A GUIDE FOR HEALTH CARE PROVIDERS

Epilepsy

EPILEPSY EDUCATION SERIES

This publication was produced by the

EEA Edmonton Epilepsy Association | The Epilepsy Association of Northern Alberta

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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.

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A Guide for Health Care Providers

Professionals and caregivers play a vital role in the physical and emotional well-being of a person with epilepsy. Often the caregiver is a family member or a person who has a close personal relationship with the individual. Sometimes it is the caregiver who provides the essential link between the individual, health care professionals, and the community at large.

A caregiver's role involves knowledge, patience, and compassion. A caregiver is in a position to have a significant influence on the quality of life of the person for whom they are caring. While living with epilepsy can result in personal challenges, it does not have to result in an inability to have a full and rewarding life. Professionals and caregivers can be instrumental in helping a person with epilepsy learn about the condition, share that information with others, find effective medical treatment, develop a support network of family and friends, and pursue what brings joy into his or her life.

Local epilepsy associations can help. Most associations can provide up-to-date medical and lifestyle information. They can assist in finding self-help and support groups. Associations can also often direct individuals to agencies that offer assistance to those with epilepsy.

Epilepsy Facts

- Epilepsy is a condition of the brain that is characterized by recurrent or multiple seizures.

- A person cannot catch epilepsy from someone else. Epilepsy is **not** a disease. It is **not** a psychological disorder. Epilepsy **is** a seizure disorder.

- Epilepsy is more common than most people realize. In the general population, one in one hundred people have epilepsy.

- Epilepsy occurs in people of all ages, ethnicities, and socioeconomic backgrounds.

- Epilepsy can begin at any age, although its onset is most often in childhood or the later years of life.

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

In many people with epilepsy, no specific cause for their seizures can be identified. Possible causes are:

- Genetic factors
- 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 tumour
- Stroke
- Cerebral degenerative disorder (e.g., Alzheimer's Disease)
- Alcohol and drug abuse

Seizure Facts

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

- There are many types of seizures. For instance, a person having a seizure may stare blankly, jerk his or her arm uncontrollably, feel a burning sensation, or have a convulsion.

- The type of seizure depends on where in the brain the excessive electrical activity occurs.

- People sometimes only experience one type of seizure. Others experience more than one type.

- Some people with epilepsy rarely have seizures. Others have them numerous times a day.

- Seizures can change with age. There may be a change in the duration, intensity, or frequency.

- In general, seizures are painless, end naturally, and are not dangerous to others.

- At least 60% of the time, seizures can be well controlled with the right anti-seizure medication.

Seizure Types

There are different types of seizures, ***focal*** and ***generalized***. If a seizure begins in a localized area of the brain it is called a focal seizure. If the seizure involves the entire brain it is called a generalized seizure.

Sometimes seizures begin as partial then spread and become generalized. These are referred to as ***partial seizures secondarily generalized.***

Focal Seizures

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

A ***focal aware*** seizure usually begins gradually and may last anywhere from seconds to minutes. It may involve symptoms that result in a person experiencing an unusual sensation, feeling, or movement called an ***aura***. An aura might be a distortion in sight, sound, or smell; sudden jerky movements of one area of the body; dizziness; a queasy feeling of nausea in the stomach rising up to the throat area; or a sudden overwhelming emotion such as fear or anxiety.

An aura is a focal aware seizure that may occur alone or may progress to a focal impaired awareness seizure or a generalized seizure.

During a ***focal impaired awareness*** seizure, a person experiences altered awareness and appears dazed and confused. A dreamlike experience may occur. The seizure can begin 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 that a seizure is about to occur.

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*** (the period that follows the seizure) of disorientation or confusion.

Generalized Seizures

A generalized seizure, without convulsions, is called an ***absence seizure.***

A generalized seizure, with convulsions, is called a ***tonic-clonic seizure.***

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. An individual may experience as many as several hundred absence seizures in a day. Absences can present with rhythmic eyelid flutter.

A ***tonic-clonic*** seizure usually lasts from one to three minutes.

The ***tonic phase*** of this seizure type typically involves crying out or groaning, 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. This movement typically involves the whole body. Urinary or bowel control may be lost and 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, 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 control, often resulting in a person falling or almost falling down, dropping objects, or nodding the head involuntarily. Typically, these seizures last only a few seconds.

A ***myoclonic*** seizure results in a sudden jerk of a part of the body such as an arm or leg. The person may fall. Typically myoclonic seizures last 2 seconds.

Sudden Unexplained Death in Epilepsy (SUDEP)

The cause of ***SUDEP***, where unexpected and unexplained death occurs is unknown. SUDEP is rare. According to Epilepsy Ontario, SUDEP is attributed to 1 death per 1000 people with epilepsy per year. Adults between 28-35 are at risk. This may be under-reported.

Lifestyle: Questions and Answers

For more information on epilepsy and lifestyle issues, contact your local epilepsy association.

Can a person with epilepsy work?

Most people with epilepsy can work and have rewarding careers. Physical disabilities are protected grounds under human rights legislation and the Canadian Human Rights Act. They do not allow discrimination by an employer due to a disability such as epilepsy. In general, persons with epilepsy should work in a safe environment, avoiding heights and dangerous equipment.

Can a person with epilepsy drive?

If a person's seizures are uncontrolled, they should not drive. If epilepsy has been diagnosed, driving is generally not allowed until a person has been seizure-free for at least 6 to 12 months with medical supervision. There are provincial and territorial differences in regulations. Drivers are required by law to report any health problems (such as epilepsy) that would interfere with driving.

Can a person with epilepsy have a sexual relationship?

People with epilepsy can have normal, healthy sexual relationships. In rare cases sexual activity can trigger seizures. Anti-seizure medication may, however, lessen a person's interest in sexual activity or affect sexual function. Changes in treatment can sometimes alleviate concerns.

Q Can a woman with epilepsy have a baby?

A Most women with epilepsy have healthy babies, but there is a slightly higher risk that having epilepsy or taking anti-seizure medication will affect the fetus. If a woman with epilepsy is planning to take or is taking birth control pills, is planning to become pregnant, or is pregnant, it is essential that she discuss these issues with her doctor in a timely manner to ensure the best possible medical care.

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 about 3% in the general population and approximately 6% if one parent has epilepsy.

Q Can a person with epilepsy drink alcohol?

A Excessive use of alcohol and subsequent withdrawal can trigger seizures, while modest or occasional alcohol consumption does not seem to increase seizure activity in individuals who are not alcoholics nor sensitive to alcohol. Alcohol use does, however, increase liver metabolism which results in lower blood levels of the anti-seizure medication. Drinking alcohol can also lower the seizure threshold. A ***seizure threshold*** is the level at which the brain will have a seizure. Some doctors recommend that individuals with uncontrolled seizures abstain from alcohol consumption. If a person with epilepsy chooses to consume alcohol, it is essential that he or she continues to take anti-seizure medication as prescribed.

The Role of the Health Care Provider

Epilepsy affects each person differently. How epilepsy affects a person's life often depends on the type and frequency of the seizures and seizure control.

In at least 60% of those with epilepsy, seizures are well controlled with medication and there may be little change in lifestyle required. In those with uncontrolled seizures, a significant change in the quality of life is present. Further investigations and new medications should be considered.

There are also other factors that could affect the well-being of a person with epilepsy including the anxiety and stress caused by the unpredictability of seizures, the attitudes of others, and the side effects of anti-seizure medication.

The support and care of a health care provider is invaluable in helping the individual to make informed decisions, to maintain a positive attitude, adhere to medical advice, and live a full and rewarding life.

> **The support and care of a professional or caregiver can be invaluable in helping the individual to make informed decisions, to maintain a positive attittude, to adhere to medical advice, and to live a full and rewarding life.**

Ensuring Safety

Professionals and caregivers can be of great assistance in managing seizures and in ensuring the safety of the individual during and after the seizure.

Sometimes, however, a caregiver is inclined to become overprotective of the individual. Although there may be safety precautions and lifestyle changes that are necessary, a person with epilepsy can often lead an active, independent life.

Most seizures last from seconds to minutes. Absence seizures usually last less than 10 seconds. The seizure starts abruptly and the person recovers quickly. With other types of seizures such as the generalized tonic-clonic seizure, a postictal period follows the seizure. This period results in the person temporarily experiencing fatigue, nausea, confusion, and/or headache. Often the person will want to sleep. It is important to talk reassuringly and stay with the person until he or she is re-oriented.

Sometimes, focal impaired awareness seizures are preceded by auras or focal aware seizures. These auras may serve as warning signs for the oncoming seizure, allowing a person to take the necessary precautions to avoid injury by laying down in a safe place. Once a seizure pattern has been established, it is easier for the caregiver to take appropriate action.

Although seizures are typically painless, end naturally, and are not dangerous to others, they can sometimes lead to complications. For example, some major seizures can cause additional stress on the heart and lungs. The laboured breathing that often occurs with major seizures can stress the lungs and create complications such as the aspiration of food and water.

Falls associated with seizures can also cause problems. If a person who has osteoporosis (thinning of the bones) falls, it could result in bone fractures or even a brain concussion.

If seizures are prolonged or occur one after another without full recovery between seizures, **immediate medical care** is necessary. This is known as ***status epilepticus***, and is a life-threatening condition.

Maintaining A Safe Environment

There is an increased risk of injury in people with uncontrolled seizures.

Safety Tips Include:

- Avoiding open flames, stoves, irons, and smoking as there is an increased risk of fire or burns if a seizure occurs.
- Using a microwave oven rather than a stove.
- Padding the edges of tables and other furniture.
- Carpeting the floor, preferably with a thick underlay.
- Taking showers rather than baths. Showers are safer than baths for those with epilepsy, but injuries can still occur. If an individual falls during a seizure, a low shower seat with a safety strap should be considered. There are other safety features available, for example, temperature control and safety taps.

Detailed lists of safety tips are available from most epilepsy associations.

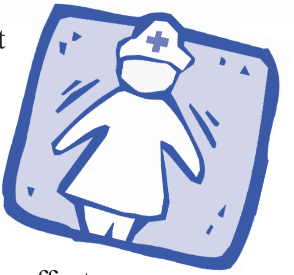
Promoting Well-Being

A person who has been diagnosed with epilepsy may experience anger, frustration and depression. Concern for the future and negative responses from friends and family can leave a person feeling vulnerable and alone. 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 anti-seizure medication.

As a caregiver, it is important to realize that mood changes can be a side effect of anti-seizure medication as a person who is distressed or is experiencing isolation may act out negatively as the result of frustration or anger. Being patient, encouraging the person to talk about his or her feelings with someone, and recording behaviour changes to provide to the doctor, are all helpful ways to promote well-being. If a person with epilepsy seems uncharacteristically depressed, encourage a visit to the doctor to discuss these feelings. The doctor may make adjustments to the anti-seizure medication in order to determine whether these issues are due to medication side effects.

Being patient, encouraging the person to talk about his or her feelings with someone, and recording behaviour changes to provide to the doctor are all helpful ways to promote well-being.

Working With The Health Care Team



Anti-seizure medication is the primary treatment for epilepsy. Medication does not cure epilepsy, but it often reduces or controls seizures by altering the activity of neurons in the brain.

The majority of people achieve seizure control with anti-seizure medication. Some anti-seizure medications may produce unpleasant side effects.

Caregivers are in a position to monitor changes in behaviour or appearance and to alert the individual and the doctor. They can assist the individual in complying with medical direction, and they can be actively involved in communicating with health care professionals.

Professionals and caregivers can assist the individual in complying with medical direction and can be actively involved in communicating with health care professionals.

It is useful to take a list of questions when visiting the doctor in order to assure that all concerns are addressed. Occasionally people feel they are not getting the treatment they would like and, in those cases, requesting a second opinion may be important.

Anti-Seizure Medications

Some of the well-known anti-seizure medications, listed by generic and (well-known brand name), used in the treatment of epilepsy include:

- carbamazepine (Tegretol)
- clobazam (Frisium)
- clonazepam (Rivotril)
- diazepam (Valium)
- ethosuximide (Zarontin)
- phenytoin (Dilantin)
- valproic acid (Depakene/Epival)

Some of the anti-seizure medications that have come into use since 1990 include:

- lacosamide (Vimpat)
- gabapentin (Neurontin)
- lamotrigine (Lamictal)
- levetiracetam (Keppra)
- oxcarbazepine (Trileptal)
- topiramate (Topamax)
- vigabatrin (Sabril)
- zonisamide (Zonegran)

Medications used in the treatment of status epilepticus and/or cluster seizures include:

- ativan (Lorazepam) (by sublingual absorption) or intravenously
- midazolam (by injection, IV, or nasal spray)
- phenobarbital (by injection)
- phenytoin (Dilantin) (by injection)

Side Effects

The most common side effects are dose-related and may include:

- drowsiness
- loss of coordination
- fatigue
- headache
- decreased appetite
- nausea
- allergic reactions such as skin rashes
- tremor
- weight gain or loss
- double or blurred vision
- dizziness
- impaired attention and memory
- overgrowth of the gums
- hair loss or excessive hair growth

Anti-Seizure Medication Tips

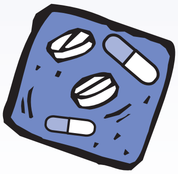
1. Anti-seizure medication should always be taken as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus. Any medication changes should be discussed with the doctor or pharmacist.

2. Use of any other medications or over the counter products should also be discussed with a doctor or pharmacist. Decongestants, Aspirin, herbal medications, diet pills, birth control pills, and marijuana can all interact with anti-seizure medication. Some drugs such as antidepressants and antibiotics can also cause interactions.

   Always use a pill organizer or dosette even when the medication seems simple.

3. Do not change from a brand name drug to a generic drug without first consulting the doctor or pharmacist. The use of different fillers, dyes, etc., can result in differences in processing by the body. Shifting from one generic drug to the next can also affect seizure control.

4. Keep a 1 to 2 week supply of the anti-seizure medication to avoid running out.



Monitoring Seizure Triggers

While some people are not able to identify specific events or circumstances that affect seizures, others are able to recognize seizure triggers. It is useful to monitor seizure triggers so that they can be avoided. Caregivers can assist an individual with epilepsy by helping to assess what triggers seizures and helping the individual to avoid them.

Some common seizure triggers include:

- Forgetting to take anti-seizure medication
- Lack of sleep
- Missing meals
- Stress, excitement, and emotional upset
- Menstrual cycle/ hormonal changes
- Illness or fever
- Low anti-seizure medication blood levels
- Medications other than prescribed anti-seizure medications
- Flickering or strobing lights
- Excessive alcohol consumption and subsequent withdrawal
- Recreational drugs
- Other drugs: cocaine, amphetamines, opioids

Recording Seizures

Keeping a record of seizures is useful. A description of the seizures will assist the doctor in making a diagnosis as well as deciding the appropriate treatment.

Caregivers and witnesses can be of great assistance by recording and providing details of the seizures. 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.

Seizure record charts are available from most epilepsy associations.

Certain medical terms are used to refer to the **stages of a seizure:**

- An ***aura*** is an unusual sensation, feeling, or movement. An aura is a focal aware seizure that may occur alone or may progress to a focal impaired awareness seizure or a generalized tonic-clonic seizure. If the aura indicates the onset of a focal impaired awareness or a generalized tonic-clonic seizure, it can sometimes be used as a warning signal to allow a person to take the necessary precautions to avoid injury.
- The ***ictus*** refers to the seizure itself.
- The ***postictal*** period follows the seizure. An individual may temporarily experience confusion (***postictal confusion***), weakness (***postictal paralysis***), or sleepiness (***postictal state***).

In the 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.

Include any information that describes the person's behaviour before, during, or after the seizure such as:

Before the seizure:

- What was the person doing before the seizure?
- Were there any provoking factors (e.g. lack of sleep, exposure to flickering lights from television, strobing lights, etc., recent illness, drug or alcohol use, missed medication, missed meals)?
- Did the person experience symptoms that preceded the seizure by many hours or days (known as ***prodrome***) such as mood changes, dizziness, anxiety, restlessness?

During the seizure:

- How did the seizure begin?
- Did the person experience an aura?
- Was there unusual or involuntary body movement? What part of the body moved first? Next?
- Was the person responsive during the seizure?
- Did the person experience daydreaming?
- Did the person stare blankly?
- Did the person experience automatisms (e.g. lip smacking, chewing movements, rapid blinking, head turning, pulling at clothing, random walking)?
- Did the person's eyelids flutter or eyes roll?
- Did the person's body become rigid?
- Did the person cry out or yell?
- Was there jerking? If so, did it occur on one side of the body more than on the other?
- Did the person's skin change colour?
- Did the person's breathing change?
- Did the person fall?
- Did the person bite his or her tongue or lip?
- Did the person lose bowel or bladder control?

After the seizure:

- Did the person experience temporary weakness, fatigue, confusion, and/or headache?
- How long did this period last?
- Was there injury as a result of the seizure?

Physical Activity and Participation

People with epilepsy can participate in most recreational activities and sports. These activities can enhance well-being and maintain health. There is evidence that regular exercise may improve seizure control.

Some activities are considered too dangerous, and others pose some risk due to the possibility of head injury. Swimming with a companion, preferably an experienced swimmer, is recommended for anyone who has seizures. If a person has uncontrolled seizures, then swimming is not advisable without constant supervision.

Participation in recreational activities and sports should be discussed with the doctor. Although seizures rarely occur while engaged in the activity, they are more prevalent afterwards.

Activities to enjoy include:

- Tennis
- Volleyball
- Track and field
- Jogging
- Cross-country skiing
- Basketball
- Hiking
- Baseball
- Golfing

Sports that pose some risk:

- Hockey
- Soccer
- Karate
- Football
- Boxing

* Possibility of head injury exists with these sports.

Activities that are considered dangerous:

- Scuba diving
- Rock climbing
- Parachuting

Support In the Community

One of the challenges facing those with epilepsy is the general lack of knowledge about the condition. Misconceptions based on historical perceptions, lack of public awareness, and inaccurate television and movie portrayals result in incorrect assumptions about epilepsy. Sometimes these misconceptions create the misguided perception that those with epilepsy are mentally disabled or are more likely to be violent. Sometimes the forms seizures take can be mistaken to be deliberate acts. They are not. Through public awareness and education, attitudes towards the condition are slowly changing.

Historical figures including Vincent Van Gogh, Beethoven, Napoleon, and Joan of Arc, had epilepsy.

While it may not be necessary to discuss a person’s epilepsy with everyone, consideration should be given as to who should be told. The decision may depend on the type and frequency of the seizures, how close the relationship is, and whether or not the person with epilepsy is likely to have a seizure in the person’s company.

Caregivers can also facilitate the development of a support system for the individual that involves family, friends, neighbours, and local epilepsy associations.

By learning about epilepsy and by sharing that information with others, professionals and caregivers can help people to understand the condition and increase awareness on how to assist a person who is having a seizure.

First Aid for Seizures

What to Do if Someone has a Non-Convulsive 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
(staring - 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 non-convulsive.

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.

In 400 BC, Hippocrates recognized that the cause of seizures was in the brain. 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: a bad 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, the 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.

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.

Tips for Professionals and Caregivers

- Accept your limitations and ask for help if you need it.

- Monitor your emotional and physical well-being. Caring for another can be draining. If you need support, talk to a friend, family member, or professional. By taking care of yourself, you will be better able to take care of another.

- Watch yourself for symptoms of stress such as sleep problems, headache, irritability, and withdrawal. Adequate sleep, exercise, and proper nutrition can all help to reduce stress.

- Take time out for yourself to do the activities you enjoy such as exercising, reading, or going out with friends.

- Be patient with yourself.

- Join a support group. Your local epilepsy association may be able to direct you to a group or put you in touch with others who are facing similar challenges.

- Learn about epilepsy. Information can be empowering.

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

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