Epilepsy and Safety

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Key Topics

Safety conversations for people who live with epilepsy and evaluating risk

General safety at work/home

Safety in sports and general activities

Driving

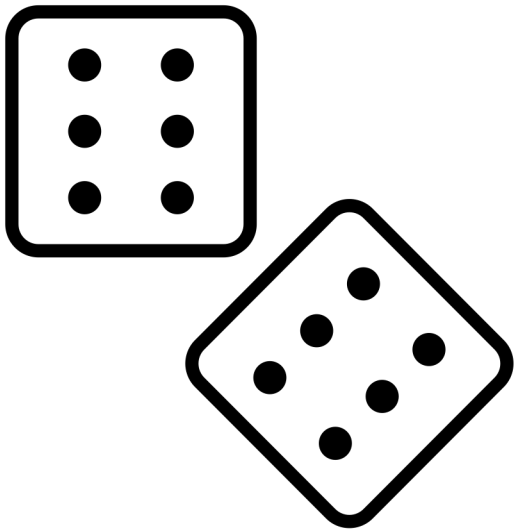
Age related considerations

- Kids
- Young adults
- Adults and seniors
- Caregivers

Safety /seizure first aid

Risk

- There are many activities and situations that carry some sort of risk, **even if you don't have epilepsy**.
- People still do these activities – otherwise no-one would ever cross the road or go out when it's icy
- Epilepsy and ongoing seizures can come with some risks to your safety.
- Putting some safety measures in place, you can lower this risk



Evaluating risk

Everyone is different.

You may find it helpful to look at your own situation to see what-the risks are to you. Be involved in decisions that may affect you. This will make you feel more in control of your epilepsy and confident about making decisions in the future.

Depending on age and situation, other people might be included when making decisions, such as your parents or partner

Risks due to epilepsy depend on:

- Are you currently having seizures
- Frequency and type of seizures
- How your seizures affect you
- Whether you have other medical conditions

Seizure Frequency and Type of Seizure

- If seizures are controlled, then your safety may not be affected
- If you are having frequent seizures, the risk of injury may increase
- Some seizure types may increase your risk of injury:
  - Seizures associated with falls or generalized tonic-clonic seizures
  - Seizures where there is a change in the level of awareness (focal seizures with impaired awareness)
  - Seizures during sleep

Knowing the type of seizure that you have, and how it affects you, is very important when assessing risk

How can you reduce the frequency of seizures?

It may not be possible to stop all seizures, but certain triggers can make seizures more likely. Identifying triggers and avoiding where possible could help you to have fewer seizures, which reduces risk.

Triggers

- Not taking medications as prescribed, missing doses
- Not sleeping well
- Stress
- Alcohol and recreational drugs
- Flickering lights(only photosensitive epilepsy)
- Illness

Reducing Seizure Triggers

- Missed medications- Use alarms, dosettes and set a routine. Keep a couple of doses on your person. Take medications as prescribed to keep a steady level in your body
- Sleep – Set a schedule, avoid screen time 1 hour before bed, limit caffeine, exercise during the day, don't take long naps in the day
- Stress – Stress is a part of everyday life, but if it is unmanageable consider lifestyle changes or talking with a therapist
- Alcohol and street drugs - Drinking alcohol is a personal choice, but for some people with epilepsy, alcohol makes their seizures worse.

  Alcohol disrupts your sleep. Drinking alcohol can trigger seizures for some people. Vomiting (being sick) may reduce the level of medications in your system. Medications can increase the effects of alcohol and alcohol can make some of the side effects of AEDs worse

What if seizures are not controlled?

- Even with the best efforts of you, your family and your medical team it may not be possible to stop all of your seizures.
- In this situation there are some general safety considerations that you may want to consider, and some are more specific to your age and season of life.
  - Kids
  - Young adults
  - Adults and seniors

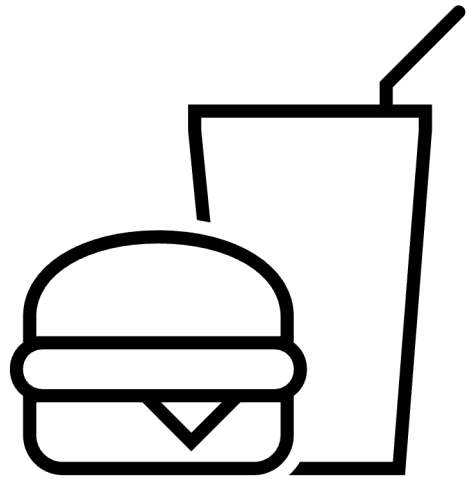
General safety at home

- Hard flooring such as ceramic tiles may be more likely to cause injury. Vinyl, or carpets may reduce the risk of an injury if you fall. Keep floor space free of clutter
- Use protective covers on sharp edges of furniture. Avoid furniture with glass
- Using heaters that are secured to the wall or floor means you can't knock them over. Open fires and gas fires are best avoided. Avoid burning candles if home alone
- Avoid climbing on ladders, chairs and other objects, especially if you are home alone
- Use appliances with automatic shut- off
- **If you are photosensitive**
  - Do not sit too close to the television or computer screen
  - Keep a light on to reduce light contrast
  - Reduce the brightness on the screen
  - Avoid watching for long periods of time.

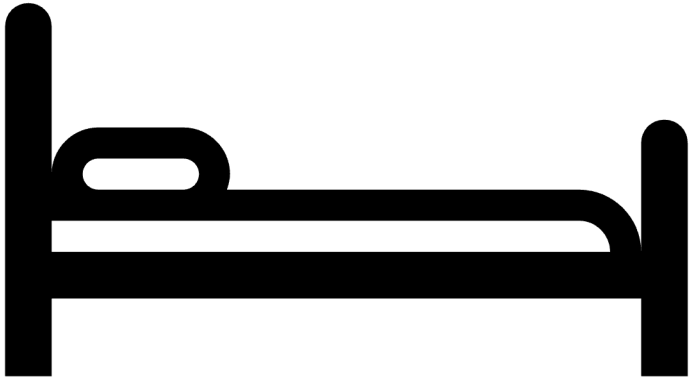
In the Kitchen

Some simple adaptations can make cooking significantly safer.

- Have someone else in the house while cooking and consider meal prepping multiple meals for later
- Microwave ovens are safer than conventional ovens as they turn off automatically after the cooking time has ended
- Using burners at the back of the stovetop can be safer than using those at the front. Turning pan handles to the side can help prevent pans being knocked over.
- Limit carrying hot pans/liquids
- Use a manual food chopper instead of knives or pre-cut food
- Eat at the table rather than on your lap, to reduce risk of hot food causing burns
- Use kettles and appliances that switch off automatically
- Avoid using a BBQ



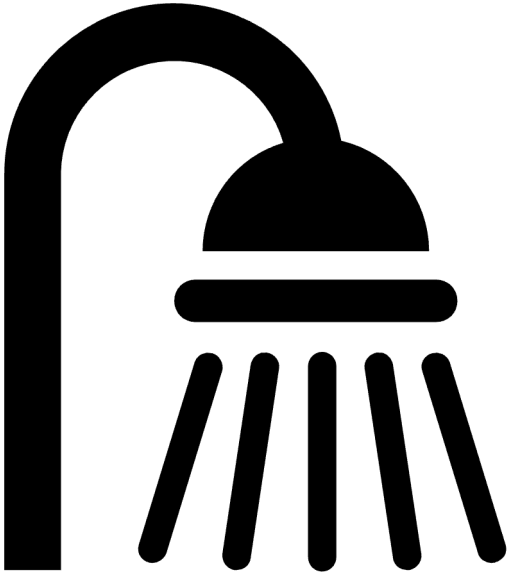
In the bedroom



- A low-level bed, or mattress on the floor, means there is less distance to fall and may lower the chance of injury if you have a seizure during your sleep
- Limit the amount of bedside furniture, nightstands
- Some people who have seizures during the night have a bed alarm that detects when they have a seizure.
- Safety pillows have small holes in so that if you are sleeping face down you may be able to breathe more easily. Limit pillows and blankets to reduce the risk of getting tangled up or tripping during a seizure.

In the bathroom

- Doors that open outwards make it easier for other people to get to you if you have a seizure and need help.
- An 'Engaged' sign on the door instead of a lock, allows privacy but means that someone else can open the door if you need help.
- Taking a shower is safer than having a bath because the water drains away and reduces the risk of drowning, if you have a seizure
- A shower curtain, rather than a door, might make it easier for someone to get to you quickly if you have a seizure
- A shower seat may help reduce the risk of injury if you fall during a seizure.
- Fitting thermostatically controlled taps means that the water will not get too hot
- If you don’t have a shower, have a bath when there is someone else is close - they can help you if you have a seizure.
- If you are alone, consider washing at the sink



Exercise, sport and leisure activities

Team Sports- Team sports, or group activities such as walking, running and hiking, can be good for increasing self-confidence and can be a way to make new friends and help with feelings of isolation.

- Most sports, including contact sports like football, hockey, basketball and baseball have not been shown to increase the chance of someone having a seizure
- Protective sports headgear helps to reduce this risk
- If you are comfortable, tell your coach or someone on the team about your epilepsy. Give them first aid information

Extreme and adventure sports

- Activities like bungee jumping, hang gliding, climbing and whitewater rafting have high levels of excitement, skill, and danger. Depending on frequency and type of seizure, these activities may be associated with more risk

In the Water

Many water sports can be made safer for people with epilepsy, by taking the right safety measures. This means considering what risk the activity involves, as well as how your epilepsy affects you

Wearing a lifejacket is recommended for most water sports. It is also important to have someone with you who knows how to help if you have a seizure, like a friend, coach, or instructor.

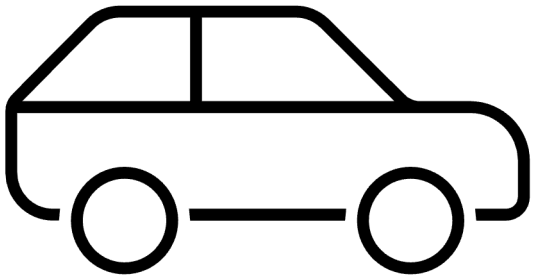
- Be realistic about the possible risks for the sport you are considering. For example, there is an additional risk if you were to have a seizure and overturn while canoeing or kayaking.
- Scuba diving is not recommended for people who have ongoing seizures, as having a seizure underwater can be life-threatening for the person with epilepsy and their diving buddy.
- Swimming is great exercise, with the right safety precautions. You could speak to medical team about safety when swimming. Swim with someone who knows how to help you if you have a seizure in the water. Swimming in a pool, where there is a lifeguard, is generally safer than swimming in the sea or open water.
- Only use a hot tub when someone is with you

Travel

- Plan ahead and make sure you have everything you need for your trip, so that travel is more enjoyable and relaxing
- Take medication in its original packaging with a pharmacy printout
- Take more medication than you think you will need, just in case your trip is delayed
- Some medicines may not be available in other countries or may have a different name. Discuss with pharmacist
- Get travel insurance and review the terms
- Traveling across different time zones and long flights are tiring, which can be a trigger for seizures. Plan to have some down- time to rest when you arrive at your destination
- If you are travelling to a different time zone, you may want to gradually adjust when you take your medication, so that you can take it at a manageable time of the day.
- If you have a vagus nerve stimulator (VNS), it may be a good idea to let airport staff know, as the VNS may set-off the airport security scanner. The scanner will not affect the VNS.

Driving

- In Alberta drivers are required by law to report any health condition that may affect their ability to drive, including epilepsy or a seizure disorder.
- Being approved to drive is decided by Driver Fitness and Monitoring at Alberta Transportation.
- As a rule, you cannot drive until you are seizure free for 6 months -There are some exceptions that you can discuss with your doctor.
- Report all seizures to your physician .If you are having seizures do not drive.
- Take your medications as prescribed. If your medication treatment plan is being changed to another drug, or different dose, there is a period of no driving.
- Everyone should avoid alcohol before driving
- If you have photosensitive epilepsy, wear polarized sunglasses.
- **If you are unable to drive**, public transportation or taxis/uber are available. Maybe family, friends, and peers can help—especially if you can assist with covering the cost of fuel. Not being able to drive can be challenging, and a difficult transition to make, but is essential for your own safety and the safety of others on the road.



Safety precautions for children with seizures

Babies and younger children

- Don't use sleep positioners, bumper pads, or other products that attach to crib sides or slats. They could trap or suffocate your baby, especially during a seizure. Consider using a bed/crib that is low to the ground.
- Give medications as prescribed
- You may want to use a baby monitor to alert you to seizures that may occur during sleep.
- Use appropriate car seats and seat belts. Use restraints when using a highchair. Do not leave your baby alone on a changing table, consider changing on the floor.
- Do not leave them alone in the bathtub/baby bath
- Inform day care providers or baby-sitters of what to do if a seizure occurs.

Safety precautions for children with seizures

Older Children

- Give medications as prescribed
- Identify potential risks and reasons for safety precautions
- Avoid top bunks
- Have your child wear a helmet when biking, skiing, or skating.
- Do not let your child swim alone- that doesn't mean no swimming
- Older children with epilepsy should take showers instead of baths -discuss privacy
- Consider telling your child's teachers and sports coaches that your child has epilepsy discuss what to do if they have a seizure at school or during practice.
- Your child may have to take medicine during school hours. Discuss a plan with the school
- A medical ID bracelet will help other people know that your child has epilepsy. It can also list any medicines your child is taking
- If your child is going for sleep- overs, consider sharing with a parent what to do if they have a seizure. Talk with your child about seizure triggers like sleep deprivation, taking medications. Often late nights and lots of excitement are associated with sleep overs!

Young Adults

As children age into adulthood, there is a period of transition and change in roles and responsibilities. Being responsible for their own health care can help on the road to a safer and independent life.

- Know the names and doses of medications, understand the importance of taking medications as prescribed and not missing doses. Use cell phone alarms, reminders and dosettes. Take extra medication with you in a bag ,so it's available if you're unexpectedly away from home
- Some medications can affect how well oral contraceptives work and can increase the risk of getting pregnant. Oral contraception can affect how some medications work.
- Drinking alcohol is a personal choice. Alcohol can trigger seizures for some people. Alcohol can also disrupt sleep. Vomiting after consuming alcohol can reduce the levels of medications in your body. Alcohol can also make the side effects of medications worse and some medications can increase the effects of alcohol!
- Driving – Discuss the rules for driving related to epilepsy and seizures.
- School and career choices- Moving away for post- secondary education and living on your own may increase risk . Discuss options
- Careers - Some jobs are difficult to maintain with ongoing seizures such as jobs that require driving, being a pilot, working with heavy machinery, being in the military

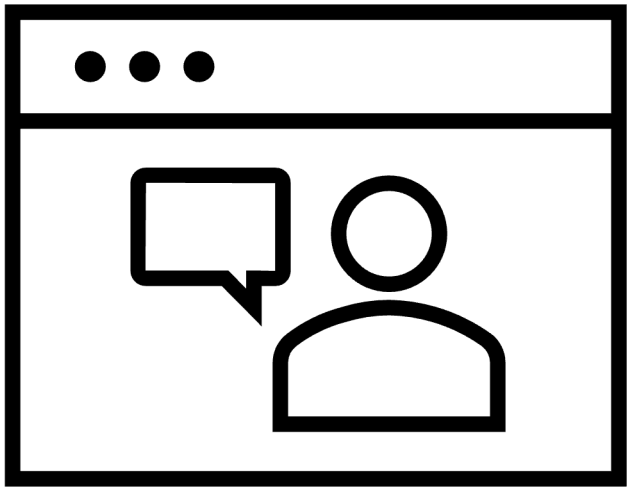
Safety at work

Most people with epilepsy can work and work in the job they want. However, there are some things to think about

- You may not be able to do jobs that risk your safety, or the safety of other people.
- As with anybody, the type of work you can do depends on your skills, qualifications and experience.

<u>Work related safety considerations</u>

- Avoid working at heights, on ladders or alone in remote areas or near open water
- Avoid operating heavy machinery or driving with a professional license
- Avoid working in a professional kitchen
- Some jobs are not possible with a history of seizures- for example a pilot
- A consistent work schedule can be helpful, such as avoiding night shifts



You do not have to tell your employer that you have seizures, but every case is different.

Planning a Pregnancy

- Discuss your epilepsy medications with your neurologist, **before** you start having a family
- Make sure that your seizures are stable, and you are on the best treatment for you. There is a small increase in risk of having a baby born with a birth defect when taking medications for epilepsy.
- Women who are planning pregnancy and are pregnant, should take folic acid
- Do not stop your medications during pregnancy and take them as prescribed- Generalized tonic- clonic seizures during pregnancy can be harmful to you and your baby
- Some medication levels need to be checked more closely, while you are pregnant. Make sure you follow-up with your neurologist and nurse

After the baby is born

Sleep deprivation is common but find ways to get as much sleep as possible.

Nap when baby naps

Get help with night feeds if possible

Try to aim for a few nights of uninterrupted 5-6 hours of sleep. Sleep in another room, without the baby monitor to wake you up

Change your baby on the floor, rather than a change table

Feed your baby while sitting on a soft floor

Give your baby a sponge bath, rather than in a bathtub filled with water

Do not do tasks such as cooking, while holding the baby

If you fall with your seizures, think about using a stroller in the house

As the baby becomes a toddler, things like playpens and baby gates become important

Breastfeeding or formula are both options – discuss with your health provider

Seizure first aid for generalized tonic- clonic seizure

- Stay calm. Let the seizure take its course.
- Time the seizure.
- Protect from injury.
- Loosen anything tight around the neck.
- DO NOT restrain the person.
- DO NOT put anything in the mouth
- 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.
- After the seizure, talk to the person reassuringly

When to call an ambulance

If a seizure lasts longer than 5 minutes.

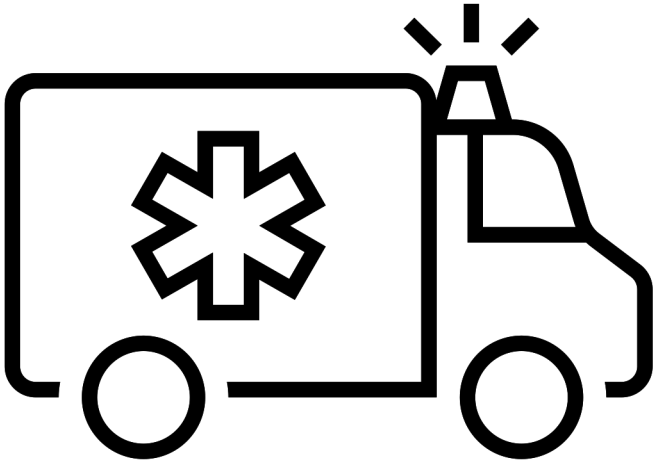
If consciousness or regular breathing does not return after the seizure has ended

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

If it is a first-time seizure, or the person is injured, pregnant, or has diabetes



SUDEP-Sudden Unexpected Death in Epilepsy

- SUDEP is when someone who has epilepsy dies suddenly and no other cause of death can be found.
- Rate of SUDEP is approximately 1 in 1,000 adults, and 1 in 4,500 children with epilepsy per year. The percentage of the population affected by SUDEP is **relatively low**.
- Knowing about SUDEP, and the risks around ongoing seizures, might help you to work out what risks apply to you, and how to reduce them so you can feel more in control.
- It is not clear why SUDEP happens, it may be a problem with the person's heart, or breathing, during or after the seizure.
- As SUDEP is thought to happen during or following a seizure, uncontrolled or poorly controlled seizures are a risk.
- The risk of SUDEP varies from one person to another but some of the risks around SUDEP can be reduced

Reducing risk

- As SUDEP is thought to be linked to seizures, getting the best seizure control possible may be a way to reduce risks
- Taking anti-seizure medication as prescribed- Use reminders, pillboxes, alarms
- Try and reduce seizure triggers
- Having a review of your treatment by your doctor might be helpful.
- If you have seizures during sleep, having a seizure alarm that alerts someone who can help if you have a seizure in bed might be helpful.

Other Resources