

## Frequently Asked Questions

### ■ What is epilepsy?

Epilepsy is a common neurological disease characterized by the tendency to have recurrent seizures. It is sometimes called a seizure disorder.

A person has epilepsy if they:

- Have had at least two unprovoked seizures, or
- Have had one seizure and are very likely to have another, or
- Are diagnosed with an epilepsy syndrome

### ■ What is a seizure?

A seizure is a sudden burst of electrical activity in the brain that causes a temporary disturbance in the way brain cells communicate with each other. The kind of seizure a person has depends on which part and how much of the brain is affected by the electrical disturbance that produces the seizure. A seizure may take many different forms, including a blank stare, uncontrolled movements, altered awareness, odd sensations, or convulsions. Seizures are typically brief and can last anywhere from a few seconds to a few minutes.

**FACT:** It is estimated that 1 out of 10 people will have a seizure in their lifetime, but most people who have a single seizure do not have epilepsy.

Seizures are divided into two main categories:

#### Generalized seizures

- Involve both hemispheres of the brain
- Two common types are absence seizures (petit mal seizures) and tonic-clonic seizures (grand mal seizures)

#### Focal seizures (partial seizures)

- Only involve one part of the brain
- Include focal impaired awareness seizures (complex partial seizures) and focal aware seizures (simple partial seizures).

People with epilepsy may experience more than one type of seizure. For more information about seizure types, see our Seizure Types *Spark* sheet.

**FACT:** About 1 in 100 Canadians have epilepsy.

### ■ Why do people have seizures?

There are many potential reasons why someone could have a seizure. Some seizures are a symptom of an acute condition, such as an illness or a recent head injury. Some people will have an isolated seizure for no apparent reason and never have another one.

When someone has epilepsy, they have an underlying brain condition that makes them more likely to have recurrent seizures. There are a wide range of causes of epilepsy.

## Frequently Asked Questions *continued*

### ■ Do people get a warning before a seizure?

Sometimes people can feel a seizure coming on. However, warnings are not experienced by everyone with epilepsy.

#### Aura

Some people have an aura at the very beginning of a focal seizure or a generalized seizure. Technically, an aura doesn't happen "before" the seizure, because it is actually part of the seizure. Some examples of auras are a sudden feeling of fear, an odd smell or taste, or a sudden tingling sensation in part of the body.

An aura can also occur by itself. For example, if the seizure activity causing the aura does not spread to other brain areas, then the seizure may not progress to a loss of awareness or loss of consciousness.

#### Prodrome

Another type of warning, called a prodrome, can occur minutes, hours, or days before the seizure begins. Some examples are headache, mood changes, or changes in thinking abilities.

### ■ How is epilepsy diagnosed?

Epilepsy is diagnosed by a physician or nurse practitioner. The healthcare professional will complete a medical history, asking questions about the seizure, such as what happened before, during, and after it.

The person will have an electroencephalogram (EEG), which is a test that records brain waves picked up by metal discs (electrodes) placed on the scalp. The brain waves show patterns of brain activity which may help the doctor identify epilepsy and provide more information about any seizures a person may have. (For more information, see our EEG *Spark* sheet.)

CT or MRI brain scans may also be helpful in some patients to look for differences in brain structure, scars, or other physical conditions that may be causing the seizures. Based on all of the information gathered, the healthcare provider may diagnose the person with epilepsy.

### ■ How is epilepsy treated?

The goal of epilepsy treatment is to prevent seizures. Anti-seizure medication is the most common way to treat epilepsy. Different medications control different types of seizures, and a medication that helps one person may not be effective for someone else.

About 70% of people with epilepsy have their seizures controlled with medication. In some cases, epilepsy surgery offers the possibility of a reduction or complete elimination of the seizures. Other non-drug treatments include specialized diets and nerve stimulation.

It's important to remember that everyone responds differently to treatment, so a person with epilepsy should discuss their care with their physician before making any changes to their treatment.

For more information, see these *Spark* sheets: Anti-Seizure Medications, Epilepsy Surgery, Complementary Therapies, and Ketogenic Diet Therapy for Epilepsy.

### ■ Do people have seizures forever?

Some types of epilepsy are limited to a certain age group or stage of development, but in many cases epilepsy is a chronic, life-long disease. There are treatment options to help people achieve seizure-freedom. Medication will be effective for many people. Some people are good candidates for epilepsy surgery.

## Frequently Asked Questions *continued*

### **I have not had a seizure for years. Do I still have epilepsy?**

If someone is taking anti-seizure medication to control their seizures, they are considered to have active epilepsy. The International League Against Epilepsy considers epilepsy to be resolved for individuals with an age-dependent epilepsy syndrome who are past the applicable age or if the individual has been seizure-free for 10 years and off medication for at least the last five years.

### ■ **How common is epilepsy?**

Epilepsy is not rare – in fact, about 1 in 100 Canadians has epilepsy and over 50 million people worldwide live with it. It can affect anyone of any gender, age, and ethnicity.

Many famous people have had (or are suspected to have had) epilepsy, including Neil Young, Florence Griffith Joyner, Derek Morris, Harriet Tubman, Hugo Weaving, Fyodor Dostoevsky, Lil Wayne, and many others.

### ■ **What causes epilepsy?**

Epilepsy is NOT contagious – you can't catch it, and you can't give it to someone else. In more than half of cases, no clear known cause can be found.

Some types of epilepsy are associated with genetic factors. Among the rest, anything that affects the way the brain works could increase the chance of developing epilepsy.

Possible causes include:

- Head injuries
- Lack of oxygen during birth
- Stroke
- Problems in development of the brain before birth
- Brain tumors
- Genetic conditions (such as tuberous sclerosis)

- Metabolic or autoimmune conditions
- Infections such as meningitis or encephalitis

### ■ **What triggers seizures?**

Triggers vary from person to person. Some people with epilepsy are able to very clearly identify situations that trigger a seizure, while others are unable to find a pattern to their seizures. A common way to identify seizure triggers is to keep a seizure record that includes tracking what happens before each seizure.

Common triggers include:

- Missed doses of anti-seizure medication (most common trigger)
- Lack of sleep or fatigue
- Stress or excitement
- Elevated body temperature
- Colds, flu or some kinds of infection
- Hormonal changes during the menstrual cycle
- Alcohol
- Flashing lights or contrasting patterns (photosensitivity), but only in about 5% of all people with epilepsy

### ■ **Can a person with epilepsy drive?**

In Ontario, you can drive with epilepsy if you meet certain criteria set out in the Ontario Highway Traffic Act. Typically, this includes being seizure-free for at least 6 months, and taking your medication as prescribed.

This is to ensure your safety, as well as the safety of those around you. Your physician is required by law to submit a report to the Ministry of Transportation when you have had a seizure that could affect your ability to safely drive.

For more information, see our Epilepsy and Driving *Spark* sheet.

## Frequently Asked Questions *continued*

### ■ Does epilepsy affect a person’s emotional well-being?

It is normal for a person who has been diagnosed with epilepsy to experience a range of emotions such as anger, frustration, fear, and sadness. Concern for the future and negative responses from friends and family can leave a person feeling vulnerable and alone.

Living with epilepsy can result in personal challenges, but it does not have to result in an inability to live a rewarding and full life.

People with epilepsy experience depression and anxiety more frequently than individuals without epilepsy. Research hasn’t yet determined why this happens, but there may be some common links between the underlying causes of these brain disorders.

For more information, see our Epilepsy and Depression and Epilepsy and Anxiety *Spark* sheets.

### ■ Does epilepsy affect intelligence?

People with epilepsy have the same range of intelligence as people without epilepsy. Some conditions that lower mental ability also cause epilepsy, but epilepsy itself does not diminish mental ability.

Some people with epilepsy struggle with memory problems for a variety of reasons. For more information and memory strategy tips, see our Epilepsy and Memory (Adults) *Spark* sheet.

If your child is struggling in school, you may find the following *Spark* sheets helpful: Epilepsy and Learning Challenges, Epilepsy and Memory (Children), Epilepsy and ADHD, or Helping Children with Organization and Planning. Can you die from epilepsy?

The vast majority of people with epilepsy live long and healthy lives. As with many other medical conditions though, for some people there is an increased risk of dying caused by epilepsy.

The overall risk of dying for a person with epilepsy is 1.6 to 3 times higher than for the general population<sup>1</sup>.

The possible causes of this increased risk include:

- Complications during or after a seizure, such as seizures that do not stop naturally (status epilepticus)
- Accidents caused by having a seizure, including drowning or car accidents
- The underlying medical cause of someone’s epilepsy
- SUDEP (Sudden Unexpected Death in Epilepsy)

**TIP:** SUDEP occurs in about 1 out of every 1000 people with epilepsy, and happens more often in people who have frequent convulsive seizures.

SUDEP is thought to happen when a person with epilepsy, who is in their usual state of health, dies unexpectedly.

The best way to reduce the risk of SUDEP is to continue your self-care routine to have as few seizures as possible. For more information about SUDEP, contact [SUDEP Aware \(www.sudepaware.org\)](http://www.sudepaware.org).

Despite these risks, it’s important to remember that it is not common for people to die from epilepsy. If you are concerned about what the possible risks of epilepsy mean for you, talk to your healthcare provider.

<sup>1</sup> Epilepsy Across the Spectrum IOM Report, 2013

## Frequently Asked Questions *continued*

### ■ What do I do if someone is having a seizure?

#### 1. Stay Calm

Most often, a seizure will run its course and end naturally within a few minutes.

#### 2. Time It

Call 911 if:

- The seizure lasts more than 5 minutes
- The seizure repeats without full recovery between seizures
- The person is pregnant
- The person has diabetes
- The person is injured from the seizure
- The seizure occurs in water
- You are not sure if the person has epilepsy

#### 3. Protect from Injury

- Move sharp objects out of the way.
- If the person falls to the ground, roll them on their side when it is safe to do so and place something soft under their head.
- If the person wanders during their seizure, stay by their side and gently steer them away from danger.
- When the seizure ends, provide reassurance and stay with the person if they are confused.

**DO NOT restrain the person.**

**NEVER put anything in the person's mouth.**

**FACT:** It is physically impossible to swallow your tongue during a seizure. Never put something in a person's mouth during a seizure.

### ■ How can I support other people with epilepsy?

One of the easiest ways to show your support is to talk about epilepsy. One of the most difficult challenges that people with epilepsy face is the stigma associated with the condition.

By spreading awareness and educating others, you can help erase the misconceptions that exist about epilepsy.

You can also support the services provided by your local epilepsy agency by becoming a volunteer or donor, or running a fundraiser.

### ■ I have just had a seizure for the first time. What do I do?

About 1 in 10 people will have a seizure in their lifetime. Having a seizure for the first time can be a frightening experience for the individual and others involved. Knowing what to do can help. First time seizures need to be evaluated by a healthcare provider to determine if the episode was a seizure and to investigate the cause.

Do not drive until you speak with a physician and get information about your medical fitness to safely operate a motor vehicle.

A healthcare provider will ask what you remember about the episode. What happened before it began and at the onset? What do you recall about the seizure? If there are parts that you do not remember, a witness may be able to fill-in other details such as how long the seizure lasted, what it looked like and what happened when it ended.

## Frequently Asked Questions *continued*

Make sure to ask questions regarding anything you are concerned about before leaving the emergency room or clinic. Some possible questions are:

- Can the cause be determined?
- What is my seizure plan if a second seizure occurs?
- What sorts of safety precautions should I take?

You may need to have some diagnostic tests and a follow-up appointment with your family doctor or a neurologist. Ask if there is a first seizure clinic in your region.

### ■ What is an epileptologist?

An epileptologist is a neurologist who has additional training and certification in the diagnosis and management of patients with epilepsy.

### ■ I am taking an anti-seizure medication but I am continuing to have seizures. What do I do?

Nearly 50% of people with epilepsy will become seizure-free with the first anti-seizure drug that is tried. If you do not become seizure-free with the

first medication, or if it causes intolerable side-effects, the next step is usually to try a different anti-seizure drug. Your healthcare provider will select the most appropriate drug to try based on the type of seizures you have, other features of your epilepsy disorder, your age, your gender, as well as considerations such as cost and whether you have drug insurance.

A little over 10% of people with epilepsy will become seizure-free on the second anti-seizure drug they try. If you do not become seizure-free with your second medication, speak to your healthcare provider about booking a consultation at a district or regional epilepsy centre. An epileptologist can do an assessment of your epilepsy and provide information about other treatment options.

For more information, see our Planning for your Healthcare Appointment *Spark* sheet and our Drug-Resistant Epilepsy *Spark* sheet.

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