

EPILEPSY

Teenagers Managing 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.

What is Epilepsy/Seizure Disorder?

Understanding epilepsy begins with understanding how your brain functions.

Epilepsy/seizure disorder is a physical disorder formed by sudden or brief changes in how the brain works. It is a symptom of a neurological disorder that affects the brain and shows itself in the form of seizures. It is a disorder, not a disease.

Epilepsy/seizure disorder is not contagious.

What are Seizures?

A seizure occurs when the normal electrical balance in the brain is lost. The brain's nerve cells fall through; they either ignite when they shouldn't or don't ignite when they should. The result is a sudden, brief, uncontrolled rush of abnormal electrical activity in the brain. Seizures are the physical effects of such unusual bursts of electrical energy in the brain. These overactive signals may keep the brain from understanding what the eyes see. The person may stare during a seizure, or they may affect leg muscle tone and cause a person to fall down. The type of seizure depends on how many cells are launched and which area of the brain is involved. A seizure may be a change in behaviour, consciousness, movement, perception and or sensation.

You are not alone. Epilepsy/seizure disorder is more common than most people realize.

Approximately one person in a hundred live with epilepsy/seizure disorder. In Canada, there are approximately 300,000 people with epilepsy/seizure disorder. An estimated 23,000 people in Manitoba and four million people in North

America live with epilepsy/seizure disorder. Epilepsy/seizure disorder often begins in childhood.

How did I get Epilepsy/Seizure Disorder?

In many situations, there is no known cause of epilepsy/seizure disorder. In others, doctors can identify the cause of your condition. Some of these known causes include:

- Genetic (e.g. inherited genes)
- Birth injury (e.g. lack of oxygen to the babies brain at birth)
- Developmental disorder (e.g. brain damage to the fetus during pregnancy)
- Brain trauma (e.g. from car accidents, sports injuries)
- Infection (e.g. meningitis, encephalitis, AIDS)
- Brain tumor
- Alcohol and drug abuse

How Is My Epilepsy/Seizure Disorder Diagnosed?

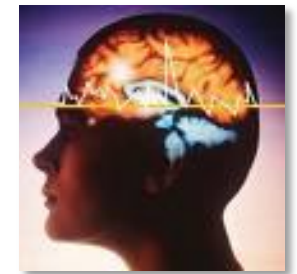
If you have had a seizure, your doctor will ask you for information regarding your medical history. The doctor will want information such as whether you have experienced infection or head injury, if you have a history of drug or alcohol use, and whether there is any family history of epilepsy/seizure disorder.

The doctor will also need a description of your seizures and information on when you first started experiencing them.

Asking those who were with you during a seizure for a description of what happened and recording that information will help the doctor in the diagnosis and treatment.

A doctor's main tool in diagnosing epilepsy/seizure disorder is a thorough physical examination. You will likely also have diagnostic tests. Another major device used is called an electroencephalograph (EEG). This machine records brain waves which are picked up by tiny wires attached to the head. Electrical signals from brain cells are recorded as wavy lines by the machine. The brain waves may show special patterns, which can possibly help the doctor diagnose the patient with epilepsy/seizure disorder. CT or MRI machines take pictures of the brain to see if there are any growths, scars, or other physical conditions in the brain that may be causing the seizures.

Other tests that show how the brain works are also sometimes used, especially if surgery is being considered.



These include magnetic resonance spectroscopy (MRS), positron emission tomography (PET), single photon emission computed tomography (SPECT), and magnetic source imaging or magnetoencephalography (MSI or MEG).

What is the Treatment for Epilepsy/Seizure Disorder?

Medication:

Seizure medication, referred to as anti-convulsants, is the primary treatment for epilepsy/seizure disorder. Drugs don't cure epilepsy/seizure disorder, but they often reduce or even stop seizures from occurring by altering the activity

of neurons in the brain. The majority of people achieve seizure control with seizure medication.

There are many different types of seizures and there are many different types of seizure medication. Sometimes a doctor will prescribe one drug. In other cases, more than one drug is needed to control seizures. A doctor might try a number of different drugs to find the most effective medication for you.



Side Effects:

A person on seizure medication can experience side effects. Side effects tend to be more common when a drug has just been started, when the dosage has been increased, or when more than one drug has been prescribed.

Side effects can vary; possibly including drowsiness, loss of coordination, headache, decreased appetite, weight gain or loss, double or blurred vision, dizziness, tremor, and even impaired attention or memory.

Long-term use of seizure medication can also result in bone loss that increases the risk of bone fractures.

Sometimes side effects are cosmetic and involve overgrowth of the gums, hair loss, or excessive hair growth. If a skin rash appears, you may be allergic to the medication.

Side effects, including cosmetic side effects that concern you, should be discussed with your doctor. The doctor may be able to prescribe a different drug depending on the type of seizure you are experiencing.

Why do I Need Blood Tests?

Blood tests monitor the amount of medication circulating in your blood. Blood tests help decide how much medication you require on a daily basis. They will show if you are taking too little or too much. Too little would not protect you from a seizure, and too much may result in side effects.



It is important to keep track of your seizures and watch for side effects. Blood tests will also be required periodically to monitor the condition of different organs (e.g., liver and kidney) involved in the metabolism of the medication.

It may take time to find the right medication or combination of medications and the right dose. It is often a matter of trial and error, which may be frustrating for you.

Once your medication has been determined, it's important to stick to a regular routine and take your medication at the same time every day.

This best protects you from seizures. You may be seizure-free for long periods of time, but this does not mean that your epilepsy/seizure disorder has been cured.

Medication does not cure epilepsy/seizure disorders. It simply reduces the likelihood that you will have a seizure.

You should **NEVER** suddenly stop your medication – this can cause your seizures to start again.

You should also **NEVER** increase or decrease your medication unless your doctor tells you to.

Surgery

Sometimes surgery is an option. Usually in cases involving surgery, seizure medication has not been effective and the injured brain tissue causing the seizures can be identified and safely removed.



Surgery may involve the removal of the part of the brain where the seizures begin. Or it may involve a surgical cut to interrupt the nerve pathways in the brain to prevent the seizures from spreading from one side of the brain to the other.

The removal of part of the temporal lobe is the most successful and the most common type of epilepsy/seizure disorder surgery and is referred to as temporal lobectomy. This surgery offers the chance of a cure in many patients and a reduction in seizures in others.

In considering surgery, extensive medical testing and evaluation are necessary to determine where the seizures originate and if it is safe to operate on that area of the brain.

Vagus Nerve Stimulation

A surgical therapy called vagus nerve stimulation (VNS) is also being used in some epilepsy/seizure disorder cases. A battery-powered device much like a heart pacemaker is implanted under the skin in the chest. A wire runs from the device to the vagus nerve in the neck. The VNS device stimulates the left vagus nerve which then sends an electrical signal to the brain. The signals help



to prevent or interrupt the electrical disturbances in the brain that result in seizures. In some people, this procedure reduces seizure frequency, intensity and duration.

Ketogenic Diet

A ketogenic diet that is high in fats and low in protein and carbohydrates is sometimes used to treat epilepsy/seizure disorder. The diet creates a chemical change in the body called ketosis that results in the body breaking down fats instead of carbohydrates. In some people, this process inhibits seizures.

The ketogenic diet is usually used to treat children but it has been used to treat teenagers. If you are on the diet, you can only eat a limited range of foods which teenagers sometimes find hard to maintain.

This diet requires medical supervision.

It has to be followed carefully and can be harmful if it is not medically supervised. Because of the strictness of the diet, people on it generally need to take nutritional supplements. Use of these supplements has to be monitored by the doctor.



What Is My Role In Treatment?

Be a part of it. Ask questions. Being involved in your treatment is an important step in taking control of your life, making your own decisions and becoming responsible.

What Can I Do to Help Control My Seizure?

Sometimes people with epilepsy/seizure disorder recognize that specific events or circumstances affect seizures.

Recognizing your seizure triggers can help you to reduce or avoid seizures.

Remembering to take your seizure medication, getting enough sleep, managing stress levels, and eating regularly and nutritiously, are all helpful in seizure control.

Common Seizure Triggers:

- Street drugs (e.g. cocaine, ecstasy, LSD, marijuana)
- Excessive alcohol consumption and subsequent withdrawal
- Flickering lights of computers, television, videos, etc.
- Medication other than prescribed seizure medication
- Low seizure medication levels
- Illness or fever
- Menstruation/hormonal changes
- Stress, excitement, emotional upset
- Missing meals
- Lack of sleep
- Forgetting to take prescribed seizure medication

What About My Life?

Will having epilepsy/seizure disorder affect my schoolwork?

Talking to your teachers about your epilepsy/seizure disorder is important. Let them know the types of seizures

you experience, how your condition and/or seizure medication might affect your schoolwork, and what the proper procedure is should you have a seizure in school. Your school should also have a medical record on file with information regarding your doctors, medications, allergies, and other medical conditions, and a description of your seizures and instructions on what to do if you have a seizure.

This could be influenced by many factors including:

- The student's anxiety
- The side effects of seizure medicine
- Teachers' attitudes
- An underlying neurological cause of epilepsy/seizure disorder.
- The seizures themselves

If you have concerns over any of these school-related issues, you and your family should discuss these with your teachers. If people understand some of the challenges you are facing, they will be better able to support you in meeting those challenges. If you would like your peers and teachers to better understand epilepsy/seizure disorder.



Will I be able to drive?

If your seizures are not controlled, there are restrictions to driving. Each province and territory has its own regulations.

Driving is not allowed until you have been seizure free for at least 6-12 months and you are under doctor's care. A shorter period may be considered upon a favorable neurologist's recommendation. If your seizures return, contact your doctor.

Drivers are generally required by law to report any health problems such as epilepsy/seizure disorder that would interfere with driving to the appropriate provincial or territorial regulatory agency.

Will I be able to work?

Having epilepsy/seizure disorder does not mean that you can't get a job, continue in a job, or be excellent at what you choose to do.

Decisions - Before applying for a job, consider how a job will fit into your schedule. Sometimes jobs available to teenagers involve working late hours and that could mean you won't get enough sleep. A job can also add stress to an already demanding school schedule. A lack of sleep and stress are both seizure triggers, so consider your job options carefully. When considering long-term career options, research your choices. Although your options are many, there may be restrictions in certain careers for safety reasons.

Discrimination - People are becoming more knowledgeable about epilepsy/seizure disorders but workers that have it sometimes still face discrimination and or an underutilization of skills in the workplace. An employer

may be biased because of a lack of knowledge about the condition or may have concerns over safety, reliability, or liability, yet studies involving people with epilepsy/seizure disorder in the workplace do not support those concerns. People with epilepsy/seizure disorder have the same range of intelligence as other people, but students with it do have a slightly higher rate of difficulty in school and learning problems than those without the condition.

Physical disabilities are protected grounds under human rights legislation. The Canadian Human Rights Act does not allow discrimination by an employer due to a disability.

Can I participate in sports?

Participation in sports is important to keep in shape and build self-esteem. Common sense is the key in a sport. Anything that involves heights, such as sky diving and rock climbing, is not a good idea.

Swimming is fine as long as there is someone with you- NEVER SWIM ALONE. Riding a bike is fine as long as you wear a helmet and try to avoid busy traffic areas. Team sports are great with the proper equipment. Also, it is very important your coach should know about your epilepsy.



Who should I tell?

This is a personal decision. In some situations, such as applying for a driver's license, you must tell someone that you have epilepsy. You should also tell people who are close to you and who see you on a regular basis, such as coaches, close friends and family. You may or may not wish to tell your teachers. This will depend on how often you have

seizures and the likelihood that you'll have a seizure at school. A medical alert bracelet will let someone know you have epilepsy if there is an emergency and you are not with anyone who knows you.

Realizing that epilepsy is not unusual and that there is nothing to be ashamed of will make you confident about telling people who care.

What will people think of me?

People often fear what they don't understand. Epilepsy/seizure disorder is still misunderstood by many people. Some people think that a seizure always involves body jerking and unconsciousness. They may be aware that seizure can involve behavior such as blank staring or uncontrolled movements, chewing or pulling at clothing. People sometimes think that a person having a seizure is behaving a certain way deliberately. They may treat those with epilepsy/seizure disorder with unkindness or avoidance out of a lack of knowledge about the condition. Misconceptions about epilepsy/seizure disorder are often based on inaccurate television and movie portrayals, or outdated views on the condition. Through public awareness and education, attitudes towards the condition are slowly changing. It has become accepted knowledge that many brilliant people - including Joan of Arc, Vincent Van Gogh, Isaac Newton and Manitoba's own Neil Young - have/had epilepsy.

Can I date?

Only you can decide how, when, and if, it is right to talk to a girlfriend or boyfriend about epilepsy/seizure disorder. Again, this may depend on how close you feel to the person or on the type and frequency of your seizures. If you have

frequent uncontrolled seizures, you may want to share information early in the relationship. If the person understands what epilepsy/seizure disorder is, then he or she may react much more positively than you can imagine.

Can I have a relationship?

Having a relationship can be a normal event in every teen's life, and there is no reason for you to be any different. If you plan to take birth control pills, let your doctor know that you are taking medication - some seizure medications decrease the effectiveness of birth control pills. Always practice safe sex.

How about smoking, alcohol, and drugs?

Smoking - Can be hazardous. If you have a seizure while smoking, burns or a fire may occur.

Drinking - Excessive amounts of alcohol and the subsequent withdrawal from alcohol can trigger seizures. Although modest occasional drinking doesn't seem to increase seizure activity in some people. Drinking alcohol can lower your seizure threshold. A seizure threshold is the level at which your brain will have a seizure. Some doctors recommend that if seizures are not fully controlled, you should not drink alcohol. If you choose to drink alcohol, it is necessary that you continue to take your seizure medication as prescribed.

Drugs - Can provoke seizures. Withdrawal from marijuana can result in an increase in seizure activity. Cocaine can cause seizures and may do brain damage leading to epilepsy/seizure disorder. Amphetamines (e.g. speed), ecstasy, and LSD are also street drugs associated with seizures.

Why can I feel so depressed?

There is an increased risk of depression in people living with epilepsy/seizure disorder. Depression may be a side effect of medication, or it may occur just before, just after, or in between seizures. Depression could also be a reaction to the insensitivity of others or the anxiety caused by not knowing when or if another seizure will occur.

You should talk about these feelings with people who care about you and your doctor. They may be able to help.

Who can I talk to?

Consider talking to a parent, teacher, friend and as well directly to the Epilepsy and Seizure Association of Manitoba. They will offer support and provide you with information to help you in making decisions.

Where can I get information?

If you have concerns or question about epilepsy/seizure disorder, contact Epilepsy and Seizure Association of Manitoba. The Association has resources for teenagers about epilepsy/seizure disorder and staff members who can provide you with information. There are support programs, public awareness, newsletters, resource libraries, and special events. The Association may be able to put you in touch with epilepsy/seizure disorder clinics, support groups, or other teenagers who are facing similar challenges.

Setting Goals

Acceptance of seizures and their uncertainties sometimes doesn't come easily.

Optimism may, at times, be hard to discover.

Take a close look at your interests and strengths. Use these to guide your decisions.

And remember, there are no guarantees in life but there are plenty of opportunities.

Reference:

Handbook of Epilepsy Treatment

Simon D. Shorvon MA, MD, GFRCF
Professor of Clinical Neurology and Chairman of the
Department of Clinical Neurology

Institute of Neurology
University College London

Will Epilepsy Change My Life?
Abbott Laboratories Ltd.

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
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