

EPILEPSY

Parents Guide for Epilepsy/ Seizure Disorder



This information provides general information about epilepsy/seizure disorders to the public. The information shared here should not be taken as full medical advice. Only your doctor can give the medical advice that is right for you.

Epilepsy/Seizure Disorders

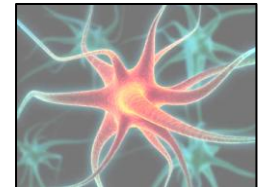
Epilepsy/seizure disorders are a condition of the brain that is characterized by recurrent seizures. Approximately one in ten Canadians will experience at least one seizure during a lifetime. A single seizure, however, is not epilepsy. Epilepsy/seizure disorders are conditions that are defined by multiple seizures.

Epilepsy/seizure disorders are **not** psychological disorders or a disease and they are **not** contagious.

They are also a condition that is more common than most people realize. In the general population, approximately one person in a hundred has epilepsy/ seizure disorders. In Canada, there are an estimated 300,000 people with epilepsy or seizure disorders.

Seizures

The brain is made up of billions of nerve cells or neurons that communicate through electrical and chemical signals.



When there is a sudden excessive electrical discharge that disrupts the normal activity of the nerve cells, a change in the person's behavior or function may result. This abnormal activity in the brain that results in a change in the person's behaviour or function is a seizure. A seizure can take many different forms. For instance, a person having a seizure might stare blankly, jerk his or her arms uncontrollably, feel a burning sensation, or have a convulsion.

The form a seizure takes depends on where in the brain the excessive electrical activity occurs.

What causes epilepsy?

In over half of all epilepsy incidents, no cause can be found. Among the rest, head injuries, brain tumors, genetic conditions, lead poisoning, problems in brain development before birth, illnesses like meningitis or encephalitis or even severe cases of measles may result in seizure disorders.

The child with epilepsy usually should not be treated differently from other children. If a seizure occurs while you're caring for a child, don't panic. Although seizures may look painful, they are not!



You may see brief changes in how a child moves or acts during a seizure, for example:

- A seizure could make a child stop what he's doing and stare for a few seconds.
- It could make a child fall suddenly to the ground perhaps with incontinence or followed by excessive fatigue.
- It could make an arm or leg shake for a minute or two.

- It could make a child feel afraid or angry or make things look different from what they really are.
- It could make a child seem confused and dazed, as if half asleep.
- It could make a child have a convulsion that results in falling, stiffness and shaking for a minute or two (Pale or bluish complexion may result from difficult breathing.)

How Serious is Epilepsy?

Epilepsy is very variable. How serious it is depends on the type of epilepsy and its impact on the child's life. Three out of four children with epilepsy have very mild cases. These children often outgrow epilepsy as they grow older. Even children with ongoing seizures requiring medical treatment respond to drugs and lead active, productive lives.

Cases of intractable or drug resistant epilepsy, however, present a real challenge to the child, family and the clinician. In some of these cases, seizures may be associated with motor problems or development delay.

Doctors Who Treat Epilepsy

The initial diagnosis of epilepsy will probably come from a family doctor or a paediatrician. While family doctors or paediatricians can diagnose and treat epilepsy, we believe that all children with serious, ongoing epilepsy should be seen by a paediatric neurologist.

Choosing a Neurologist

The following suggestions may help you choose a neurologist that is right for you.

- Ask a doctor; your family doctor or paediatrician to recommend a neurologist
- Find out what hospital affiliation the neurologist has
- Look for a neurologist you feel you can talk to, who answers your questions and who is willing to seek a second opinion if necessary
- Become a member of your local epilepsy organization and attend awareness events where you can talk to the local neurologists and to the parents of the children they treat.
- Remember, you can be referred to a neurologist only by another doctor.



How You Can Help Your Doctor?

Doctors need to determine the type of seizures your child has before they can prescribe the right medication. Because they often do not actually see the seizures, they rely on your description to distinguish among the possible seizure types. We suggest that you keep written records or if you have a video camera, record them and show your doctor.

Clinical Programs for Children with Epilepsy

- With proper medication, most seizures can be controlled. Some types of seizures, however, resist drug control and continue to occur despite the best anticonvulsant therapy. These seizures are sometimes associated with development delay or with behavior problems.
- If your child continues to have seizures despite good medical treatment, your doctor may wish to refer him or her to a center that specializes in the treatment of drug-resistant epilepsy. To be admitted, your child must be referred by a medical doctor.

Medications for Epilepsy

Drug therapy is the most common treatment for epilepsy. The drugs used to treat epilepsy are called anticonvulsants, anti-epileptic drugs or anti-seizure drugs.

Anticonvulsant medications come in a wide variety of preparations, including liquids, tablets, controlled-release tablets, chewable tablets, etc. They also come in different strengths. The same drug may come in several different formulations. Discuss with your doctor or pharmacist which formulation is best for you.

Brand name drugs and generic drugs do not always release the same amount of medication into the child's system. You should ask your pharmacist not to substitute one for the other.

When storing anticonvulsant medication, store it and all other medicines out of reach of children. Keep the medication in a dry place. Liquid medications may require refrigeration.

Anticonvulsant medications should be taken at the same time(s) each day. If your child misses a dose, give it as soon as possible. If more than one dose is missed, follow your regular schedule and take the missed dosage at bedtime. If an entire day is missed, consult your doctor.

Before emergency treatment or any kind of surgery is undertaken, tell the doctor or the dentist that medication is being taken.

Some anticonvulsant medications may make your child dizzy, drowsy, clumsy or less alert than normal. If this occurs, your child's teacher should be told that the child is taking medicine that may cause these effects.



If you are travelling across international borders, get a note from your doctor describing your child's condition and need for medications.

Anticonvulsant drugs may interact with other drugs the child is taking. Your doctor knows these interactions, so be sure s/he is informed of all the drugs your child is taking.

As female children grow older, it is important to remember that anticonvulsant drugs may reduce the effectiveness of oral contraceptives.

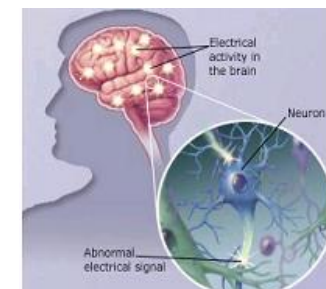
Surgery for Epilepsy

Surgery is considered only when seizures are frequent and when drugs have failed. Seizure surgery is never undertaken lightly. Surgery is far less dangerous than people think and recovery is often quite rapid. Surgery should be considered by parents whose children have uncontrolled partial seizures, particularly if the child is experiencing serious drug side effects. You must be referred to a surgeon by a doctor or neurologist.

Who Is a Candidate?

The child must have:

- frequent, drug-resistant seizures that disrupt life
- seizures which always come from the same part of the brain
- seizures which come from a part of the brain that can be removed



Not all children with drug-resistant seizures are candidates for seizure surgery. Children with seizures arising from many sites or with primary generalized seizures are usually not helped by surgery.

Ketogenic Diet

The ketogenic diet is a medical diet used to treat children with seizures that have failed to be controlled by traditional medications. This diet must be given under medical supervision.

The ketogenic diet is a high fat, low carbohydrate diet, which drives the body to produce ketones. The body prefers to use glucose (carbohydrate) as its source of fuel, which is stored in the body in the form of glycogen. When there is insufficient glucose or when glycogen stores are depleted, the body will use fat as its major energy source. assure that you are prepared and that your concerns are addressed

This process of burning fat in the absence of glucose produces ketones. Ketones have been demonstrated to reduce seizures in some children.

The ketogenic diet provides complete control of seizures for approximately 1/3 of children, partial control for another 1/3, and does not work at all for the remaining 1/3 of children who try it.

What are the Risks of the Diet?

The ketogenic diet does not provide all the vitamins and minerals needed to be healthy. Therefore, without appropriate nutritional supplements, vitamin and mineral deficiencies may occur.

The diet may increase blood cholesterol and triglyceride levels.

The diet may produce lower-than-normal blood sugar, which may cause adverse effects such as low energy, confusion, and irritability. Therefore, blood sugars are closely monitored by using a glucose meter at home.

Kidney stone formation has been documented, therefore it is important to endure adequate fluid intake and appropriate monitoring by a physician.

This diet may alter the function of white blood cells, affecting the body's resistance to infection.

The MCT-ketogenic diet may produce gastrointestinal upset (diarrhea, cramps, etc.)

Epilepsy and the Family

Each family member may respond differently to having a child in the family with seizures. Some of the usual feelings may be confusion, guilt, fear, loss, inadequacy, anxiety, disbelief, shock, shame and embarrassment. Each family member, depending on their previous experience with seizures, may cope differently with their feelings. Sometimes these feelings can become problematic, interfering with relationships and day-to-day life. Should this occur, parents may want to consider talking with a professional epilepsy counsellor.

It is usual to seek counselling should you want help to work through feelings about your child's epilepsy.

Talking to other parents can be helpful in realizing that you are not alone with your feelings and experiences. Parents who have been down the road before can help to identify the road ahead and parents looking back can see how far they have come. Meeting other parents can be an invaluable way to gain knowledge and support.

Parenting at Different Stages

Pre-Schoolers (3 years to 5 years)

When a child has seizures, the concerns and worries of the parent may push them to parent differently than they would have if their child did not have seizures. Some parents view their child as being constantly at risk to danger, which leads them to being excessively protective. This may lead to their child being inhibited and frightened of trying new things.

Other parents view their child as special or sick and feel so sorry for them that they become excessively permissive. This may lead to their child being disinhibited or not able to manage feelings or behavior.



At this stage it is extremely important to set rules and expectations, exposing your child to various social situations with an appropriate amount of supervision where the child can learn about and practice new skills with others. Again, the balance between what a child needs in order to grow up, and making it reasonably safe for your child is one that each parent struggles with and finds on their own.

Latency Age (7 years to 11 years)

A child's sense of self-esteem comes from feeling good about their accomplishments and successes and realizing that they can make it happen. When children have seizures, they may be held back from activities and from experimenting with social situations for fear of lack or safety. If the message they hear is "You can't do that," they may learn that they should not even try because they may fail. Growing up means taking risks and achieving benefits from those risks. Your child, like any child, needs to be given that opportunity.

At this stage, children must be told about their seizures, what happens to them during a seizure and to be able to explain this to their friends.

Adolescence (12 years to 18 years)

Adolescence is a challenging and exciting phase of life for both adolescents and their parents. Most adolescents argue with their parents, test limits, spend increasing amounts of time away from home with their peers and being to think about life after high school. It is usual that parents worry if their child is getting into trouble, making the right choices and not being responsible enough.

When this phase is combined with seizures, the level of worry for parents can be exacerbated. Some children may find that they are just like their peers and pay no attention to their safety. Others are inhibited and never find a peer group to belong to because they feel so different.

Parents can help their adolescent through this phase so that there is only a minimal amount of turmoil. They can encourage their adolescent to become involved in safe peer group activities. Independence and safety can be discussed through ongoing dialogue rather than arguments, so that both parties will get what they want.



Your adolescent will not remain an adolescent. s/he will move on to adulthood and will need to learn to function in adult systems. A parent's job is to prepare them for that, to provide them with the equipment and skills necessary to survive in an adult world.

Brothers and Sisters

When you have a child with seizures, there are many things to attend to and preoccupy yourself with. Parents have expressed concern about their other children feeling left out or neglected. Siblings are at risk of feeling left out, jealous, scared, or unnecessarily responsible.

Some suggestions to help minimize the impact of these risks are:

- Take time to talk with your children about epilepsy
- Plan for one-to-one time with the sibling as well
- Give your child with epilepsy responsibilities, duties and privileges as you do your other children in the family

- Don't give in to your child for fear s/he will have a seizure
- Don't limit play opportunities between your child with epilepsy and their brothers and sisters



Siblings as Care Givers

It is important to remember that brothers and sisters play a significant role in the life of your child with epilepsy. Siblings who understand the seizures and are not fearful of them can often be helpful by making sure that other children do not overreact to a seizure and by calling a designated adult to assist the seizing child.

It is important to note that placing responsibility on the sibling to supervise a child with seizures is not recommended. This places the sibling in a parent role and gives them too much responsibility.

School

It is important to know that most children with epilepsy do well in school and do not have a learning problem. There are a number of factors that may affect your child's learning potential and development. If your child is experiencing learning difficulties in school, you must consider more than the actual seizures and look at other potential contributing factors.

The frequency of seizures may affect your child's learning experience, as may your child's attitude toward school, intellectual ability, self-image, medication side effects, the teacher's attitude towards epilepsy, and the attitude of fellow classmates.

Self-Esteem

Parents have a very influential role when it comes to encouraging and building self-esteem in their children. Self-esteem may in fact be the single most important attribute a child can develop. For a child with a chronic disorder such as epilepsy, developing self-esteem may be an even greater challenge. Parents must talk about epilepsy with your child and encourage them to play an active part in the management of their seizures.



First Aid and Safety

Generalized-convulsive Type Seizures

- **Keep Calm.** A convulsive seizure is often dramatic and frightening, but it usually lasts only a few minutes and usually does not require medical aid. Let the seizure take its course. Do not try to stop the seizure or revive the child. Observe carefully to later report to doctors.
- **Protect the child from further injury.** Move hard, sharp or other dangerous objects away, but do not interfere with the child's movements. Place anything small or soft under the head. Loosen tight clothing.



- **Do not force anything between the child's teeth.** Teeth and jaws may be damaged by so doing. The tongue may be bitten, but will heal.
- **Roll the child to the side when jerking has stopped** to allow saliva or other fluid to drain away, helping to clear the airway.

Partial-non-convulsive Type Seizures

- **Stay with the child.** Do not try to stop the seizure, but let it take its course.
- **Gently guide child away from danger** and move dangerous objects out of the way
- Partial seizures may spread to other areas of the brain.

After all types of Seizures

- Talk gently to the child, comfort, and reassure them as they strive to re-orient themselves. Some individuals will need to rest or be accompanied home.
- Encourage bystanders to disperse.

Everyone faces limits of some kind for different reasons. Change your perspective, and you'll find obstacles become challenges – defining what you can and cannot do.

*Take control.
Don't let epilepsy get in the way of a satisfying life.*

Epilepsy and Seizure Association of Manitoba

One of the major goals of the Association is education. There are over 23,000 Manitobans, of all ages, with epilepsy/seizure disorders. Here are some of the services we provide:

- Free Information Packages
- School Awareness Programs
- Community Education
- Print and Video Library
- Support Groups

If you have any further questions and/or would like to discuss epilepsy/seizure disorder with our Association, please feel free to contact us.

For more information
or to become a member
contact:



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**Epilepsy and Seizure Association of Manitoba
is a member of
Canadian Epilepsy Alliance**