





EPILEPSY EDUCATION SERIES

This publication was produced by the

Edmonton Epilepsy Association The Epilepsy Association of Northern Alberta

Phone: 780-488-9600 Toll Free: 1-866-374-5377 Fax: 780-447-5486 Email: <u>info@edmontonepilepsy.org</u> Website: <u>www.edmontonepilepsy.org</u>

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.



Free Canada-wide distribution of this publication was made possible by a sponsorship from UCB Canada Inc.

© Edmonton Epilepsy Association, 2018

Index

Personal Choices	1
Taking Seizure Medication	2
Being Prepared	2
Monitoring What May Trigger A Seizure	3
Safety at Home	4
Safety at Work	10
Safety in Sports and Recreational Activities	11
Safety While Travelling	12
Epilepsy Associations	13
First Aid	14

Safety and Epilepsy

There is an increased risk of injury in people with epilepsy.

Seizures can take many different forms including a blank stare, muscle spasms, uncontrolled movements, altered awareness, odd sensations, or a convulsion.

For some people with epilepsy, their seizures pose a minimal risk of injury. For others, their seizures may require extra precaution to avoid injury. For example, seizures that occur without warning or those involving falls, loss of awareness, or postictal confusion after the seizure could result in injury. Precaution in the home, workplace, educational settings, or while travelling or participating in activities may be necessary.

Assessing the risks associated with the type and frequency of the seizures experienced and then implementing the necessary safety procedures are important steps in assuring personal safety and well-being.

- Personal Choices
 - Maintain a healthy and well-balanced lifestyle. Get plenty of sleep, manage stress levels, eat a well-balanced and nutritious diet, and avoid excessive alcohol consumption and street drugs.
 - ✓ Always take seizure medication as prescribed.
 - ✓ Monitor what may trigger a seizure.
 - ✓ Record seizures on a seizure record chart.
 - ✓ Inform your pharmacist and dentist of your condition and of any seizure medication you are taking.
 - ✓ Wear a medical identification bracelet or necklace. Children should wear a medical identification bracelet, not a necklace.
 - ✓ Teach others appropriate first aid procedures and post first aid procedures in an obvious place in your home.
 - ✓ Learn and teach others first aid for choking.
 - ✓ Provide contact, medical, and emergency phone numbers to those who may be with you when a seizure occurs.
 - \checkmark If you live alone, arrange for someone to check on you routinely.

Taking Seizure Medication

- Seizure medication should always be taken as prescribed. Sudden discontinuation of medication can result in withdrawal seizures or status epilepticus.
- 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.
- Don't change from a brand name drug to a generic drug without first consulting your doctor. The use of different fillers, dyes, etc., can result in differences in processing by the body.



Keep a one to two week supply of your seizure medication to assure that you don't run out.

Being Prepared

- ✓ Carrying a pre-programmed cell phone or beeper is useful in case you need help.
- ✓ If seizure medication or seizures affect memory, using a watch with an alarm, a day-timer, and a medication dispenser may be helpful.
- New safety aids are continually being developed. High tech devices such as seizure-specific alarms triggered by seizure movements in bed, electronic tracking devices, and adapted showers that use infrared technology to shut off the water supply if a person falls are a few.
- ✓ Although still very difficult to obtain and expensive to train, seizure service dogs are successfully being used by some people with epilepsy. The dogs are trained to respond once a seizure starts by seeking help or assisting in protecting the person during the seizure. Studies suggest that some dogs seem capable of predicting a seizure and of then alerting the individual.

Monitoring What May Trigger A Seizure

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 learn your seizure triggers so that seizures can be avoided.

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 medications
- Excessive alcohol consumption and subsequent withdrawal
- · Flickering lights of computers, television, videos, etc.
- Street drugs (e.g. cocaine, amphetamines, ecstasy, LSD, withdrawal from marijuana)

For further information on seizure triggers, taking medication, and available safety devices, contact your local epilepsy association.

<u>ty at Home</u>

In General

- ✓ Use of hot appliances (e.g. stoves, irons) and open flames (e.g. fireplaces, candles) increases the risk of burns or a fire should a seizure occur. Smoking is also hazardous for those with seizures.
- ✓ Forced air heating is preferable to radiators, baseboards, and freestanding heaters. If your home has radiators, use radiator guards to increase safety.
- ✓ Bungalows or first floor apartments reduce the risks associated with stairs. Short sections of stairs with landings are preferable to long, steep staircases. If your home has stairs, a safety gate at the top of the stairs may help.
- ✓ Furniture with round rather than sharp edges is recommended. Sharp edges on tables and other furniture should be padded.
- ✓ Carpeting the floors, preferably with a thick underlay, may be necessary.
- ✓ Using appliances and tools with automatic shut-off switches provides additional safety.
- \checkmark Use outdoor carpeting on concrete steps, porches, etc.

Post emergency and medical phone numbers and first aid procedures in an obvious place in your home.

In Kitchens

- Use a microwave oven rather than a stove.
- If using a stove, use back burners.
- Place pot handles facing to the back of the stove.
- Serve hot liquids or food onto plates at the stove rather than carrying them to the table.
- Do not carry boiling water.
- If possible, cook when someone else is home.
- Use plastic rather than glass dishware in your kitchen.
- Use cups with lids.
- Limit use of sharp knives.
 A blender or food processor is preferable.
- Use pre-cut or prepared foods.
- Sit down to do tasks when possible.



- Place sharp utensils downwards in the dishwasher.
- Wear rubber gloves if washing glass or using sharp utensils.
- Keep frequently used items within easy reach to avoid having to climb up to high cupboards.
- Keep electrical appliances away from sinks.

In Bathrooms

• Take showers rather than baths. Showers are safer than baths for those with epilepsy, but injuries can still occur. If you experience falls during a seizure, a low shower seat with a safety strap should be considered.



- Use a shower with a temperature monitor.
- Adjust the water heater to a lower temperature.
- Turn cold water on first and off last to prevent burns.
- Use rubber mats or non-skid strips on the floor of the shower.
- Shower when someone else is home.
- Use a hand held shower nozzle.
- Assure that shower and bathtub drains are working properly.
- Use a recessed soap tray in showers.
- Use a shower with a flat floor rather than an enclosed base where water can accumulate.
- Do not lock bathroom doors. An "occupied" sign can be used to offer privacy.
- Avoid the use of electrical appliances near water.
- Hang bathroom doors to open outwards in case a fall against a closed door prevents access to those needing to assist you.
- Use mirrors and shower doors with safety glass or plastic.
- Use a padded toilet seat.
- Keep your bathroom ventilated to avoid overheating.

In Bedrooms

- Use a monitor in your bedroom so that someone who lives with you will be alerted if you have a seizure.
- Use beds low to the ground and avoid bunk beds.
- Avoid beds with hard edges on bed frames.
- Avoid waterbeds.
- Use "smother-proof" pillows.
- Avoid sharp-edged night tables beside the bed.

In Living Rooms

- Avoid decorating with glass or mirrors.
- Consider using hanging lamps instead of floor or table lamps.



For Those With Photosensitive Epilepsy

Lights flickering at a certain speed and brightness (e.g. from televisions, computer screens) can trigger a seizure in people with photosensitive epilepsy.

- Limit situations that expose you to flickering light.
- Do not sit too close to the television.
- Watch television in a room that is well lit.
- Take breaks from using the computer.
- Monitor which video and computer games could trigger seizures.
- Use computers with less flicker.
- Wear polarized sunglasses outdoors to diminish the effect of flicker from natural light (e.g. sunlight reflecting on water).



In Work Rooms

- Use a tabletop ironing board or one that is mounted on the wall.
- Use tools with automatic shut-offs.
- Sit at a low workbench.
- If using machinery, wear protective gear such as gloves, safety glasses, and boots.

In Parenting

- Use safety gates and playpens.
- Use a stroller 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.



- Change diapers or clothes on a pad on the floor or on a change table that has a strap to secure your child.
- Keep supplies on each level of your home to avoid unnecessarily having to climb stairs with your child.
- If you are alone, give your baby a sponge bath rather than using a bathtub.
- Avoid carrying or drinking hot liquids or smoking near your child.

- Secure your baby into an infant seat on the floor or in a high chair for bottle feedings and meals.
- If you are breast-feeding, feed your baby while sitting on the floor surrounded by a soft surface.
- If sleep deprivation is one of your seizure triggers, then arrange for someone to help out with either night-time feedings or a daytime feeding when you can catch up on your sleep.
 Women who are breast-feeding can pump breast-milk into a bottle so that others will be able to help with feedings.



- Keep outside doors and gates locked.
- Keep your seizure medication out of reach of children.
- 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.



Explain to your child what should be done in case of a seizure and post any emergency or contact phone numbers in an obvious place.

1 at Work

- ✓ Avoid work that involves heights, heavy machinery, extreme heat, fire, or molten material, or being over water.
- ✓ Use safety guards and automatic shut-offs if working with machinery or power tools.
- ✓ If using machinery, wear appropriate gloves, safety glasses, boots, etc.
- Keep consistent work hours to maintain a healthy lifestyle and to avoid sleep deprivation.



- \checkmark Learn coping methods to manage stress.
- ✓ Assure that co-workers know appropriate first aid.
- ✓ Explore options regarding *accommodation* in the workplace.

Duty To Accommodate

Accommodation is the process through which a worksite is modified to remove barriers for a person with a disability. Under the Canadian Human Rights Act and under some provincial codes, it is the duty of employers to make reasonable efforts to accommodate individuals with epilepsy in the workplace unless such accommodation would cause undue hardship. Accommodation can be as simple as moving furniture in an office or allowing you to trade work with another employee. Details on how safety can be improved in a job through reasonable accommodation are available through local organizations offering employment assistance for persons with disabilities and through The Canadian Council on Rehabilitation and Work (CCRW).

Safety in Sports and Recreational Activities

- Take extra precaution in sports that increase the risk of head injury including contact sports such as football, hockey, karate, and soccer.
- ✓ Always use proper safety gear such as helmets, flotation devices, and knee and elbow pads.
- ✓ Avoid activities that are considered too dangerous such as scuba diving and rock climbing.
- ✓ Ride bicycles on side roads or bike paths.
- ✓ If you have uncontrolled seizures, do not swim without constant supervision. Swimming with a companion, preferably an experienced swimmer, is recommended for anyone who has seizures.
- \checkmark Swim in a pool rather than open water.
- ✓ Exercise on soft rather than hard surfaces (e.g. mats, grass).
- \checkmark Do activities such as skiing, boating, or hiking with a friend.
- \checkmark Use a safety hook and strap when using a ski lift.
- Discuss participation in sports and recreational activities with your doctor.
- ✓ Avoid related problems such as low blood sugar, dehydration, or overexertion, which could increase the risk of seizures.
- ✓ Inform lifeguards, coaches, counsellors, etc. of your condition and how to respond should a seizure occur.
- ✓ If your seizures are induced by flickering light, wear polarized sunglasses during outdoor activities to reduce the effect of flickering light patterns such as sunlight reflecting on water.

First Aid if a Seizure Occurs When a Person is in Water

- Support the person's head.
- Keep the person's face out of the water.
- Tilt head back to keep airway clear.
- Get the person to the side of the pool or to the shore.
- Roll the person onto his or her side.
- Check airway.
- If the person is not breathing, begin resuscitation.
- Call for emergency assistance. Immediate medical treatment is required even if the person seems to have recovered. Inhaling water can cause heart or lung damage.

<u> While Travellin</u>

- ✓ There are restrictions to driving if your seizures are not controlled. Driving is generally not allowed until you have been seizure free for at least 6 to 12 months, and you are under a doctor's care.
- ✓ Carry a copy of important medical information, phone numbers, and a list of your seizure medication with you.
- ✓ Assure that you stand back from roads or the edge of platforms while travelling by bus or subway.
- \checkmark Use elevators rather than escalators or stairs.
- ✓ Have someone accompany you if you are going to be outdoors during extremely hot or extremely low temperatures.
- ✓ If travelling by air, consider whether to inform airline officials of your condition in advance to allow for preparation in case of a seizure.



- Carry some seizure medication on your person in the event of lost luggage.
- ✓ Take all seizure medication in the original bottles that you will be needing during your stay in case of unavailability. Extra medication should also be taken in the event that some is lost or your stay is extended.
- ✓ If crossing time zones, assure that you maintain your seizure medication schedule as prescribed.
- ✓ Before having a vaccination, ask your doctor about any medication interactions or concerns.
- ✓ Find out if travel companies provide discounted transportation for an escort capable of providing the required assistance if it is medically necessary.
- ✓ Wear a medical identification bracelet.



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.



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

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.

Status Epilepticus

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

Sudden Unexplained Death in Epilepsy (SUDEP)

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

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



Alliance canadienne de l'épilepsie

I-866-EPILEPSY

info@canadianepilepsyalliance.org www.canadianepilepsyalliance.org **Canadian League** Against Epilepsy



Canadienne Contre l'Épilepsie

905-415-3917

info@claegroup.org

www.claegroup.org

Your Local Contact Information:



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

Free Canada-wide distribution of this publication was made possible by a sponsorship from UCB Canada Inc.