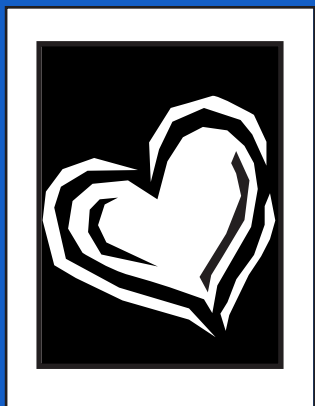


**A GUIDE FOR PROFESSIONALS
AND CAREGIVERS**

Epilepsy



EPILEPSY EDUCATION SERIES

This publication was produced by the


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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.

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.



Inspired by **patients.**
Driven by **science.**

Inspirés par les patients. Guidés par la science.

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A Guide for Professionals and Caregivers

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. Although 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 to learn about the condition, to share that information with others, to find effective medical treatment, to develop a support network of family and friends, and to 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 and 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, approximately one person in a hundred has epilepsy.
- People of all ages and all nationalities have epilepsy.
- Epilepsy can begin at any age although its onset is most often in childhood or in the later years of life.
- The causes of epilepsy vary according to the age of the onset of epilepsy.

In many epilepsy cases, no specific cause of epilepsy and seizures can be identified. In other cases, some of the causes include:

- Genetic
- 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

S *Seizure Facts*

- 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, this may result in a change in the person's behavior or function. This abnormal activity in the brain that results in a change in the person's behavior or function is a seizure.
- There are many types of seizures. 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.
- 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 of the seizures as a person reaches the senior years.
- In general, seizures are painless, end naturally, and are not dangerous to others.
- In well over half of those with epilepsy, seizures can be well controlled with seizure medication.

S *Seizure Types*

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* (formerly called focal) seizure usually begins suddenly and lasts seconds to minutes.

It may involve 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 a sudden 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** (formerly called psychomotor or temporal lobe) 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 (or the period that follows the seizure) of disorientation or confusion.

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. An individual may experience as many as several hundred absence seizures in a day.

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

usually involves a convulsion and there is jerking and twitching of the muscles in all four limbs. The movement typically involves 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, 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 often 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.

Lifestyle: Questions and Answers

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

Q Can a person with epilepsy work?

A Most people with epilepsy can work and can have rewarding careers. Physical disabilities are protected grounds under human rights legislation and the Canadian Human Rights Act does not allow discrimination by an employer due to a disability such as epilepsy. If seizures do prevent a person from working, there are many ways to use skills including volunteering, developing a hobby, or pursuing an artistic talent.

Q Can a person with epilepsy drive?

A If a person's seizures are uncontrolled, then driving is restricted. If epilepsy has been diagnosed, driving is generally not allowed until a person has been seizure free for at least 6 to 12 months and the person is under a doctor's care. There are provincial and territorial differences in regulations. Drivers are also required by law to report any health problems such as epilepsy that would interfere with driving to the appropriate provincial or territorial regulatory agency.

Q Can a person with epilepsy have a sexual relationship?

A 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, this could also affect sexual function. Changes in treatment can sometimes alleviate these 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 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 so that the best possible medical care can be established.



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 a person with epilepsy drink alcohol?

A While excessive use of alcohol and subsequent withdrawal can trigger seizures, modest occasional alcohol consumption does not seem to increase seizure activity in individuals who are not alcoholics or who are not sensitive to alcohol. Alcohol use can, however, lower the metabolism which results in lower blood levels of the seizure medication that is also metabolized by the liver. 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 seizure medication as prescribed.

The Role of the Professional and the Caregiver

Epilepsy affects each person differently. How epilepsy affects a person's life often depends on the type and frequency of the seizures a person is experiencing and on the outcome of the treatment prescribed.

In well over half of those with epilepsy, seizures are well controlled with seizure medication and there may be little change in lifestyle required. In those with uncontrolled seizures, significant change may be necessary.

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 seizure medication.

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

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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 too 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. With some seizures such as absence seizures, the seizure generally lasts for less than 10 seconds and the person regains alertness quickly following the seizure. With other types of seizures such as the tonic clonic seizure, a postictal period often follows the seizure. This period results in the person temporarily experiencing fatigue, confusion, and/or headache. Often the person will want to sleep. Talking reassuringly and staying with the person until he or she is re-oriented is important.

Sometimes complex partial seizures are preceded by auras or simple partial seizures. These auras can be used as warning signals to allow a person to take the necessary precaution to avoid injury. A professional or caregiver will be able to assist the person in preparing for the seizure. In complex partial seizures, once a pattern for the seizures has been established, the same set of actions often occurs with each seizure. Being aware of what a typical seizure involves allows the professional or caregiver to provide the appropriate care.

Although seizures are typically painless, end naturally, and are not dangerous to others, they can sometimes lead to complications. For example, although most seizures do not result in injury, some major seizures can cause additional stress on the heart and lungs. The labored breathing that sometimes occurs with major seizures can stress the lungs and create complications for those with lung disorders.

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

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*, a life-threatening condition. The seizures may be convulsive or non-convulsive.

Maintaining A Safe Environment

There is an increased risk of injury in people with epilepsy. If seizures are uncontrolled, then a person is at greater risk.

Precaution can be taken to reduce risks. 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 experiences falls during a seizure, a low shower seat with a safety strap should be considered.
- Standing back from roads or the edge of platforms while traveling by bus or subway.



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

Promoting Well-Being

A person who has been diagnosed with epilepsy may experience a range of emotions such as 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 seizure medication.

As a professional or caregiver, it is important to realize that mood changes can be a side effect of seizure medication or that 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 behavior 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 in the 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 behavior changes to provide to the doctor are all helpful ways to promote well-being.

Working With The Health Care Team

Seizure medication is the primary treatment for epilepsy. Medication does not cure epilepsy, but it often reduces or even stops seizures from occurring by altering the activity of neurons in the brain.



The majority of people achieve seizure control with seizure medication. Some seizure medication may produce side effects.

Professionals and caregivers are in a position to monitor changes in behavior or appearance and to alert both the individual and the doctor. They can assist the individual in complying with medical direction and 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 concerns are addressed. Occasionally people feel that they are not getting the treatment they would like and, in those cases, requesting a second opinion may be important.

Side Effects

The most common side effects are those related to the level of the drug in the blood and can include:

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

Seizure Medication Tips

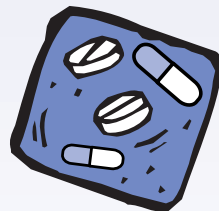
1 Seizure medication should always be taken as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus. Any changes in taking seizure medication should be discussed with the doctor.

2 Use of any other medications or vitamins should be discussed with the 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 seizure medication.

To learn more about possible interactions and/or adverse side effects, ask the doctor, pharmacist, or local epilepsy association for detailed information on each seizure medication.

3 Don't change from a brand name drug to a generic drug without first consulting the doctor. The use of different fillers, dyes, etc., can result in differences in processing by the body.

4 Keep a one to two week supply of the 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 definite seizure triggers. It is useful to monitor seizure triggers so that seizures can be avoided. Professionals and caregivers can assist an individual with epilepsy by helping to assess what triggers seizures and by helping the individual to avoid them.

Some common seizure triggers include:

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

Recording Seizures

Keeping a record of 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.

Professionals and caregivers can be of great assistance by recording 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 or use a notebook or create a chart.



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

- An **aura** results in an unusual sensation, feeling, or movement. An aura is a simple partial seizure that may occur alone or may progress to a complex partial seizure or a generalized seizure. If the aura indicates the onset of a complex partial or generalized 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 behavior 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, strobe lights, etc., recent illness, drug or alcohol abuse, 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 and if so, did it occur on one side of the body more than on the other?
- Did the person's skin change color?
- 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 in any part of the body, fatigue, confusion, and/or headache?
- How long did this period last?
- Was there injury as a result of the seizure?

Encouraging Participation

People with epilepsy can participate in most recreational activities and sports. These activities can enhance well-being and maintain health. There is some 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.

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

Supporting the Person Within the Community

One of the challenges facing those with epilepsy is the public's lack of knowledge about the condition. Misconceptions based on historical perceptions, lack of public awareness, and inaccurate television and movie portrayals do result in incorrect assumptions about epilepsy. Sometimes these 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.

As a group, people with epilepsy have the same range of intelligence as the general public. As in any cross section of the population, people with epilepsy have varying intellectual abilities.

Through public awareness and education, attitudes towards the condition are slowly changing. It has become accepted knowledge that many brilliant historical figures including Vincent Van Gogh, Feodor Dostoyevski, and Isaac Newton had epilepsy.

While it may not be necessary to discuss a person's epilepsy with everyone, thought should be given as to who should be told. The decision may depend partially 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.

Professionals and caregivers can also facilitate the development of a support system for the individual within the community that involves family, friends, neighbors, and professionals.

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

Managing Seizures

It is important for professionals and caregivers of a person with epilepsy to know the appropriate first aid procedures. They should also inform others who may be with the individual during a seizure of these procedures.

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 complete awareness returns.

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.** The person will not swallow his or her tongue.
- 7 Gently roll the person onto his or her side as the convulsive seizure subsides** to allow saliva or other fluids to drain away and keep the airway clear.
- 8 After the seizure, talk to the person reassuringly.** Do not leave until the person is re-oriented. The person may need to rest or sleep.



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 gray color) or labored 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 one 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 damage.
- 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.

Tips for Professionals and Caregivers

- Keep realistic expectations.
- 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 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.
- 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 Associations

If you have concerns, questions, or ideas to share regarding epilepsy, contact 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.

Consider becoming a member of your local epilepsy association and help to make a difference in the lives of those with epilepsy. 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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