

Important facts to know about seizures and epilepsy

Seizures might be scary when you first experience them. The person having the seizure is often doing unusual things and may even be on the ground shaking, drooling, or even turning blue. It can be frightening because no matter how hard you try you cannot stop a seizure. You have to let it run its course. However, the more you learn about seizures the less scary they will become.

Seizures are usually not a disorder themselves but rather a symptom or clue of something else. There may have been a brain injury, or an infection, or a family tendency towards having seizures. We have also learned that certain changes in our genes (the instructions which make our bodies) can cause seizures. Often, an EEG (electroencephalogram), a study looking at brain waves, will show where the abnormal electrical activity related to seizures is coming from. However, in some cases the only sign that there is anything wrong will be the seizures themselves.

For children having seizures, usually the size and shape of the brain are normal and so pictures of the brain are not needed. However, in some cases, an abnormal area of the brain may exist to explain why a person is having seizures. A brain MRI (magnetic resonance imaging) may be useful in these instances. Your health care provider will review your child's seizures in detail and decide if this test is needed.

Here are some important facts for you to know:

- **The majority of seizures last less than five minutes** and you do not have to call 911.
- **Most seizures do not cause brain damage** but the underlying brain disorder may cause problems.
- **Children rarely die from a seizure.** If death occurs, it is usually from an underlying severe brain problem.
- **Many children outgrow their seizures by the time they reach adulthood.**
- **The way you see seizures usually shown and treated on television or in movies is not accurate. It's just fiction.**

What is a seizure?

A **seizure** is a symptom of a disturbance in the electricity and chemistry of brain cells making them act differently than they normally would. Normally, brain cells (neurons) work together in their own groups or networks. They process information coming in from the body and control the body's actions. Although, we are always learning how brain cells behave during seizures, it is well known that during a seizure, groups of cells that normally work separately in their own networks suddenly start to work together with neurons in other groups. For example, this might be like the "wave" you see performed at a sporting event. Before the wave, everyone in the crowd is doing their own thing, like, watching the game, or talking, or eating. Suddenly along comes someone who gets the crowd to do the "wave" and each person stops what they were doing and whole sections work together spreading the wave around the entire arena. Seizures work like this. They can act like a super coordinated or hypersynchronous (HY-per-sin-cron-us) event.

Can different types of seizures occur? Yes, the way a seizure looks will depend on which part of the brain it started in and where it spreads to. For example, if it starts in a small area and spreads only a little bit, like a small ripple in a pond, it may present in only a part of the body, or on one side, or the person may even seem sort of aware and doing repeated actions (like lip smacking or walking in a circle). This is called a focal seizure.

If the seizure occurs in the whole brain it may look like a big "whole body" convulsion. This is called a generalized seizure.

How does the brain work?

The brain has two halves (hemispheres) and a stalk (brain stem) at its base. The two halves and the stalk are connected by a number of networks that help them "talk" to each other. Each half of the brain controls the **other** side of the face and body. For example, the **left** side of the brain controls the **right** side of the face and the body. Therefore if the seizure occurs only in the left side of the brain (a focal area) you would expect to see the seizure happening on the right side of the face and body. When the seizure involves the whole brain, you would expect to see the whole body involved and the person is usually completely unaware the seizure is occurring. Your health care provider will discuss your child's particular type of seizure(s) with you in greater detail.

What is epilepsy?

Although some experts call epilepsy a disease, many others consider it NOT a disease but a **seizure disorder or a chronic health condition**. Regardless of debate over this, you can still be in good health and have epilepsy at the same time. Epilepsy is caused by a neurological (brain) condition that causes a person to have repeated (recurring) seizures. A person is said to have epilepsy when they have had at least two seizures that were not caused by a reversible health condition. Some experts say a person has epilepsy if they have had one seizure and a strong possibility they will have another, for example, if they have related findings on their EEG, and/or a brain abnormality seen on the MRI that is known to cause repetitive seizures.

What are the treatment goals for epilepsy?

There are two main goals for the treatment of epilepsy:

NO SEIZURES AND NO MEDICATION SIDE EFFECTS

Often these goals are met by prescribing one of the many available medications. It is important to note that medications do not cure epilepsy, but prevent seizures from occurring. Typically, a daily medication will be prescribed by your health care provider, and once seizures have not occurred for a one to two year period, it may be weaned to see if the seizures have stopped completely. In the majority of cases in children without any visible causes in the brain, the seizures will not reappear.

More Good News: In the majority of cases, seizures are controlled with the first medication. However, in some instances when the first medication fails, a substitute medication or even more than one medication is needed to control seizures.

How can you help?

Therefore it is important that you:

- **Keep track of all your child's seizures using a seizure diary.**
- **Bring the seizure diary to ALL clinic appointments**
- **Keep track of all medication changes and side effects using a seizure diary**
- **Bring ALL your child's medications to each clinic appointment**

Tip: Use your cell phone to take pictures of the medication labels

- Discuss your and your child's goals of care with your health care provider
- Tell your health care provider what type of medication insurance you have

Why is it so important to fill out a seizure diary?

- Keeping track of seizures on a calendar-style diary gives you a good, overall picture of how often and what types of seizures are occurring on a monthly basis and lets you compare quickly your child's response to any medication changes.
- The diary gives you a place to write down any side effects from medications. It is important to let your healthcare team know any side effects your child is having so they can minimize or eliminate them.
- The best way to figure out which kind of seizure your child is having is by watching it closely and writing down as much detail you can.
- The kind of medication that will be chosen to treat your child's epilepsy and how well it works will depend on what kind of seizures they are having.

What should I be looking for when I observe a seizure?

Watching your child have a seizure can be frightening. Having an idea of what to look for before the seizure starts can help you stay calm and remember what you are seeing.

There are **3 things** that are important when observing a seizure.

- What happened at the **beginning of the seizure**?
 - Was there a warning sign before it began?
 - Did your child tell you they were about to have a seizure?
 - Did the seizure start in one part of the body?
 - Did your child's eyes or head move to one side first?
 - Was there any unusual movement?
 - Did your child report they had a smell, emotion, thought beforehand, or did you see a change in their mood?
- What happened **during the seizure**?
 - How long did it last?
 - What did it look like? (For example, body was limp/stiff, had muscle jerks)
 - If your child fell, how did they fall? (For example, crumpled to the ground or fell straight over like a tree)

- What happened **after the seizure**?
 - Did your child return to normal right away or were they confused after the seizure, have trouble talking or moving or throw up?
 - If they were confused, how long did it take your child to return to normal?
 - Did they sleep? For how long?

‡ **If possible, VIDEO** the seizure so you can show it to your healthcare team. But please don't follow your child around waiting for a seizure to happen. They need to be reassured they are still normal and able to do the things they want to.

SEIZURE FIRST AID: REMEMBER: SAFE....TIME.....CALM.....

- **SAFETY: Remember most seizures last less than 5 minutes. With these short seizures you do NOT need to call 911**
- During a seizure, **protect** your child from injuring themselves on things around them. Do not restrain them as you can't stop the seizure. **Do not put anything in their mouth.** It is a myth they can swallow their tongue. If possible, roll them onto their side (recovery position)
- **TIME** the seizure
- 📱 **If a convulsive seizure lasts more than 5 minutes or continues to repeat in an "on again/off again" pattern, get medical assistance immediately by calling 911 and have your child taken to the Emergency Room (ER)**
- Give your child a **rescue medication** if it has been prescribed. Talk to your healthcare team if you are not sure what this is.
- **Please stay CALM.** Reassure your child if they seem partially aware and those around you. Staying calm lets you remain in charge and able to give directions to others if more help is needed.

Living with epilepsy

It is important that you encourage your child to live with this condition in a positive, healthy manner. Many children with epilepsy participate fully in all aspects of normal daily living. **Your child usually does not have to limit their activities**, but you do want them to take some simple everyday precautions.

- Wear a medical identification (ID) tag (E.g. Medic Alert bracelet or necklace) if they are going somewhere without you

- Wear a helmet with high risk activities such as bike riding, skiing, skating, snowboarding
- Never swim alone
- Never lock the door when bathing; showers are encouraged instead

In fact, many people (including famous people) live full and normal lives with epilepsy.

Is there anyone famous I might know with epilepsy?

See how many you recognize below. As 1 out of 100 people has epilepsy, you may even know others close to you with epilepsy.

Sir Isaac Newton (scientist)	Charles Dickens (author)
Thomas Edison (inventor)	Leonardo da Vinci (artist)
Alfred Nobel (founder of Nobel prize)	Vincent Van Gogh (artist)
Danny Glover (actor, Lethal Weapon)	Lil Wayne (rap superstar)
Hugo Weaving (actor, Lord of the Rings)	Derek Morris (NHL)

What web resources are available to help me?

- *Paediatric Neurology Program, Children's Hospital, LHSC www.lhsc.on.ca/childneuro (check out our easy to use list of medications and copies of this note are also available)
- *Epilepsy Support Centre, London Ontario <http://epilepsysupport.ca/>
- *All About Epilepsy (for kids 8 and up) www.aboutkidshealth.ca
- *How the Body Works (interactive site) www.sickkids.ca/childphysiology
- *Epilepsy Ontario <http://epilepsyontario.org>
- *Epilepsy Foundation www.epilepsy.com
- *SUDEPAWARE www.sudepaware.org
- *Tracking seizures www.seizuretracker.com
- *American Epilepsy Society www.aesnet.org
- *International league against epilepsy www.ilae.org
- *Medic alert www.nochildwithout.ca

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