

# Seizure Information

## What is epilepsy?

Nerve cells in the brain communicate with one another via small bursts of electrical activity. A **seizure** is a sudden excessive electrical disturbance in the brain which disturbs the normal activity of these nerve cells. It is estimated that one in ten Canadians will have a seizure in their lifetime.

Seizures can be divided into 2 main categories. They can be of focal onset which means that only one part of the brain is affected or generalized meaning that the whole brain is affected.

A seizure can look very different from one child to another. You might either see that your child has abnormal movements, an odd behavior, a change in his/her level of awareness, is staring blankly ahead or reports odd sensations. The area of the brain that is disturbed by this excessive electrical signal will determine the form the seizure will take.

Seizures usually last a few seconds to a few minutes and will most of the time stop on their own. The term **status epilepticus** is used to describe a prolonged seizure or multiple seizures one after the other without the child returning to normal in between. It is a medical emergency.

Recovery after a seizure is highly variable and depends on the duration and type of seizure that your child has had. Your child can be entirely back to normal after the seizure or might complain of feeling tired, be confused and/or have muscle aches.

**Epilepsy** is a chronic seizure disorder meaning that the brain has an underlying predisposition to generate seizures. This diagnosis can be made if a person:

1. Has had 2 or more unprovoked (without any identifiable cause such as an active brain infection) seizures
2. Has had one unprovoked seizure and is considered at high-risk of having another one
3. Is diagnosed with an epilepsy syndrome

It is estimated that approximately 1-2% of the population in Canada has epilepsy. There are many different causes of epilepsy including a brain injury, lesion, scar or tangle of blood vessels as well as genetic factors. Epilepsy often begins during childhood. Sometimes, the cause of the seizures remains unknown. There are many effective treatment options for epilepsy. Often, seizures can be controlled with medication. When seizures are difficult to control with medication only, there are other treatments that can be discussed.



Figure 1: Retrieved at <https://epilepsyco.org/about-epilepsy/what-is-epilepsy>

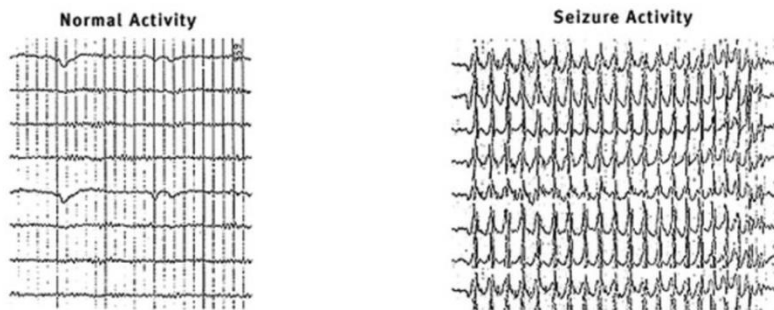


Figure 2: Retrieved at <https://www.canadianepilepsyalliance.org/about-epilepsy/explaining-epilepsy>

## Seizure precautions

When you have epilepsy, certain activities can put you at risk of being hurt if a seizure was to occur. However, it is important to balance safety and quality of life. The instructions found below will ensure that your child lives a safe and fulfilled life.

1. Ensure family, friends, caregivers, teachers and coworkers know what to do if a seizure occurs.
2. Take showers instead of baths. If you are showering, ensure that someone else is at home and leave the bathroom door unlocked at all times. If you are showering in a tub, make sure to remove the drain stop. If your child must take a bath, ensure that an adult is present in the bathroom and is able to watch him/her at all times.
3. Always wear a helmet when doing sports in which it is generally recommended to wear one such as biking, roller-blading, skiing and ice-skating.
4. For young children, if they are swimming in a pool, an supervising adult should be within reaching distance in the water at all times. For older children and teenagers, they should ensure that they are swimming with a designated buddy who is an experienced swimmer and will be able to call for help if needed. They should also only be swimming in the presence of an adult/lifeguard who knows about their seizure disorder and is watching them closely at all times.
5. If the individual is swimming in open water such as a lake, he/she should wear a life-vest and ensure that an adult who knows about his/her seizures is watching you at all times. If he/she is on a boat or close to open water, he/she should also be wearing a life-vest and be supervised by an adult at all times.
6. The SAAQ (Société de assurance automobile du Québec) requires that license holders have seizures controlled for a certain period of time before they can drive. The length of this period should be discussed with your neurologist before you start driving again.
7. If the individual is cooking using the stove, ensure to do it with an adult present. Ensure that pan handles are facing the back of the stove.
8. Avoid carrying hot items such as hot beverages or pots of hot food which could result in burns in case of a seizure.



## Seizure First Aid – What to do in case of a seizure

If your child has a seizure, remain calm and remember the following:



**1. Do not put anything in the child's mouth**

Jaw and face muscles may tighten during a seizure, causing the child to bite down. If this happens when something is in the mouth, the child may break and swallow the object or break their teeth. A child cannot swallow their tongue during a seizure.

**2. Do not try to forcibly stop the seizure**

Trying to stop movements or forcibly holding a person down does not stop a seizure and can result in injuries. Remember that most seizures will end on their own after a few seconds or a few minutes.

**3. Position the child on his/her side (if possible)**

Vomiting may occur during a seizure. If the child is on his/her back, vomit may go to the lungs instead of the stomach. The side position also prevents saliva from blocking the airway.

**4. Clear the area**

Your child may be shaking his/her arms and legs during a seizure and may hit things that are nearby which could lead to an injury. Try and move things that might be in the way of the child.

**5. Monitor the child's breathing**

During a seizure, it may look like the child has stopped breathing. This happens when the chest muscles tighten during the tonic (stiff limbs) phase of a seizure. As this part of the seizure ends, the muscles will relax and breathing will resume normally. Rescue breathing or CPR is generally not needed during these seizure-induced changes in a child's breathing.

**6. Time it**

When the seizure starts, try to check the time in order to be able to determine how long it lasts. To the person watching, it may seem like a long time when in reality a much shorter period of time has passed.

**7. Do not give anything by mouth unless child is fully alert**

If the child is not fully alert or aware of what is going on, he/she might not be able to swallow correctly. Food, liquid, or pills, could go to the lungs instead of the stomach if child tries to drink or eat at this time.

**8. Speak calmly to the child**

Talking calmly and reassuringly to the child during and after the seizure will help as he/she recovers from the seizure.

**You should call 911 if:**

- The seizure lasts more than 5 minutes
- The seizures occur one right after another without the child regaining consciousness or without recovering to his/her baseline in between seizures
- The seizures occur closer together and are more frequent than usual
- Breathing becomes difficult or the child appears to be choking
- The seizure occurs in water and there is concern that the child may have inhaled water
- If you have administered a 'rescue medication' such as Midazolam (Versed), Ativan, or Diastat and the seizure continues

*If your child has a seizure which lasts less than 5 minutes, and recovers completely post-seizure, it is usually not necessary to bring your child to the Emergency Room. Please inform the nurses in neurology of the seizure (see "Important contact information").*

## ***What is Sudden Unexpected Death in Epilepsy?***

Sudden Unexpected Death in Epilepsy (SUDEP) refers to the sudden death of someone known for epilepsy without an identifiable cause and without prior warning signs.

It is important to remember that the vast majority of patients with epilepsy live long and happy lives. However, compared with the risk of death in the general population, the risk of death of someone with epilepsy is slightly higher. The rate of SUDEP is estimated to be approximately 1 in 1000 people with epilepsy a year. The underlying cause of SUDEP is unknown. Most SUDEP deaths are unwitnessed and occur during sleep. There has been some evidence that SUDEP is often preceded by a seizure.

The most important identified risk factor for SUDEP is the presence and frequency of generalized tonic-clonic seizures. The more frequent the child has generalized tonic-clonic seizures, the higher the risk of SUDEP. It is important to know that seizure freedom is associated with a lower risk of SUDEP. Therefore, optimizing seizure control is essential to lower the risk of SUDEP. Other risk factors for SUDEP have been identified and these include not taking antiseizure medication reliably, being alone during a seizure and using alcohol/street drugs.

In order to lower your risk of SUDEP, you can do the following:

- Ensure regular follow-up with your neurologist and primary health-care provider
- Ensure to take your anti-seizure medication as prescribed (no miss doses)
- Identify and avoid seizure triggers
- If seizure control remains sub-optimal despite antiseizure medications, ask your neurologist about other treatment options for epilepsy (ketogenic diet, surgical interventions)
- Avoid alcohol and street drugs
- Ensure regular and adequate sleeping patterns for age, regular healthy meals and staying active

## **Important contact information**

Montreal Children's Hospital – Pediatric Neurology Department: 514-412-4446

### **Pediatric Neurology Nurses:**

Heather Davies, N MSc (A), CNN(C)  
Advanced Practice Nurse  
514-412-4400 extension 23267

Sanaz Shadvar, N MSc(A)  
Nurse Clinician  
514-412-4400 extension 23703

For children followed by Dr. Myriam Srour, Dr. Michael Shevell, Dr. Élisabeth Simard-Tremblay and Dr. Ken Myers, please contact Heather Davies. Heather is also available for families whose child is on the Ketogenic Diet, whose child is taking CBD and for families whose child is transitioning to adult health care.

For children who are followed by Dr. Chantal Poulin, Dr. Geneviève Legault, Dr. Guillaume Sébire, Dr. Maryam Oskoui and Dr. Osterman, please contact Sanaz Shadvar.

When calling the nurses, please leave a detailed message including the **reason for your call, your child's hospital card number** (number at the top right corner of the red hospital card) and your **contact information**. Calls will be triaged according to the details you have provided. Given the high number of children who are followed in Neurology, the nurses will contact you within 72 hours. If you feel that your child's situation is urgent, please present to the Montreal Children's Hospital Emergency Room.

Of note, unless specified by the neurologist, all test results will be given to you at your child's next clinic appointment.

For questions concerning appointments or prescription renewals (where medication does not need any adjusting), please contact the Neurology secretary at 514-412-4446.

## **Additional resources**

A great resource is the website of the **Canadian Epilepsy Alliance** ([www.canadianepilepsyalliance.org](http://www.canadianepilepsyalliance.org)). In the section "Resources", you will find the subsection "Educational booklets". On this page, you will be able to download and print various booklets with a lot of information on epilepsy. You will find booklets specifically designed for teenagers and in the form of an educational activity book for children as well as a guide for parents and much more.

Other helpful websites include:

1. [www.aboutkidshealth.ca](http://www.aboutkidshealth.ca)
2. [www.claegroup.org](http://www.claegroup.org)
3. [www.ilae.org](http://www.ilae.org)
4. [www.epilepsy.com](http://www.epilepsy.com)

## References

1. Canadian Epilepsy Alliance. Available at <https://www.canadianepilepsyalliance.org>. Retrieved on April 30<sup>th</sup> 2020.
2. About Kids Health - Epilepsy. Available at <https://www.aboutkidshealth.ca/Article?contentid=845&language=English&hub=epilepsy>. Retrieved on April 30<sup>th</sup> 2020.
3. Epilepsy South Central Ontario. Available at <https://epilepsysco.org>. Retrieved on April 30<sup>th</sup> 2020.
4. Up To Date – Sudden unexpected death in epilepsy. Available at [https://www.uptodate.com/contents/sudden-unexpected-death-in-epilepsy?search=sudep&source=search\\_result&selectedTitle=1~20&usage\\_type=default&display\\_rank=1](https://www.uptodate.com/contents/sudden-unexpected-death-in-epilepsy?search=sudep&source=search_result&selectedTitle=1~20&usage_type=default&display_rank=1). Retrieved on April 30<sup>th</sup> 2020.