy Awareness and to spread the word about epilepsy to bring it out of the shadows and help people learn more about it!



The Social Stigma of Epilepsy

Stigma is a word that means the shame or disgrace attached to something that is considered socially unacceptable. Unfortunately, epilepsy is one disorder that carries a degree of social stigma. Some people discriminate against those with epilepsy. They might be afraid epilepsy is contagious; nervous they will not be able to help someone who is having a seizure; or unsure if a person with epilepsy can participate in "regular" activities. Employers may discriminate against employees with epilepsy because they think the disorder will get in the way of their ability to work. Some people even believe that epilepsy is caused by witchcraft or evil spirits! It's unfortunate that many people don't understand what it means to have epilepsy, and that people with epilepsy still lead safe, productive, and normal lives. Many people with epilepsy are scared to tell others, because they don't want to be treated differently. Understandably, keeping such a big secret from friends is quite confusing and stressful, especially for children and teens!

You might be wondering what you can do personally to change public perception about epilepsy and reduce the social stigma surrounding it. If you have epilepsy, keep a positive attitude about your abilities. Educate everyone you know about the facts of epilepsy, and dispel any myths your peers may mistakenly believe. Come up with a creative way to fundraise for epilepsy awareness and research. Advocate for yourself or your friend if someone is being discriminated against. Avoid using your epilepsy as an excuse for things you don't want to do.

HOW CAN BIG BROTHERS/BIG SISTERS OR PARENTS HELP REDUCE THE STIGMA OF EPILEPSY?

Parents and Big Brothers/Big Sisters can help build strength and resilience in their children – the ability to adapt and deal with stress in a positive way that promotes self-confidence and learning. Children will mimic the adults in their lives when it comes to how they react to and cope with their epilepsy so it is important to keep a positive and upbeat attitude regarding their diagnosis. Address negative coping strategies (eg. if your Little stays home frequently rather than going out with friends) and model positive responses to negative attention and comments. Don't let your Little use epilepsy as an excuse for isolating him or herself or refusing to try new activities. Utilize the resources listed on the first page of this article. For example, *The Center for Seizure and Epilepsy Education* in Abbotsford holds events for children to interact and meet with their peers and would be happy to offer you guidance and resources to help you better understand your Little and his or her unique needs.



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Resources

Available from the Fraser Valley Regional Library

WHAT IF MY LITTLE HAS EPILEPSY?

- ⇒ Learn how to help if your Little has a seizure. Ask his or her parents what you should do when it happens, and keep emergency contact information on hand. The average seizure is not a medical emergency if it ends shortly without any problems and the child appears to be back to normal. Ask your Little's parents what to look for and in what circumstances they would like you to call 9-1-1. Don't give medication to the child unless you have been authorized to do so. Ask which warning signs to look for that indicate a seizure is on its way.
- ⇒ Help your Little research a famous person with epilepsy that accomplished great things in their lifetime. Role models are great to have, especially ones who demonstrate that a disorder or disability doesn't limit opportunities.
- ⇒ Drug and alcohol experimentation is especially dangerous for people with epilepsy. Discuss ways to deal with peer pressure when it comes to drugs and alcohol, and why it's not a good idea for teens with epilepsy to partake in these activities.
- ⇒ Littles with epilepsy may face additional issues related to self-esteem, independence, fitting in, maintaining employment, dealing with depression, overcoming social stigma, etc. Encourage your Little to share his or her feelings with you.
- ⇒ Educate yourself on the side effects of your Little's medication so you know which symptoms are medically dangerous. Also realize some of these medications can lead to side effects that affect your Little's body image and self-esteem, like weight gain/loss, rashes, drowsiness, dizziness, gum overgrowth, and hair loss/excessive growth. Keep in mind epilepsy can also affect a child's learning, behavior, and memory.
- ⇒ Tell your Little's family about summer camps that offer sessions for children with epilepsy, such as *The Zajac Ranch for Children* in Mission, BC or the *Easter Seals Camps* located across Canada.



Thank you to the following members of our Panel for

Reviewing this Article:

- ◇ Dr Lionel Traverse, MD
- ◇ The Center for Seizure and Epilepsy Education

FOR LITTLES (6-12)

My Friend has Epilepsy. Anna Levene. MN: Chrysalis Education, 2003.

Epilepsy. Hayley Mitchell Haugen. MI: Kidhaven Press, 2005.

Becky the Brave: A Story About Epilepsy. Laurie Lears. Ill: A. Whitman, 2002

For TEENS (13-17)

Epilepsy: The Ultimate Teen Guide. Kathlyn Gay and Sean McGarrahan. MD: Scarecrow Press, 2002.

For BIG BROTHERS/BIG SISTERS & PARENTS

Children with Seizures. Martin L. Kutscher. Philadelphia: Jessica Kingsley, 2006.

Growing Up with Epilepsy: A Practical Guide for Parents. Lynn Bennett Blackburn. NY: Demos, 2003.

Epilepsy and the Family: A New Guide. Richard Lechtenberg. Mass: Harvard University Press, 1999.

Seizures and Epilepsy in Children: A Guide for Parents. John M. Freeman, Eileen P.G. Vining, Diana J. Pillas. Baltimore: John Hopkins University Press, 1997.

Your Child and Epilepsy: A Guide to Living Well. Robert J. Gummit. NY: Demos Vermande, 1995.

The Center for Seizure and Epilepsy Education provides a wealth of educational resources free to anyone affected by Epilepsy. Contact them for more information.
(See Resources on page 1)



FAMOUS PEOPLE WITH EPILEPSY

Epilepsy is definitely not a mental illness, nor a sign of decreased intelligence. In fact, many people known for their superior intelligence and creativity throughout history, including writers, artists and inventors, had epilepsy. Some of these famous personalities include the great thinker Socrates, Roman military leader Julius Caesar, famous authors Charles Dickens (pictured above), Lewis Carroll (the author of *Alice in Wonderland*) Edgar Allan Poe, Fyodor Dostoyevsky, and Agatha Christie. Alfred Nobel—the creator of the Nobel Peace Prize is also said to have suffered from epilepsy, as well as musical composers Tchaikovsky and Beethoven. A few modern day examples of celebs with epilepsy include actor Danny Glover, and Olympic medalist Chanda Gunn. Learn from their example: People with epilepsy achieve great things!