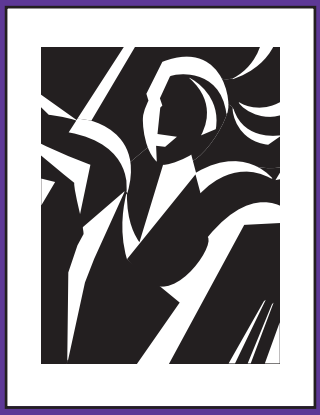
WOMEN AND Epilepsy



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. People with epilepsy should not make changes based on this information. Always consult your physician prior to making any changes.

Special thanks to our consulting team, which included epilepsy specialist neurologists & neuroscience nurses, hospital epilepsy clinic staff, educators, individuals with epilepsy, and their family members.

Contents

Women and Epilepsy

For women with epilepsy, there are special considerations.

Epilepsy may affect puberty, menstruation, pregnancy, and menopause. Learning more about epilepsy will help you make informed decisions regarding medical treatment, safety, and lifestyle choices.

Although you will have to take your epilepsy into consideration, it should not interfere significantly with your choices in life.

Epilepsy

Epilepsy is characterized by recurrent seizures. Approximately 1 in 10 Canadians will experience at least 1 seizure during a lifetime. This does not mean they have epilepsy. Someone with epilepsy experiences multiple, unprovoked seizures.

Epilepsy **is** a seizure disorder. It is **not** a psychological disorder. It is **not** contagious.

It is more common than most people realize. In the general population, approximately 1 person in 100 has epilepsy.

Seizures

The brain is made up of approximately 100 billion nerve cells or neurons that communicate through electrical and chemical signals. When there is a sudden, excessive electrical discharge that disrupts the nerve cells' normal activity, a change in the person's behaviour or function may result. This abnormal brain activity is a seizure.

There are many different types of seizures. For instance, a person having a seizure might stare blankly, jerk an arm uncontrollably, feel a burning sensation, or have a convulsion.

What the seizure looks like depends on where the excessive electrical activity in the brain is occurring and how widespread it is.

Seizure Types

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

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

If the entire brain is involved, it is called a **generalized seizure**. Sometimes seizures begin as focal and then spread. These are called **focal seizures secondarily generalized**.

Focal Seizures

The two most common kinds of focal seizures are **focal aware** and **focal impaired awareness seizures**.

A **focal aware** seizure usually begins suddenly and lasts from seconds to minutes. It results in an unusual sensation, feeling, or movement called an **aura**. An aura may be a distortion in sight, sound, or smell, sudden jerky movements of one area of the body, dizziness, or an overwhelming emotion.

An aura may progress into a focal impaired awareness seizure or a generalized seizure.

During a **focal impaired awareness** seizure, a person 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 1-2 minutes and is often followed by a postictal period of disorientation or confusion.

A focal impaired awareness 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

There are two main types of generalized seizure: **absence** (without convulsions) or **tonic-clonic** (with convulsions).

An **absence** 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** seizure usually lasts from 1-3 minutes.

The tonic phase of this type of seizure typically involves a scream or a groan, a loss of awareness, and a fall as consciousness is lost and muscles stiffen. The second phase or clonic phase of the seizure involves convulsions with jerking and twitching of the muscles in all four limbs. Usually the movements involve the whole body. Urinary

or bowel control may be lost, there may be shallow breathing, a bluish or grey skin colour, 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.

Two other types of generalized seizures are atonic and myoclonic seizures.

An **atonic** seizure involves a sudden loss of muscle control resulting in a person falling or almost falling, dropping objects, or involuntarily nodding the head. 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. The seizure is very brief.

Sudden Unexplained Death in Epilepsy (SUDEP)

The cause of SUDEP, where death occurs suddenly for no discernible reason, is unknown. Close monitoring of seizure recovery may help prevent this rare condition.

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 and determining the appropriate treatment. The seizure record should describe the seizure and provide information, including duration and frequency of seizures. It will help in the identification of possible 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 create your own.

The seizure record should include:

- the time of the seizure
- the date of the seizure
- how long the seizure lasted
- a description of behaviour occurring before, during, or after the seizure

Causes of Epilepsy and Seizures

Epilepsy may be caused by either genetic or acquired factors, though it is often a combination.

In many cases, no specific cause for the seizures is identified. In other cases, causes include:

- Genetic
- Birth injury (e.g., lack of oxygen to the baby's brain at birth, mechanical trauma)
- Developmental disorder
- Brain trauma (e.g., car accidents, sports injuries)
- Infection (e.g., meningitis, encephalitis, AIDS)
- Brain tumour
- Stroke
- Cerebral degenerative disorder
- Alcohol and drug abuse

Diagnosis

A thorough physical and neurological examination with a complete family history and targeted diagnostic tests are used to establish a diagnosis of epilepsy.

For a diagnosis of epilepsy, a complete medical history, as well as an accurate description of any seizures, are important.

Diagnostic tests usually include an electroencephalogram (EEG). An EEG is used to record the brain's electrical activity.

Neuroimaging tests may also be used to obtain images of the brain.

Computed tomography (CT or CAT) and magnetic resonance imaging (MRI) scans help visualize the brain structures.

Other neuroimaging tests such as magnetic resonance spectroscopy (MRS) and positron emission tomography (PET) show the metabolic activity in the brain and may be useful when considering epilepsy surgery.

Treatment

Anti-Seizure Medication

Anti-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 medication (at least 65%).

There are many different medications available. **Monotherapy** (treatment with one drug) is preferable, but sometimes more than one drug, or **polytherapy**, is required.

Side Effects

In general, side effects tend to be more common when a drug has just been started, the dosage has been increased, or more than one drug is being taken.

Side effects include drowsiness, loss of coordination, headache, decreased appetite, nausea, tremor, weight gain or loss, dizziness, double or blurred vision, and impaired attention and memory. Sometimes dose-related side effects are cosmetic and may 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 term use of some anti-seizure medications, 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 possible side effects and risks of reactions with other medications, 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 anti-seizure medication. Certain antidepressants and antibiotics may also interact with your anti-seizure medication.

Discontinuing Or Not Taking Medication As Prescribed

Stopping or decreasing your anti-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. Some doctors will advise you to discontinue your medication after you are seizure-free for a period of time.

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

Safe reduction of anti-seizure medication can only be done after considering a number of factors.

Osteoporosis

Long-term use of certain anti-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 anti-seizure medication (especially Tegretol and Dilantin).

People with osteoporosis are more susceptible to bone fractures and breakages. Seizures which involve falls can lead to fractures.

Women with epilepsy who are taking anti-seizure medication should discuss these risks with their doctor. Often doctors will prescribe calcium supplements. Medical tests may be required to monitor 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

Patients considered for surgery usually have **intractable** seizures. This means that they do not respond to anticonvulsant medications. Sometimes, the quality of life with medication is so poor that surgery becomes an option.

Extensive medical testing and evaluation are necessary to determine the origin of the seizures in order to decide if it is safe to operate.

Surgery may involve removing 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.

Surgery is irreversible, and changes in personality or cognitive abilities, disturbances in sensation, vision, or speech could result.

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 implanting of a battery-powered device called a Vagus Nerve Stimulator 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 signal helps to prevent or interrupt the electrical disturbances in the brain that result in seizures.

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

Complementary Therapies

Although some of the complementary therapies may not have been scientifically proven, there are people with epilepsy who have found them helpful.

These include aromatherapy, yoga, massage therapy, meditation, herbal remedies or CBD oil, art, music and pet therapy, reflexology, and biofeedback.

All therapies should be discussed with your 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 bring a list of questions when visiting your doctor to ensure that your concerns are addressed.

Often your general practitioner will refer you to a neurologist. Neurologists specialize in the area of medicine relating to the nervous system.

Occasionally, people are dissatisfied with the treatment they receive, in which case a second opinion may be important.

Personal Well-Being

Having epilepsy will affect your life to some degree, depending on the severity and frequency of your seizures and the type of epilepsy with which you are diagnosed.

Following the diagnosis, you may feel depressed, angry, or frustrated. This is not unusual.

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

In fact, depression is more common in individuals with epilepsy than it is in the general population. This could be due to neurological factors influencing the balance between seizure control and mood control. Medication may also be a factor. 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.

Educating yourself and others about your condition, finding the appropriate medical treatment, using your support network, and continuing to live your life as normally as possible are all important in achieving a fulfilling quality of life.

Relationships

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

Although it might not be necessary to discuss your condition with everyone, consider telling the people that you spend the most time with about your epilepsy so that they can help if you have a seizure.

Only you can decide how, when, and if, the time is right to discuss your epilepsy with a romantic partner. If you have frequent uncontrolled seizures, you may want to share information early in the relationship. Understanding your condition may lead to acceptance.

General Health and Seizure Triggers

It is important to identify possible seizure triggers.

The most common seizure triggers include forgetting to take anti-seizure medication as prescribed, lack of sleep, and stress. Other triggers include poor diet, excessive alcohol consumption and subsequent withdrawal, and the use of street and recreational drugs, such as marijuana. Flashing or flickering lights can provoke seizures in a certain type of epilepsy 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.

Puberty

During puberty, there are hormonal changes. As a result of both the body's hormonal and metabolic changes, there may be a change in seizures.

Anti-seizure medication blood levels may also be affected by hormone levels. Seizures may increase or decrease in frequency, and in some cases, they stop altogether. A change in medication may be required. There are types of epilepsy which begin with puberty.

It is important that adolescents continue to take anti-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 dose reduction can cause problems. Discussing any issues with your doctor, including side effects that are of concern, can help.

Menstruation

Seizure patterns may be affected by the monthly menstrual cycle. There are a number of reasons for this:

- Estrogen has an excitatory effect on neurons in the brain, whereas progesterone has an inhibitory effect.
- The body produces less progesterone during the second half of the menstrual cycle.
- Medication levels are also affected. Liver metabolism may increase towards the time of menstruation, which may result in an increased seizure frequency.

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

Keeping track of your seizures and your menstrual periods will help you to determine whether or not monthly hormonal changes are influencing your seizures. Other important factors to write down include loss of sleep, illness, or overexertion.

Sharing this record with your doctor will assist in a diagnosis and determine whether there may be changes in medication or other therapies that can help.

Sexual Activity

In general, people with epilepsy have normal sexual relationships. Only in rare cases, does sexual activity trigger seizures. Anti-seizure medication may, however, lessen a person's interest in sexual activity or affect sexual function.

Concerns about sexual activity may be discussed with your doctor. There may be medication changes or other treatments that can help alleviate these problems.

Birth Control

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

Break through bleeding during your cycle may be an indication that your contraceptive medications are not working effectively.

In some cases, your doctor may recommend a second birth control method.

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 your medication may be required.

Pregnancy

Most women with epilepsy have healthy babies.

There are important things to consider before a woman with epilepsy chooses to get pregnant. She should consult with her neurologist, obstetrician, and family doctor.

The hormonal changes and the increase in body volume can both affect seizure control.

The hormonal changes and the increase in body volume can both affect your seizure control.

There is also a slightly higher risk that having epilepsy and/or taking anti-seizure medication will affect the fetus. Some medications have more of an effect than others.

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 anti-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. Anti-seizure medication can also play an important role.

Do seizures change during pregnancy?

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, anti-seizure medication levels in the blood may fluctuate, resulting in a change in seizures. Other factors that could affect seizures during pregnancy include:

- higher hormone levels during pregnancy.
- an increase in seizure triggers such as higher stress levels and loss of sleep.
- a decrease in medication blood levels due to a fear of harmful effects on the fetus. **Changes in anti-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 anti-seizure medication for most women with epilepsy.**

Is there a greater risk of complications during pregnancy?

Yes, complications during pregnancy and labour are slightly higher in women with epilepsy. Both anti-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 anti-seizure medication.

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

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

In general, however, most women with epilepsy will have a normal pregnancy, labour, 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 anti-seizure medication up to the time of and during labour. It is important that you take your anti-seizure medication with you to the hospital in case of a lengthy labour and that you inform hospital staff 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 anti-seizure medication. The 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.

Talk To Your Doctor Prior To Becoming Pregnant

As the greatest risks relating to pregnancy occur during the first trimester, it is advised that you talk to your doctor prior to becoming pregnant.

Harmful effects of anti-seizure medication 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 anti-seizure medication and/or dosages, as well as vitamin supplements such as folic acid, may be required.

It is essential that you continue to take anti-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. The risks to the fetus of having uncontrolled seizures are higher than those associated with taking anti-seizure medication as prescribed.

Q Are anti-seizure medication levels affected by pregnancy?

A Yes. 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. Testing medication blood levels may become necessary if seizure frequency increases.

Anti-seizure medication levels can also fluctuate during the postpartum period following delivery. Blood levels may need to be monitored in the postpartum period.

Q Can anti-seizure medication harm the fetus?

A Yes. Polytherapy, or treatment using more than one anti-seizure medication, has a higher risk of causing harm than monotherapy, or the use of one anti-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 anti-seizure medication, decreased polytherapy, 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 who are trying to conceive.

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

Women with epilepsy have a greater than 90 percent chance of having a healthy baby as long as they follow the accepted guidelines.

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

While evidence suggests that 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, and/or oxygen deficiency to the fetus.

Q A Will my baby be healthy?

In general, women with epilepsy have a greater than 90% 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 for the general population is 2%-3% and 4%-6% for women with epilepsy. The percentage is higher if a woman with epilepsy is taking more than one anti-seizure medication.

This increased risk is related to anti-seizure medication effects and genetic factors.

Birth defects can include major malformations such as spina bifida (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 smoking during pregnancy.

Q Will my child have epilepsy?

A There is a higher risk of a child developing epilepsy if a parent has epilepsy. The overall risk of a child having unprovoked seizures is 1%-2% in the general population and approximately 6% if a parent has epilepsy.

Q Can I breastfeed?

A Breastfeeding is generally safe and recommended for women with epilepsy. Medication levels in the breast milk tend to be low.

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

It is important to discuss breastfeeding with your doctor to establish the healthiest approach for your child.

Parenting

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.

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

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.

Safety Tips Continued

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 climbing the 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 meals.

8. When you are breastfeeding, nurse your baby while sitting on a couch, bed, or on the floor to avoid falls.

9. If sleep deprivation is one of your seizure triggers, arrange for someone to help with either nighttime feedings or a daytime feeding so you can catch up on your sleep.

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.

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 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 neighbours 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.

Menopause

At menopause, some women experience a change in the patterns of their seizures.

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. These fluctuations may affect seizure frequency and severity. With the changes in the body's metabolism at this time of life, blood levels of anti-seizure medication may change and dosages may have to be adjusted.

With the changes in the body's metabolism at this time of life, blood levels of anti-seizure medication may change and dosages may have to be altered.

Hormone replacement therapy is an option for women with epilepsy, but possible interactions of this treatment with your anti-seizure medication, and any impact it might have on your seizures should be considered. Do not make any changes in your medication without consulting your doctor.

First Aid for Seizures

What to Do if Someone has a NonConvulsive Seizure
(staring blankly, confused, not responding, movements are purposeless)

1. **Stay with the person.** Let the seizure take its course. Speak calmly and explain to others what is happening.
2. **Move dangerous objects out of the way.**
3. **DO NOT restrain the person.**
4. **Gently guide the person away from danger or block access to hazards.**
5. **After the seizure, talk reassuringly to the person.** Stay with the person until the person wakes up.

What to do if Someone has a Convulsive Seizure
(characterized by stiffening, falling, jerking)

1. **Stay calm.** Let the seizure take its course.
2. **Time the seizure.**
3. **Protect from injury.** If necessary, ease the person to the floor. Move hard or sharp objects out of the way. Place something soft under the head.
4. **Loosen anything tight around the neck.** Check for medical identification.
5. **DO NOT restrain the person.**
6. **DO NOT put anything in the mouth.**
7. **Gently roll the person onto his or her side when the convulsions have stopped, after making sure they are still breathing to allow saliva and other fluids to drain from the airway.**
8. **After the seizure, talk to the person reassuringly.** Do not leave until the person is reoriented. The person may need to rest or sleep.

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 nonconvulsive.

Calling An Ambulance

In assessing the need to call an ambulance, a combination of factors has to be considered. For example, if cyanosis (blue or grey colour) or laboured breathing accompanies the seizure, then an ambulance may be called earlier. If a person is known to have epilepsy and the seizure pattern is uncomplicated and predictable, then ambulance help may not be necessary.

CALL AN AMBULANCE:

- If a convulsive seizure lasts longer than 5 minutes.
- If consciousness or regular breathing does not return after the seizure has ended.
- If seizure repeats without full recovery between seizures.
- If confusion after a seizure persists for more than 1 hour.
- If a seizure occurs in water and there is any chance that the person has inhaled water. Inhaling water can cause heart or lung complications.
- If it is a first-time seizure, or the person is injured, pregnant, or has diabetes. A person with diabetes may experience a seizure as a result of extremely high or low blood sugar levels.

Epilepsy Education Series

A Brief Guide Introducing the new classification of epilepsy

Classification systems used for animals, plants and diseases have led to an improved understanding while allowing more effective communication among caregivers, researchers, patients, and other interested parties.

This also applies to the classification of seizures, epilepsy types, and epilepsy syndromes.

Hippocrates recognized that the cause of seizures was in the brain approximately 400 BCE. He understood that the seizures could result from severe brain trauma, and he observed that one-sided seizures resulted from trauma on the opposite side of the brain. He also reported the connection between seizures, alcohol, and genetic factors. Most seizures were considered to be idiopathic: an interaction between phlegm and black bile. Hippocrates wrote "On The Sacred Disease," but also asked: Why are seizures divine and other diseases not?"

In the middle of the 19th century, the terms 'Grand Mal', and 'Absence' were being used in French hospitals, and the Western world followed.

The most recent classification with which most of us are familiar was drawn up 28 years go by the Commission for Classification and Terminology of the International League Against Epilepsy (ILAE).

Early in 2017, ILAE published a position paper in which a revised terminology framework was proposed. The epilepsy types recognized include focal, generalized, combined generalized and focal, and unknown. Terms such as 'complex partial seizures' will be simplified to 'focal onset, impaired awareness', 'simple partial seizures' become 'focal onset, aware'.

Robert S. Fisher, MD, PhD, who was the chairman of the Classification Committee, reported the ILAE approval of the new classification during the 70th Annual Meeting of the American Epilepsy Society.

Those interested in reading more about the new classification system may look up "The 2017 ILAE Classification of Seizures - Epilepsy Foundation" on the internet for a clear and concise review. Understandably, it will be a challenge for many to adjust to this new terminology after working with one system for 28 years.

To familiarize the reader with the essential changes in the proposed terminology a partial list of old and new terms is provided.

OLD TERMINOLOGY	NEW TERMINOLOGY
Tonic-Clonic Seizure, “Grand Mal”	Generalized Tonic-Clonic of Unknown Onset
Absence / “Petit Mal”	Generalized Absence (typical, atypical, myoclonic, or with eyelid myoclonia)
Simple Partial Seizure	Focal Aware Seizure
Complex Partial Seizure	Focal Impaired Awareness Seizure
Psychomotor Seizure	Focal Impaired Awareness Seizure
Atonic / “Drop Attack”	Focal or Generalized Atonic
Secondary Generalized Tonic-Clonic	Focal to Bilateral Tonic-Clonic (onset can be aware or impaired aware)
Infantile Spasms	Focal, Generalized, Unknown Onset Epileptic Spasms
Arrest, Freeze, Pause	Behaviour Arrest

Epilepsy Associations

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

Consider becoming a member of your local epilepsy association. Epilepsy associations have much to offer including support groups, programmes, 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 programmes, 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 Epilepsy Educational Booklet Series Includes:

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 Health Care Providers

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).

All booklets are available as a free downloadable pdf from www.edmontonepilepsy.org

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

Canadian epilepsy Alliance

Alliance canadienne de l'épilepsie

Canadian League Against Epilepsy

CLAE LCCE

La Ligue Canadienne Contre l'Épilepsie

1-866-EPILEPSY

info@canadianepilepsyalliance.org

www.canadianepilepsyalliance.org

905-415-3917

info@claegroup.org

www.claegroup.org

EEA

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