

# EPILEPSY

## Epilepsy/ Seizure Disorder Information/ Guidelines for Professionals & Caregivers



This information provides general information about epilepsy/seizure disorders to the public. The information shared here should not be taken as full medical advice. Only your doctor can give the medical advice that is right for you.

Professionals and caregivers play a crucial role in the physical and emotional well-being of a person with epilepsy or a seizure disorder. Caregivers for people with seizures are a family member or people who have a close relationship with the individual. Sometimes it is the caregivers who provide 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 or a seizure disorder 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 or a seizure disorder achieve optimum quality of life -- by learning about the condition; by sharing that information with others; by finding effective medical treatment; by developing a support network of family and friends; and by helping the person to pursue what brings joy into their life.

### Epilepsy and Seizure Disorder Facts

- The causes of epilepsy or seizure disorder may vary according to the age of the person with epilepsy or seizure disorder.
- Epilepsy or a seizure disorder can begin at any time in any person's life.
- People of all ages and nationalities can have epilepsy or seizure disorder.

- Epilepsy or seizure disorders are more common than most people realize.
- A person cannot catch epilepsy or seizure disorder from someone else. Epilepsy or seizure disorder is not a disease.
- Epilepsy or a seizure disorder is not a psychological disorder.
- Epilepsy is a condition of the brain that is characterized by recurrent or multiple seizures.

In several cases, no specific cause of epilepsy or seizure disorders 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. car accidents, sports injuries)
- Infection (e.g. meningitis, AIDS)
- Brain tumor
- Stroke
- Cerebral degenerative disorder (e.g. those associated with Alzheimer's Disease)
- Alcohol and drug abuse

## Seizure Facts

- The brain is made up of billions of nerve cells or neurons that communicate through electrical and chemical signals. Where 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 is a seizure.

- There are several types of seizures.
- The form the seizure takes depends on where in the brain the excessive electrical activity occurs.
- Some people experience only one form of seizures while others experience more than one type.
- Some people with epilepsy or a seizure disorder rarely have seizures, while others can have several a day.
- Seizures can change with age. Seizures may change in the duration, intensity, or frequency of the seizures as a person reaches the senior years.
- Seizures are generally painless, end naturally, and are not dangerous to others.
- Seizures can be well controlled with seizure medication in about 60% of cases.

## 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 kind of partial seizures are simple partial and complex partial. During a simple partial seizure, awareness remains intact. In a complex partial seizure, awareness is impaired.

A **simple partial seizure** usually begins suddenly and lasts seconds to minutes, to hours. This 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, inability to talk, sudden jerky movements of one area of the body, dizziness, or a sudden overwhelming emotion.

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

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

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

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

## Generalized Seizures

A generalized seizure commonly takes one of two forms: **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 seizure 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* 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 or a Seizure Disorder

The cause of sudden unexplained death in epilepsy or a seizure disorder where death occurs suddenly for no reason, is unknown. This is very rare.

## Lifestyles: Q & A

### Q: Can people with Epilepsy or a Seizure Disorder be employed?

A: Yes. Some people who are seizure free and except for having to take medication, are no different from any other worker. Some still may have seizures, but working at the right place, they would be valuable workers. Each person's abilities or limitations should be considered.

### Q: Can a person with Epilepsy or a Seizure Disorder get a driver's license?

A: Yes, if the seizures are under control and he or she is under doctor's care. Different provinces have different rules about how long a person must be seizure free before being allowed driving.

### Q: Can people with Epilepsy or a Seizure Disorder drink alcohol?

A: Some can and some can not. Heavy use of alcohol is likely to make seizures worse and should be avoided. Moderate use depends on the reaction of individual. There may also be an increased risk of seizures if alcohol is being used when

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anti-seizure medication is being taken. Many doctors advise their patients with epilepsy or a seizure disorder to avoid alcohol altogether.

**Q: Can a person with Epilepsy or a Seizure Disorder have a Sexual Relationship?**

**A:** Yes, people with epilepsy or seizure disorder have healthy sexual relationships consistent with the overall population. Only in rare cases, does sexual activity trigger seizures. Seizure medication may, however, lessen a person's interest in sexual activity or affect sexual function. If seizures are uncontrolled or a person has poor self esteem, this could also affect sexual function. Any of these concerns regarding sexual activity should be discussed with your doctor. There may be medication changes or other treatments that can help to alleviate these problems.

**The Role of the Professional and the Caregiver**

Epilepsy or a Seizure Disorder affects each person differently. How it affects a person's life often depends on the type and frequency of the seizures a person is experiencing as well as on the outcome and response to the medication prescribed.

The support and care of a professional or caregiver can be crucially helpful to the individual: to maintain a positive and supportive attitude; to help in making informed decisions; and ultimately to live a full and rewarding life.

There are factors that could affect the well being of a person with epilepsy or seizure disorder including the stresses of

the unpredictability of the seizures, the attitudes of others, and side effects of the seizure medication.

In well over half of those with epilepsy or seizure disorder, 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.

**Safety**

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

At times, the 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 or seizure disorder can often lead an active, independent life.

Most seizures last from seconds to minutes. With some seizures such as absence seizures, the seizures generally last for less than 10 seconds and the person regains alertness quickly following the seizure. With other types of seizures postictal period 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.

Seizures are typically painless, end naturally, and are not dangerous to others. Being aware of what a typical seizure involves allows the professional or caregiver to provide the appropriate care.

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## Maintaining A Safe Environment

There is an increased risk of injury in people with epilepsy or a seizure disorder. If seizures are uncontrolled, then a person is at greater risk than others. Precaution can be taken to reduce risks. Safety tips include:

- Avoid stoves, irons, and smoking as there is an increased risk of fire or burns if a seizure occurs.
- Using a microwave rather a stove.
- Pad edges of tables and other furniture.
- Preferably have thick underlay when carpeting the floor.
- Take showers rather than baths. Showers are safer than baths for those with epilepsy or a seizure disorder.

## Well-Being

A person who has been diagnosed with epilepsy or a seizure disorder may experience a range of emotions. Concern for the future and negative responses from friends and family can leave person feeling alone. Depression is more common in individuals with epilepsy or a seizure disorder.

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 experiencing isolation may act out. Being patient, encouraging the person to talk about his or her feeling and recording behavior changes to provide to the doctor, are all helpful ways to promote well-being.

## Working With Health Care Professionals

Seizure medication is the primary treatment for epilepsy or a seizure disorder. Medication **does not** cure epilepsy or a seizure disorder, but reduces or even stops seizures from occurring. Most people can control their seizures with medication; and have to find the right one to control their seizures and not have intense side effects.

## Common Side Effects

- Fatigue
- Drowsiness
- Loss of coordination
- Headache
- Nausea
- Drooling
- Decreased appetite
- Tremor
- Weight loss or gain
- Blurred vision
- Dizziness
- Impaired attention of memory

Professionals and caregivers are in a position to monitor changes in behavior or appearance and to alert the individuals doctor. They can assist the individual in complying with medical direction and can be actively involved in communication with health care professionals.

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## Seizure Medication Tips

1. Medication should always be taken as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or *status epilepticus*. Any changes in taking medication should be discussed with the doctor.
2. Use of any other medications or vitamins should be discussed with the doctor to learn more about possible interactions and/or adverse effect.
3. Keep a one to two week supply of the medication to avoid running out.
4. Don't change from a brand name drug to a generic drug without consulting the doctor.

## Monitor 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 or a seizure disorder by helping to assess what triggers seizures and by helping the individual avoid them.

## Common Seizure Triggers

- Forgetting to take seizure medication
- Missing meals
- Lack of sleep

- Stress, excitement, emotional upset
- Illness
- Menstrual cycle/Hormonal changes
- Low seizure medication
- Medications other than seizure medication
- Excessive alcohol consumption
- Street drugs (e.g. cocaine, amphetamines, ecstasy, LSD, marijuana)
- Flickering of lights from computers, television, videos, etc.

## Record Seizures

Keeping a record of a seizure is useful. A description of the seizure will assist the doctor in making a diagnosis as well as in the decision regarding the appropriate treatment. Professionals and caregivers can be a great assistance by recording detailed seizures detailing the characteristics of the seizures, a record will also provide information regarding the frequency and duration of the seizures.

## Encourage Participation

People with epilepsy or a seizure disorder can participate in most recreational activities and sports. These activities can enhance well-being and maintain a healthy lifestyle. There is some evidence that regular exercise may improve seizure control. Some activities may be too dangerous and other pose some risk to the possibility of head injury.

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## Support

People often fear what they don't understand. Epilepsy or a seizure disorder is still misunderstood by many people. Some people think that a seizure always involves body jerking and unconsciousness. They may be aware that a seizure can involve behavior such as blank staring or uncontrolled movements such as chewing or pulling at clothing. People sometimes think that a person having a seizure is behaving a certain way deliberately. They may treat those with epilepsy or a seizure disorder with unkindness or avoidance out of a lack of knowledge about the condition.

Misconceptions about epilepsy or a seizure disorder are often based on inaccurate television and movie portrayals, or outdated views on the condition. Through public awareness and education, attitudes towards the condition are slowly changing. It has become accepted knowledge that many brilliant people including Joan of Arc, Vincent Gogh, Isaac Newton and Manitoba's own Neil Young have/had Epilepsy.

## Managing Seizures

It is important for professionals and caregivers of a person with epilepsy or a seizure disorder to know the appropriate first aid procedures. They should also inform others who may be with the individual during the seizure if 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 if others are around explain to them 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

## 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.
4. Loosen anything tight around the neck.
5. **DO NOT** restrain the person.
6. **DO NOT** put anything in the mouth.
7. Gently roll the person onto his or her side as the convulsive seizure subsides.
8. After the seizure, talk to the person reassuringly.

## Tips for Professionals & Caregivers

- Keep realistic expectations.
- Accept limitations and ask for help if **you** need it.
- Monitor **your** emotional and physical well-being. Caring for another can be draining.
- Be patient.
- Join a support group.



# Epilepsy and Seizure Association of Manitoba

One of the major goals of the Association is education. There are over 23,000 Manitobans, of all ages, with epilepsy/seizure disorders. Here are some of the services we provide:

- Free Information Packages
- School Awareness Programs
- Community Education
- Print and Video Library
- Support Groups

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

For more information  
or to become a member  
contact:



**EPILEPSY AND  
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**Epilepsy and Seizure Association of Manitoba  
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