

**W O M E N   A N D**

# *Epilepsy*



**EPILEPSY EDUCATION SERIES**

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This booklet is designed to provide general information about Epilepsy to the public. It does not include specific medical advice, and people with Epilepsy should not make changes based on this information to previously prescribed treatment or activities without first consulting their physician.

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Special thanks to our Consulting Team, which was comprised of Epilepsy Specialist Neurologists & Neuroscience Nurses, Hospital Epilepsy Clinic Staff, Educators, Individuals with Epilepsy, and Family Members of Individuals with Epilepsy.

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# *Women and Epilepsy*

For women with epilepsy, there are special considerations.

Puberty, menstruation, pregnancy, and menopause can all be affected by epilepsy. Learning more about how epilepsy may influence certain aspects of your life will help you to make informed decisions regarding medical treatment, safety, and lifestyle choices.

Epilepsy is a condition. It is not a lifestyle. Although you will have to consider having epilepsy in the decisions you make, having epilepsy does not mean that you are unable to pursue your dreams or enjoy a fulfilling life.



# Epilepsy

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Epilepsy is 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 is a condition that is defined by multiple seizures.

Epilepsy **is** a seizure disorder, **not** a psychological disorder or a disease and it is **not** contagious.

It is also a condition that is more common than most people realize. In the general population, approximately one person in a hundred has epilepsy. In Canada, there are over 330,000 people with epilepsy.

# Seizures

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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 the seizure takes depends on where in the brain the excessive electrical activity occurs.

# S Seizure Types

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There are many types of seizures. The different types begin in different areas of the brain and they are grouped into two categories: *partial* and *generalized*.

If the sudden excessive electrical activity occurs in one part of the brain, it is called a *partial* seizure.

If the excessive electrical activity involves the whole brain, the seizure is called a *generalized* seizure. Sometimes seizures begin as partial and then spread and become generalized. These are referred to as *partial seizures secondarily generalized*.

## *Partial Seizures*

The two most common kinds of partial seizures are *simple partial* and *complex partial*. During a simple partial seizure, awareness remains intact. In a complex partial seizure, awareness is impaired.

A *simple partial* seizure usually begins suddenly and lasts seconds to minutes. It involves symptoms that result in a person experiencing an unusual sensation, feeling, or movement called an *aura*. An aura can take many different forms. For example, an aura might be a distortion in sight, sound, or smell, sudden jerky movements of one area of the body, dizziness, or an overwhelming emotion.

An aura is a simple partial seizure that may occur alone or may progress to a complex partial seizure or a generalized seizure.

During a *complex partial* seizure, a person experiences altered awareness and may appear dazed and confused. A dreamlike experience may occur.

The seizure often begins with an unusual sensation, feeling, or movement referred to as an *aura*. The aura often occurs just before awareness is altered and can be used as a warning.

Random purposeless movements over which the individual has no control called *automatisms* often characterize the seizure. These may include movements such as chewing motions, lip smacking, pulling at clothing, or random walking.

The seizure usually lasts between one and two minutes and is often followed by a postictal period of disorientation or confusion.

**A complex partial seizure often begins with an unusual sensation, feeling, or movement referred to as an *aura*. The aura often occurs just before awareness is altered and can be used as a warning.**

## *Generalized Seizures*

A generalized seizure commonly takes one of two forms: *absence* (without convulsions) or *tonic clonic* (with convulsions).

An *absence* (formerly called petit mal) seizure results in a blank stare usually lasting less than 10 seconds. The seizure starts and ends abruptly, and awareness is impaired during the seizure. These seizures are sometimes misinterpreted as daydreaming or inattentiveness. Following the seizure, alertness is regained quickly.

A *tonic clonic* (formerly called grand mal) seizure usually lasts from one to three minutes.

The tonic phase of this seizure type typically involves a crying out or groan, a loss of awareness, and a fall as consciousness is lost and muscles stiffen. The second phase or clonic phase of the seizure typically involves a convulsion and there is jerking and twitching of the muscles in all four limbs. Usually the movements involve the

whole body. Urinary or bowel control may be lost and there may be shallow breathing, a bluish or gray skin color, and drooling.

Awareness is regained slowly and the person often experiences a postictal period of fatigue, confusion, and/or a severe headache after the seizure.

Other types of generalized seizures include *atonic* and *myoclonic* seizures.

An *atonic* seizure involves a sudden loss of muscle tone resulting in a person falling down or almost falling down, dropping objects, or nodding the head involuntarily. Typically, these seizures last for a few seconds.

A *myoclonic* seizure results in a sudden jerk of part of the body such as the arm or leg. The person may fall over. The seizure is very brief.

## *Status Epilepticus*

A continuous seizure state, or *status epilepticus*, is a life-threatening condition. Seizures are prolonged or occur one after another without full recovery between seizures. ***Immediate medical care is necessary.*** The seizures may be convulsive or non-convulsive.

## *Sudden Unexplained Death in Epilepsy (SUDEP)*

The cause of SUDEP, where death occurs suddenly for no discernible reason, is unknown. This is rare.



## Keeping a Seizure Record

Keeping a record of your seizures is very useful. A description of the seizures will assist the doctor in making a diagnosis as well as in the decision regarding the appropriate treatment. In addition to detailing the characteristics of the seizures, a record will also provide information regarding the frequency and duration of the seizures. It may also help to identify any consistent seizure triggers. Asking those who were with you during the seizure for a description of what happened is helpful. Seizure record charts are available from most epilepsy associations or you could use a notebook or create your own chart.



**In your seizure record, it is important to record information such as:**

- the time the seizure occurred
- the date the seizure occurred
- how long the seizure lasted
- information that describes your behavior before, during, or after the seizure.

# *C* Causes of Epilepsy and Seizures

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

The causes vary according to the age of the onset of epilepsy.

In many epilepsy 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

# D Diagnosis

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In addition to possible laboratory tests such as blood tests and a thorough physical examination, the procedures used to establish a diagnosis of epilepsy 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.

Other neuroimaging tests such as magnetic resonance spectroscopy (MRS) and positron emission tomography (PET) show how the brain functions and are used to evaluate the possibilities for epilepsy surgery.

# Treatment

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## Seizure Medication

Seizure medication is the primary treatment for epilepsy. Drugs do not cure epilepsy, 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, there are many different medications. *Monotherapy* (treatment with one drug) is preferable in the treatment of epilepsy but sometimes more than one drug, or *polytherapy*, is required.

Most epilepsy associations can provide a list of useful tips relating to taking 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. 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.

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

## *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 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 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 epilepsy-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.



# *P* Personal Well-Being

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For some women, having epilepsy will require few changes in lifestyle. For others with uncontrolled seizures, their lives may change significantly.

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

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

**For some women, having epilepsy will require few changes in lifestyle. For others with uncontrolled seizures, their lives may change significantly.**

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.

# R Relationships

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Consider carefully with whom you want to discuss your epilepsy. 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 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. A person who understands what epilepsy is may react much more positively than you imagine.

# G General Health and Seizure Triggers

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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 a certain type of epilepsy known as photosensitive epilepsy.

# Hormones

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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.

# Puberty

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During puberty, there are hormonal changes. Hormones stimulate changes in the body at this time in a young girl's life. As a result of both the body's hormonal and metabolic changes, there may be a change in seizures.

Seizure medication blood levels may also be affected resulting in changes in seizure frequency or patterns. An alteration in seizure medication dosages may be required.

Some young women find that seizures stop at puberty. Others find that there is an onset of seizures at puberty.

With the increased interest in peer groups at this age, some adolescents may question why they have to take seizure medication. ***It is important that adolescents continue to take seizure medication as prescribed by their doctor. A sudden discontinuation can result in withdrawal seizures or a life-threatening condition known as status epilepticus. Even a reduction of dosages of prescribed seizure medication can result in problems. Discussing any issues with your doctor, including side effects that are of concern, can be helpful.***

# M *Menstruation*

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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 a diagnosis as well as in determining whether there may be changes in medication or other therapies that can help.

## *S*exual Activity

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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.

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.

## *B*irth Control

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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

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*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.

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

There is also a slightly higher risk that having epilepsy and/or taking seizure medication will affect the fetus.

## Frequently Asked Questions Regarding Pregnancy And Women With Epilepsy

### **Q** Will I have difficulty getting pregnant?

**A** While women with epilepsy have fewer children and a lower fertility rate than those in the general population, there has been an increase in pregnancies in women with epilepsy in recent years. Likely this increase has been influenced by both the improved control of seizures and a better understanding of epilepsy resulting in more women with epilepsy developing relationships.

Personal choices as well as a higher rate of menstrual irregularities and other gynecological problems resulting from seizure medication are likely factors in the lower rate of pregnancies in women with epilepsy.

The temporal lobes of the brain are associated with the areas of the brain that regulate hormones in the body. If a woman experiences seizures that occur in a temporal lobe, there appears to be a higher incidence of reproductive disorders such as polycystic ovaries (many cysts on the ovaries), early menopause, and irregular or no ovulation. All of these conditions could make getting pregnant more difficult.

Seizure medication can also affect how the body regulates hormones. This can also result in reproductive changes in the body.

## Q Do seizures change during pregnancy?

**A** Most women have no change in seizure frequency during pregnancy. Some even have a reduction in seizures.

Others do, however, experience an increase in seizures when they are pregnant.

With the physical changes that occur in the body during pregnancy, seizure medication levels in the blood may fluctuate resulting in a change in seizures. Other factors that could affect seizures during pregnancy include:

- higher estrogen levels during pregnancy.
- an increase in situations that are known to trigger seizures such as higher stress levels and loss of sleep.
- a reduction in seizure medication due to a woman's concern over the possibility of harmful effects to the fetus. **Changes in seizure medication should only be done on your doctor's advice as the risks associated with uncontrolled seizures are higher than those associated with taking seizure medication for most women with epilepsy.**

## Q Is there a greater risk of complication during pregnancy?

**A** Yes, complications during pregnancy and labor are slightly higher in women with epilepsy. Both seizure medication and uncontrolled seizures pose risks during pregnancy. The risks associated with uncontrolled seizures are considered to be higher than those associated with taking seizure medication.



While most seizures do not have harmful effects on the fetus, having a tonic clonic seizure can increase the risk of miscarriage, trauma to the abdomen, and/or oxygen deficiency to the fetus.

In women with epilepsy, there is also a small increase in the risk of premature labor and delivery, morning sickness, vaginal bleeding, and placental detachment. There is also a slight increase in fetal loss late in the pregnancy, stillbirths, and the need for a caesarean section in women with epilepsy.

In general, however, most women with epilepsy will have a normal pregnancy, labor, and delivery.

Having a seizure during delivery is generally not dangerous but it may result in a more difficult delivery. It is recommended that you continue to take seizure medication up to the time of and during labor. It is important that you take your seizure medication with you to the hospital in case of a lengthy labor and that you inform staff on the hospital ward that you have epilepsy.

The risk of a baby developing internal bleeding within the first 24 hours after birth is also slightly higher if the mother has epilepsy and is taking certain seizure medication. The risk of this occurring is low and doctors often prescribe vitamin K in the weeks prior to delivery as a preventative measure. Often newborns are given vitamin K following birth to ensure proper blood clotting.

## *T*alk To Your Doctor Prior To Becoming Pregnant

As the greatest risk of possible birth defect occurs in the first trimester of pregnancy, it is advised 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.

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.

## **Q** Are seizure medication levels affected by pregnancy?

**A** With physical changes in the body during pregnancy, seizure medication levels may decrease during pregnancy. Reasons for this include water retention that can create an increased volume of distribution, a faster metabolism, a decrease in absorption, and faster clearance from the body. Frequent blood tests to monitor the drug levels in your blood may be necessary.

Seizure medication levels can also fluctuate during the postpartum period following delivery. It is important that blood levels continue to be monitored following pregnancy as well.

## **Q** Can seizure medication harm the fetus?

**A** Some types of seizure medication can carry the risk of causing harm to a fetus. Polytherapy, or treatment using more than one seizure medication, has a higher risk of causing harm than does monotherapy, or the use of one seizure medication.

In recent years, however, there has been a decrease in the risk of birth defects in children of women with epilepsy. This has been partially attributed to an improvement in the available seizure medication, a decreased use of polytherapy in the treatment of pregnant women, and an increased use of folic acid as prescribed by the doctor. Folic acid is thought to prevent birth defects and is recommended for all women of childbearing age.

Following birth, babies sometimes experience withdrawal symptoms from the mother's seizure medications but these symptoms typically wear off over a few days or weeks and do not cause long-term effects.

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

**Q If I have a seizure, will it harm the fetus?**

**A** While evidence suggests that having brief seizures or partial seizures do not harm the fetus, a prolonged seizure carries the risk of causing harm.

For example, having a tonic clonic seizure can increase the risk of miscarriage, trauma to the abdomen, and/or oxygen deficiency to the fetus.

**Q Will my baby be healthy?**

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

There is, however, a greater risk of having a child with a birth defect in women with epilepsy than in the general population. The rate is 2 to 3 percent of having a child with a birth defect in the general population, and 4 to 6 percent in women with epilepsy who are being treated with seizure medication during pregnancy. The percentage may be higher if a woman with epilepsy is taking more than one seizure medication.

This increased risk of having a child with a birth defect may be the result of a number of factors including the effects of seizure medication and the influence of inherited genetic traits.

Though rare, birth defects can include major malformations such as spina bifida (or malformation of the spinal cord) or other neurological problems, heart abnormalities, and cleft lip/palate. Minor malformations such as differences in the shape of fingers or widely spaced eyes can also occur.

All women should avoid alcohol, street drugs, and cigarette smoking during pregnancy.

### **Q** Will my child have epilepsy?

**A** There is only a slightly higher risk of a child developing epilepsy if a parent has epilepsy. The overall risk of a child having unprovoked seizures is one to two percent in the general population and approximately six percent if a parent has epilepsy.

### **Q** Can I breast-feed?

**A** Breast-feeding is generally safe and recommended for women with epilepsy. Seizure medication levels in the breast-milk tend to be of low concentration with no adverse side effects.

Some seizure medications, however, can cause drowsiness or irritability in a breast-fed baby and your neurologist or obstetrician may recommend that breast-milk be supplemented with bottle feedings.

It is important to discuss breast-feeding with your doctor to establish the healthiest approach for your child.

# P Parenting

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Although most women with epilepsy 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.

- 3 Change diapers or clothes on a pad on the floor or on a change table that has a strap to secure your child.
- 4 Keep baby supplies on each level of your home to avoid unnecessarily having to climb stairs with your baby.
- 5 If you are alone, give your baby a sponge bath rather than using a bathtub.
- 6 Avoid carrying or drinking hot liquids or smoking near your baby.
- 7 Secure the baby into an infant seat on the floor or in a high chair for bottle feedings and meals.
- 8 If you are breast-feeding, feed your baby while sitting on the floor surrounded by a soft surface.
- 9 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.
- 10 Keep outside doors and gates locked.
- 11 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.
- 12 Post the phone numbers of those your family should call in case you need assistance.

# A Abuse

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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 with epilepsy 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.



# M *Menopause*

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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.

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.

**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.**

# *Epilepsy Associations*

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If you have concerns, questions, or ideas to share regarding epilepsy, contact your local epilepsy association. Epilepsy associations can provide you with, or direct you to, up-to-date medical and lifestyle information. New information, research, and medical technology are continually improving the understanding of and treatment for epilepsy.

Consider becoming a member of your local epilepsy association. Epilepsy associations have much to offer including support groups, programs, educational forums, public awareness, newsletters, resource libraries, referrals, special events, and advocacy. Becoming a member will give you the opportunity to learn more about epilepsy, to volunteer, to network with others in your community, and to share information.

By volunteering with your local epilepsy association, you can make a difference in helping others to better understand epilepsy and in improving the quality of life of those with epilepsy. Most epilepsy associations require volunteers to assist in areas such as peer-support programs, educational activities, administrative duties, and fundraising events. Volunteers are also needed to serve on committees and Boards of Directors.

Your local epilepsy association can be of assistance to you but you can also be of assistance to others living with epilepsy. By getting involved, you can help to make a difference in your community. Contact your local epilepsy association or call 1-866-EPILEPSY (374-5377) toll-free to connect directly with the association in your area.

## Epilepsy Education Series

The Edmonton Epilepsy Association has produced a series of epilepsy educational booklets, including:

Epilepsy: An Overview

Living with Epilepsy

Epilepsy: A Guide for Parents

Let's Learn About Epilepsy:  
An Activity Book for Children

Teens and Epilepsy

Epilepsy: A Guide for Teachers

Women and Epilepsy

Seniors and Epilepsy

Epilepsy: A Guide for Professionals and Caregivers

Epilepsy: Seizures and First Aid

Safety and Epilepsy

For more information, or to order copies of these booklets, contact your local Epilepsy Association at 1-866-EPILEPSY (374-5377).

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# Partners in Improving the Quality of Life for Those Who Live With Epilepsy:

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Canadian League  
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**Your Local Contact Information:**



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