

# EPILEPSY

## Women Managing Epilepsy or Seizure Disorder



This document provides general information about epilepsy and seizure disorders.

This information should not be taken as medical advice -- only your doctor can give the medical advice that is right for you.



EPILEPSY AND  
SEIZURE  
ASSOCIATION  
OF MANITOBA

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## **Women Managing Epilepsy or Seizure Disorders**

Despite the fact that 50% of people with epilepsy or seizure disorders are female; being a woman that has seizures is not the same as being a man that does.

Epilepsy or seizure disorders especially affect puberty, menstruation, pregnancy, and menopause. No doctor can be said to effectively manage epilepsy or seizure disorders unless he or she pays attention to and informs the patient about the factors; and ensures that his or her female patients have been thoroughly investigated, fully counselled and are taking the appropriate medication.

Learning more about how epilepsy may influence certain aspects of a woman's life will help you to make informed decisions regarding medical treatment, safety, and lifestyle choices.

Although you will have to consider having epilepsy or seizure disorders in the decisions you make, it does not mean that you are unable to pursue your dreams or enjoy a fulfilling life.

### **Epilepsy or Seizure Disorders**

Epilepsy or 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 or seizure disorders are conditions that are defined by multiple seizures.

Epilepsy or 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 or 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 behavior 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 arm 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.

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## ***Causes of Epilepsy or Seizure Disorders***

Seizures are caused by a number of factors that affect the brain. The cause is sometimes genetic and sometimes acquired but often includes both genetic and acquired factors.

The cases vary according to the age of the onset of seizures. In many cases, no specific cause of the seizures can be identified. In other cases, some of the causes include:

- Genetic (e.g. inherited genes)
- Birth injury (e.g. lack of oxygen to the baby's 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
- Stroke
- Cerebral degenerative disorder (e.g. those associated with Alzheimer's Disease)
- Alcohol and drug abuse

## ***Diagnosis***

In addition to possible laboratory tests and a thorough physical examination, the procedures used to establish a diagnosis of seizures generally include a medical history and diagnostic tests.

Medical history is important in a doctor's assessment. Typically it involves a family health history and a detailed description of the characteristics, onset, and frequency of the seizures.

Diagnostic tests usually include an electroencephalogram (EEG), an important tool in the diagnosis of epilepsy. An EEG is used to record the brain's electrical activity.

Neuroimaging tests are also sometimes used to provide pictures of the brain.

Computed tomography (CT or CAT) and magnetic resonance imaging (MRI) scans provide pictures of the brain structures.

## ***Seizure Medication***

Seizure medication is the primary treatment for epilepsy or seizure disorders. Drugs do not cure seizures, 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.

Due to the number of different types of epilepsy or seizure disorders, there are many different medications. ***Monotherapy*** (treatment with one drug) is preferable in the treatment, but sometimes more than one drug, or ***polytherapy***, is required.

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Most epilepsy and seizure disorder associations can provide a list of useful tips relating to taking seizure medication.

### ***Seizure Medication Side Effects***

In general, 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 involve drowsiness, loss of coordination, headache, decreased appetite, nausea, tremor, weight gain or loss, dizziness, double or blurred vision, and even impaired attention and memory. Sometimes dose-related side effects can be cosmetic and can include overgrowth of the gums, hair loss, or excessive hair growth. Skin rash may often be the first sign of an allergic reaction to a drug. With long time use of seizure medication, osteoporosis can occur. Your doctor may prescribe vitamins and/or supplements if there is evidence of reduced bone density.

### ***Physicians should be consulted regarding side effects.***

For more information on the possible adverse side effects of each drug or the risk of interactions with other medications or vitamins, consult your doctor, pharmacist, or contact your local epilepsy association.

Discuss the use of any other medications or vitamins with your doctor or pharmacist, eg:

- Women taking tegretol (carbamazepine) should be aware that eating grapefruit or drinking anything that contains grapefruit could alter the way their tegretol works.
- Decongestants, acetylsalicylic acid products (ASA) such as Aspirin, herbal medications, diet pills, and birth control pills can all interact with seizure medication.
- Even some therapeutic drugs such as antidepressants and antibiotics could interact with your seizure medication.

### ***Discontinuing Or Not Taking Medication As Prescribed***

***Discontinuing (or stopping) seizure medication can cause serious complications and should only be done with a doctor's advice and supervision.***

**Sudden discontinuation** of medication could result in withdrawal seizures or status epilepticus, a continuous seizure state that can be life threatening.

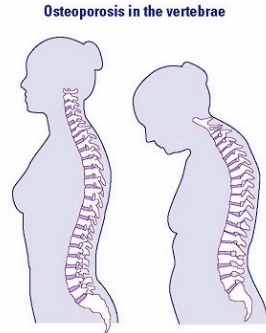
**Reducing the prescribed dosage of seizure medication** can also result in problems. Some doctors will advise people with epilepsy to discontinue medication after two years without a

seizure. Other doctors do so after four or five years of medication without a seizure.

Safe reduction of seizure medication can only be done if a number of factors have been carefully considered.

## **Osteoporosis**

Long-term use of certain seizure medications is associated with a loss of bone density or bone thinning. If bone loss is severe, a condition called osteoporosis can result.



The risk of osteoporosis increases for all women as they age but the risks are higher for women following the long-term use of seizure medication.

Osteoporosis is a serious condition that results in the bones becoming thin and brittle. People with osteoporosis are more susceptible to bone fractures and breakages. If seizures involve falls, then there is an added risk of injury.

Women with epilepsy or a seizure disorder who are taking seizure medication should discuss the risks associated with osteoporosis with their doctor. Often doctors will prescribe calcium supplements and medical tests may be required to monitor any changes in bone density.

## **Lifestyle choices can also influence bone health.**

To reduce the risk of osteoporosis, it is recommended that a person:

- gets regular exercise throughout life
- eats a diet rich in calcium
- limits alcohol intake
- avoids smoking

## **Surgery**

Typically, patients considered for surgery have seizures that are **medically refractory** or **intractable**. This means that they do not respond to medical treatment such as the use of seizure medication. In some cases, the person's quality of life while on medication is poor and surgery may be an option.

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.

Surgery may involve the removal of the part of the brain where the seizures originate or it may involve a surgical cut to prevent seizures from spreading from one side of the brain to the other by interrupting the nerve pathways.

Surgery is irreversible and changes in personality or cognitive abilities, or disturbances in sensation, vision, or speech could result although the risk of

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severe neurologic complication is low. As with any surgery, there is always the possibility of serious complications.

When successful, however, surgery can be very effective in improving seizure control. With recent technological advances, surgery has become safer and more widely used.

### ***Vagus Nerve Stimulation***

Vagus Nerve Stimulation (VNS) is a surgical therapy that involves the implantation of a battery-powered device called a Vagus Nerve Stimulator under the skin in the chest. The device is similar to a heart pacemaker. 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.

VNS is not suitable for everyone with epilepsy. It is being used in patients who do not respond to medication and who are not suitable for seizure-related surgery.

### ***Complementary Therapies***

There are many complementary therapies that some individuals have found helpful in seizure control. Although some of these methods may not have been scientifically proven, there are people with epilepsy who have found that they help in

reducing seizures. Complementary therapies include techniques such as aromatherapy, yoga, massage therapy, meditation, herbal remedies, art, music and pet therapy, reflexology, and biofeedback.

***It is important to remember that all therapies should be discussed with a doctor. Complementary therapies are used to supplement and not to replace accepted treatments.***

### ***Choosing a Doctor***

Establishing a ***positive relationship with your doctor*** is very important. It is helpful to have a doctor in whom you have confidence and with whom you can talk openly. It is useful to take a list of questions when visiting your doctor in order to assure that you are prepared and that your concerns are addressed.

Often your general practitioner will refer you to a neurologist and possibly to an obstetrician. Neurologists specialize in the area of medicine relating to the nervous system and obstetricians specialize in childbirth.

Occasionally people feel that they are not getting the treatment they would like and, in those cases, requesting a second opinion may be important.

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## **Personal Well-Being**

For many women, having epilepsy or a seizure disorder will require few changes in lifestyle. For others with uncontrolled seizures, their lives may change significantly.

Following a diagnosis of epilepsy or a seizure disorder, some people feel depressed, angry, or frustrated. This is not unusual.

In fact, depression is more common in individuals with epilepsy or a seizure disorder than it is in the general population. This could be due to psychosocial factors, the seizures themselves, and/or seizure medication. If you find that you are unusually depressed, discuss your feelings with your doctors. There may be medical treatment or lifestyle changes that could help.

Educating yourself and others about your condition, finding the appropriate medical treatment, developing a support network, and continuing to pursue what brings joy into your life are all important in achieving a fulfilling quality of life.

## **Relationships**

Consider carefully with whom you want to discuss your epilepsy or seizure disorder. The decision may depend partly on the type and frequency of your seizures.



Sometimes the decision may be based on how close you feel to the person. Although it might not be necessary to discuss your condition with everyone, it is important that those you are with often know how to help if you have a seizure.

Only you can decide how, when and if, it is right to talk to a person you are involved with romantically about having epilepsy. Again, this may depend on how close you feel to the person on the type and frequency of your seizures. If you have frequent uncontrolled seizures, you may want to share information early in the relationship.

A person who understands what epilepsy or a seizure disorder is may react much more positively than you imagine.

## **General Health and Seizure Triggers**

It is important to maintain a healthy and well-balanced lifestyle. Monitoring what may trigger a seizure is also helpful for people with epilepsy.



The most common seizure triggers include forgetting to take seizure medication as prescribed, lack of sleep, and stress. Other triggers include poor diet, excessive alcohol consumption and subsequent withdrawal, and use of street drugs. Flashing or flickering lights can provoke seizures in

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a certain type of epilepsy or seizure disorders known as photosensitive epilepsy.

### **Hormones**

Hormones are chemical substances in the blood that control some of the biologic processes in the body. The female hormones of estrogen and progesterone have a known influence on seizures. As the hormones fluctuate with monthly menstruation cycles, puberty, pregnancy, and menopause, women often find that the changes in hormonal levels do affect their seizures.

### **Menstruation**

Sometimes there is a change in the frequency or pattern of seizures related to menstruation. There are a number of reasons why seizures may change at certain times during your menstruation cycle:

- There may be a disturbance in the levels of estrogen and progesterone at different times during the menstrual cycle. Estrogen excites brain cells often triggering seizures while progesterone inhibits seizures in some women.
- In the second half of the monthly cycle, the body may be producing less progesterone.
- Seizure medication levels in the blood may decrease just before menstruation resulting in seizures. This may be due to an increased metabolism of seizure medication by the liver premenstrually.

These changes in seizures sometimes occur between periods at the time of ovulation, or just prior to, or during menstruation. Less commonly, they can also occur after menstruation.

When seizure occurrence is linked to the menstrual period, it is diagnosed as **catamenial epilepsy**.

Keeping track of your seizures and your monthly menstrual periods on a seizure record chart will help you to determine whether or not monthly hormonal changes are influencing your seizures. Other factors that may be influencing your menstruation period such as stress, loss of sleep, illness, or overexertion should also be noted on your seizure record.

Sharing this record with your doctor will assist in diagnosis as well as in determining whether there may be changes in medication or other therapies that can help.

### **Sexual Activity**

In general, people with epilepsy have healthy sexual relationships consistent with the overall population. Only in rare cases, does sexual activity trigger seizures. Seizure medication may, however, lessen a person's interest in sexual activity or affect sexual function. If seizures are uncontrolled or a person has poor self-esteem, this could also affect sexual function.

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Any of these concerns regarding sexual activity should be discussed with your doctor. There may be medication changes or other treatments that can help to alleviate these problems.

### **Birth Control**

All common birth control methods can be used by women with epilepsy. Some types of seizure medication, however, can interfere with the effectiveness of birth control pills.

Bleeding in the middle of your menstrual cycle is sometimes an indication that your contraceptive medications are not working effectively.

In some cases, your doctor may recommend using a second birth control method such as a diaphragm or a condom with spermicidal cream in combination with birth control pills.

If you are planning to use or are taking birth control pills, are planning to become pregnant, or are pregnant, it is essential that you talk with your doctor. Changes in seizure medication levels or prescribed drugs may be required.

### **Pregnancy**

***Most women with epilepsy have healthy babies and the risks involved in their pregnancies are the same as for any pregnancy.***

Women with epilepsy, however, should be aware that there are special considerations related to pregnancy.

***If at all possible, a woman who has epilepsy should consult with her doctor before becoming pregnant to plan for the healthiest possible pregnancy.***

Pregnancy can affect the way your body is using your seizure medication and/or it could affect the pattern or frequency of your seizures. There is also a slightly higher risk that having epilepsy and/or taking seizure medication will affect the fetus.

### **Talk to Your Doctor Prior to Becoming Pregnant**

As the greatest risk of possible birth defect occurs in the first trimester of pregnancy, it is essential that you talk to your doctor prior to becoming pregnant.

Harmful effects of seizure medication to the fetus could occur in the early weeks of pregnancy before pregnancy is medically confirmed. Planning for pregnancy will allow you to work with your doctor to establish the best possible treatment for the health of both you and your baby. If you discover that you are pregnant and have not discussed this with your doctor, do so as soon as possible. Changes in seizure medication and/or dosages as well as vitamin supplements may be required.

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It is essential that you continue to take seizure medication as prescribed by your doctor during your pregnancy. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus, a life-threatening condition, and the risks to the fetus of having uncontrolled seizures are considered to be higher than those associated with taking prescribed seizure medication.

***In general, women with epilepsy have a greater than 90 percent chance of having a healthy baby.***

### ***Breast Feeding***

Drug concentrations in breast-milk are generally low. Breast-feeding is therefore acceptable unless the mother is taking high doses of phenobarbital, ethosuximide or benzodiazepine drugs. Particular caution is advised in the case of maternal phenobarbital ingestion as in newborns the half-life of phenobarbital is long and the free fraction is higher than in adults; neonatal levels can therefore sometimes exceed maternal levels.

Neonatal phenytoin and valproate half-lives are also increased. Neonatal lethargy, irritability and feeding difficulties have also been attributed to maternal antiepileptic drug intake, although evidence is slight and symptoms do not seem to be correlated with maternal drug dosage or serum level.

### ***Parenting***

Although most women with epilepsy or seizure disorders can provide safe care for their children, changes in routines may be necessary depending on the frequency or type of seizures you experience.

If your seizures are not controlled, working with health care professionals will help to assure your child's safety. If you experience auras or warnings before seizures, you may have the opportunity to take the necessary precautions for your child's safety.



Developing a network of family and friends to assist you in case you need help is also worthwhile.

### ***Safety Tips for Parenting***

Depending on the frequency and type of seizures you experience, it may be necessary to incorporate some or all of the following safety tips into your daily routine:

1. Use safety gates and playpens in case of a seizure.
2. Use a stroller for transporting your baby rather than carrying your child, even in your own home. Use a stroller with brakes, a child harness, or a wrist bungee cord when you go out.

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3. Change diapers or clothes in the crib with the side up. This keeps the baby safe and prevents the parent from falling forward on the baby should a seizure occur.
  4. When feeding the baby, sit on the floor. If you always fall on the same side during a seizure, position yourself to prevent you from falling on the baby.
  5. Keep baby supplies on each level of your home to avoid unnecessarily having to climb stairs with your baby.
  6. If you are alone, give your baby a sponge bath rather than using a bathtub.
  7. Avoid carrying or drinking hot liquids or smoking near your baby.
  8. Secure the baby into an infant seat on the floor or in a high chair for bottle feedings and meals.
  9. If you are breast-feeding, feed your baby while sitting on the floor surrounded by a soft surface.
  10. If sleep deprivation is one of your seizure triggers, then arrange for someone to help out with either nighttime feedings or a daytime feeding when you can catch up on your sleep. If you are breast-feeding, breast-milk can be pumped into a bottle so that others will be able to help you with feedings.

11. Keep outside doors and gates locked.
12. When your child is old enough to understand, discuss your epilepsy with your child. This may alleviate some of the child's concerns. It will also help your child to know how to respond if you have a seizure.
13. Post the phone numbers of those your family should call in case you need assistance.

### **Menopause**

At menopause, some women experience a change in the patterns of their seizures. As hormonal changes occur, some women experience seizures for the first time in menopause or their seizures change. Other women experience a recurrence of seizures that were previously controlled.

During perimenopause, or the years leading up to menopause, there is a gradual decline in the amounts of estrogen and progesterone in the blood as the ovaries produce less of these hormones. The fluctuation of these hormones in the system can affect seizures. With the changes in the body's metabolism at this time of life, blood levels of seizure medication may change and dosages may have to be altered.

With the unpredictability of ovulation during this period, unplanned pregnancies can also occur.

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Hormone replacement therapy is an option for women with epilepsy but possible interactions of this treatment with your seizure medication and any impact it might have on your seizures should be considered.

### **Abuse**

Women with a disability may be vulnerable to abuse and/or violence. Abuse can take the form of physical, emotional, or sexual abuse. It can also involve neglect or control. In some cases, an abuser could be a family member or a caregiver. In other cases, it could be a stranger.

A woman with a disability may be at risk due to an increased dependency on others, a lack of knowledge about her rights, the negative attitude of others, or because she is more isolated. Women who have seizures that involve a loss of awareness or subsequent confusion, could be susceptible to abuse.

Becoming involved in your community, informing friends and neighbors of your seizures, being as independent as possible, and finding out about your rights are all ways to help to prevent abuse.

If you are experiencing abuse, call your local crisis line, women's shelter, or police department.

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***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/seizure disorders get in the way of a satisfying life.***

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### **References:**

Epilepsy Foundation web site  
(<http://www.epilepsyfoundation.org/>)

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# 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 or seizure disorders. Here are some of the services we provide:

- Free information packages
- School awareness programs
  - Community education
  - Print and video library
- Peer support networks/ individual advocacy
  - Provincial and national newsletters
  - Website: [www.manitobaepilepsy.org](http://www.manitobaepilepsy.org)

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

For more information  
or to become a member  
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