



Men and Epilepsy

Live your life to the fullest!

You are a man who has epilepsy? You wonder how epilepsy will affect your life. Put your mind at ease. Epilepsy doesn't have to be the focus of your universe. The more you learn about your condition and actively cope with it, the less epilepsy will be a concern in your life. You may have to make a few alterations to your daily routine, but you can still live your life to the fullest!

A new routine: taking your medication

Men with epilepsy sometimes feel they can "do it alone" or "tough it out". They may even deny they have epilepsy. The truth is, strength and independence are more about taking control of your life – by taking the necessary steps to live well.

Following your doctor's advice is the best way to boost your independence. Your doctor is like a coach who knows how to play the game – the best strategies for treating epilepsy.

If you want better seizure control, you must learn to "play the game". You and your doctor are part of a team. You must learn to work together.

Taking your medication, as prescribed, means:

- do not miss pills
- do not reduce your dosage
- do not stop taking your pills

Stopping your medication, without consulting your doctor, can be dangerous. You can have a seizure – a sudden, breakthrough seizure – just when you think everything is under control. It can happen almost immediately or quite a while after you miss or stop your pills.

As a result, your epilepsy may be more difficult to treat than before. Status epilepticus, a life-threatening condition, can occur after suddenly stopping antiepileptic medication, i.e. "cold turkey".

Tips

- Take your pill at a convenient time – at bedtime, mealtime or after brushing your teeth.
- Use a pillbox or daily-dose holder.
- Refill your prescription on time. Never run out of pills. Write a note on your calendar to remind yourself.
- Ask your doctor ahead of time what to do if you miss a pill.
- Don't take an extra pill when you feel a seizure coming on. It won't help. There won't be enough time for the drug to take effect. Antiepileptic drugs have to be taken on a regular basis in order for them to be effective.

Stay motivated! Taking your medication, as prescribed, improves your chances of effective seizure control. That betters your chances of getting a driving license, avoiding seizures in public and living a better life.



Behind the wheel

Now that you have epilepsy, will you be able to drive? Yes, but only under certain conditions. The main concern is safety: yours and others'.

Uncontrolled seizures and driving don't mix. If your seizures aren't well controlled, you'll have to take the bus or ask a friend to give you a ride. It may be annoying, but it's better than the consequences.

Laws about driving and epilepsy

Across Canada, two regulations for drivers with epilepsy apply in all Canadian provinces and territories:

1. By law, drivers must report to the Ministry of Transportation any medical condition that may interfere with their ability to drive safely.
2. People with epilepsy must have their seizures controlled either on or off medication for a specific period of time (varying across provinces and territories) before they can drive.

Ask your doctor if your seizures:

- Occur only during sleep
- Leave consciousness intact
- Are preceded by a reliable aura
- Are controlled by a vagus nerve stimulator
- Are the result of a medication change or missed pill

Safe driving

You can drive if:

- You are totally seizure-free
- You are taking your medication and have not missed any pills
- You are not sleepy or tired
- Your doctor gives you permission to do so

If you drive against medical advice, you may be liable for accidents – even if they are not your fault. Your insurance may not cover your damage.

While driving, if you feel a seizure coming on:

- Get off the road.

If you run out of pills:

- Ask someone to drive you to the pharmacy
- Get your prescription delivered
- Ask a friend to pick up your prescription

If you have a seizure:

- Ask someone to drive you to the doctor's office.

If your medication is changed or discontinued:

- Until you and your doctor know how it will affect you, wait before driving

Never drink and drive. Alcohol increases the likelihood of seizures. Antiepileptic drugs amplify how alcohol affects your body.

Working as a driver

In many places, people with epilepsy cannot work as professional drivers or operate heavy motor vehicles. If you plan to drive one of the following motor vehicles, you should ask the Ministry of Transportation of your province or territory to find out about any driving restrictions or conditions for:

- Heavy trucks and vans
- Emergency vehicles (ambulance or fire truck)
- Public transportation (buses or subways)
- Taxis
- Minibuses
- Heavy private motor vehicles (motor homes or trailers)

Getting around

- Car pool
- Walk
- Take public transportation (buses or subways)
- Take a taxi
- Use special transit services (eg. HandiDart)
- Ask friends, relatives or co-workers for a ride

Car insurance

In BC your insurance rates are based on where your vehicle is driven, where your vehicle is located when not in use, what your vehicle is used for, and your driving record.

At work

If you're qualified for a job, epilepsy shouldn't keep you from getting it. Seizures are brief and don't usually interfere with work performance.

A few jobs have some restrictions, for safety reasons. Unfortunately, it may be harder or even impossible for you to do the following jobs, especially if your seizures are not under control:

- Airline pilot
- Transportation and professional driver
- Construction worker
- Surgeon
- Dentist
- Military services: Before you can sign up for The Canadian Armed Forces, your seizures must be well controlled. Even if your seizures are controlled, there may be restrictions on the use of firearms or driving heavy vehicles.
- Royal Canadian Mounted Police: Each man is assessed on an individual basis by a doctor.
- Fire fighters and police officers: It depends on each fire or police department's policy, but the decision to hire is usually based on a doctor's recommendation.

If you're turned down for a job, don't give up. For anyone, finding a job requires patience, perseverance and a positive attitude.

Should I tell the employer about my epilepsy?

To disclose epilepsy or not? This question often arises when you're searching for or starting a new job. It's a delicate matter – and a personal decision. Consider this information as a guide:

- If seizures are going to affect your work performance or your safety and others', it may be wise to disclose. It will protect you and your co-workers from potential injuries, and it will give your boss the opportunity to make accommodations in your working environment.
- If epilepsy does not affect your work performance or your safety and others', it's your choice whether to disclose or not. Many men find it better to disclose their epilepsy after being hired – to relieve any stress or worry over the possibility of having a seizure at work.

When to disclose?

Before you're hired

Advantages

- Honesty
- Peace of mind
- Opportunity to discuss epilepsy
- Opportunity to discuss job accommodation

Disadvantages

- Discrimination
- Emphasis on epilepsy instead of your ability to do the job

Other considerations:

- Do you feel comfortable talking about your epilepsy?

After you get the job

Advantages

- You have a chance to prove yourself.
- In some provinces, if disclosure affects your job status, you may take legal action against your employer.

Disadvantages

- Fear of having a seizure on the job.
- It could affect your relationship with coworkers.
- If you have a seizure, co-workers won't be prepared or know how to react.

Other considerations:

- The longer you wait, the harder it may be to disclose your epilepsy.
- You may not know how to disclose and to whom.

Never disclose

Advantages

You are safe from discrimination – as long as you don't have a seizure on the job.

Disadvantages

- Fear of having a seizure on the job
- Without disclosure, having a seizure at work can be a source of myths and misunderstandings.
- If you have a seizure, you may be hurt by co-workers' inappropriate reactions.

Other considerations

- Studies show that people who do not disclose have a higher chance of having a seizure on the job.
- If you've been seizure-free for a long time or if your seizures are unlikely to happen at work, disclosure may be less important for you.

How to disclose?

Be prepared. Anticipate questions your boss or co-workers may ask. Get ready to give them clear answers. Your attitude about your epilepsy and the way you talk about it will affect the way people see your condition. Be positive, factual and realistic. Do not dwell on epilepsy. It is not and should not be the main concern in your workplace.

Employers are usually concerned with how seizures will affect your job performance and safety in the workplace. Explain to your employer how epilepsy will not affect your job.

What you can tell your boss

Studies show that people with epilepsy:

- Do not take more days off than other workers.
- Do not cause more accidents at work.
- Often want to prove themselves, so their output is as good as or better than other workers.

If changes to your work environment may reduce the likelihood of seizures, discuss them with your boss.

It may be a good move to teach your coworkers what to do if you have a seizure. The more people know about seizures, the less they'll be afraid and nervous if you have one.

Ask your doctor to write a letter explaining your condition to your boss.

When deciding whom to tell about your epilepsy, be selective. Your employer is probably the first person to inform. Your boss is in the best position to make any changes in the workplace. Should you tell your co-workers about your epilepsy? That's up to you.

Discrimination and your rights

Unfortunately, discrimination against men with epilepsy does happen sometimes – often due to ignorance and misconceptions.

Because most jobs fall under the jurisdiction of provinces and territories, rules and laws for employment differ across Canada. Here are some reasons to appeal to your provincial or federal human rights commission for help against discrimination:

- The employer makes a distinction between you and other workers.
- The employer refuses you a job, based on a prognosis of a medical condition – i.e., based on what could happen with your epilepsy in future instead of your current medical condition.
- The employer fires or refuses to hire you, because of your eligibility for pension or insurance plans.
- The employer has more severe job requirements for you than others, because of your epilepsy (e.g., a higher education).

Canada/Quebec Pension Plan disability benefits

Most men with epilepsy are able to work, but some cannot. If your epilepsy prevents you from working, you could be eligible for the Canadian Pension Plan Disability. This federal plan pays a monthly benefit to people unable to work. Quebec has its own pension plan disability benefits. If you live in that province, contact the Regie des Rentes du Québec.

Are you eligible?

- You have contributed to the Canada/Quebec Pension Plan Disability in four of the last six years.
- Your disability is severe and prolonged.
- You are incapable of earning any substantial income and can no longer hold your previous job.

You need to know:

- Each case is reviewed on an individual basis.
- If accepted, it takes a minimum of one year from your application date before you can get disability benefits.
- When you turn 65, your Canadian Pension Plan for Disability benefits will be automatically converted to Canadian Pension Plan retirement benefits, based on your income at the time you became disabled.

Some similar plans may be available in your province or territory. For information, contact the pension board in your region.

Life insurance

For men living with epilepsy, it's harder to get life insurance. Some companies refuse to insure you. Others accept your business but at higher premiums.

Tips

Looking for life insurance

- Shop around! Every insurance company is different. An insurance broker, who deals with many insurance companies, can help. Talk to this person about your epilepsy.
- Join a group or organization with collective life insurance. There is usually no medical inquiry for collective life insurance that applies to more than 10 members. A collective life insurance plan may be available at your work place.
- Insurance with limited coverage without medical inquiry is sometimes easier to get. These policies are expensive for their coverage. Some contain exclusion conditions for accidents arising from a medical condition. It's important to verify.
- Never falsify medical information! An insurance policy is a contract. If you lie on the application, the company may not be obligated to respect the contract.
- If your application is refused, ask for the reasons for rejection in writing. The insurer may review your application more closely and reverse the decision. And, you'll have a chance to reply and describe your situation in detail.
- Reapply when your situation improves.

Epilepsy from the inside out

Epilepsy and your looks

Your medication can change your physical appearance. Weight changes, rash, acne, gum overgrowth, subtle tremors, hair loss or thinning or excessive hair growth are side effects of some medicines. If these changes bother you, ask your doctor to adjust your dosage or change your medication.

Epilepsy and how you feel

Because it affects the way your brain works, epilepsy can affect the way you feel. So can your medication. It can cause irritability, mood changes or tiredness.

Life with epilepsy can be difficult. At times, you may feel anxious, angry or even depressed – part of the ups and downs of everyday life. Denying your feelings won't help. Accepting and learning how to deal with them are the only things to do. That's easier said than done but, with the support of others, you can do it! Asking for help is a sign of strength, not weakness. It is a signal that you have the will to do something about it.

Having a hard time?

Have you felt out of sorts for some time? Share your experiences with your doctor or a psychologist. They will know how to help if you:

- Cannot sleep
- Always feel tired or sleep excessively
- Have lost your appetite or overeat
- Have no interest in sex
- Feel no motivation to do anything
- Feel no pleasure in life anymore
- Have suicidal thoughts

Epilepsy and violence

Does epilepsy make you more violent or aggressive during or after a seizure? Not likely. During a seizure, it's extremely rare for a man with epilepsy to become violent. Spontaneous acts may seem violent and even hurt someone unintentionally, but it is almost impossible for you to directly and intentionally attack someone during a seizure.

After a seizure, you may feel confused, act more aggressively and be combative – without remembering afterward. This behaviour tends to recur. If you have a history of being aggressive after a seizure, tell the people around you, so they will know how to react and not try to restrain you.

Epilepsy doesn't stop a heart from loving

Accepting yourself and your epilepsy is important before you have an intimate relationship with another person. As you and your partner get to know each other better, a time will come when talking about your epilepsy is essential. Only you can decide when you're ready. It depends on how comfortable you are with your epilepsy.

Talking about epilepsy is something you will have to do, if you are already involved in a relationship. You have fears, worries and questions about how epilepsy will change your life, and so does your partner.

Expressing feelings is not easy for any man. But the truth is, expressing emotions is not natural for anybody. It's something you learn. Talking comfortably about your epilepsy may be hard at first, but it gets easier over time. And, it brings more peace of mind and harmony to your partner.

Let's talk about sex!

There's a good chance that epilepsy will not affect your sexual performance, especially if your seizures are well controlled. But epilepsy can influence sexuality, depending on where seizures originate in your brain. Some parietal lobe seizures (the parietal lobe is a specific area of the brain) can, but rarely, cause erections, ejaculation, and sexual feelings. More often, seizures due to abnormal activity in another area of the brain – the temporal lobe – lessen sexual desire.

Sexual activity is very unlikely to trigger seizures- this only happens in rare cases. A good sexual life is part of feeling well. It can reduce stress, creating better conditions for seizure control.

Are you certain I won't have any sexual problems?

Although epilepsy usually has little impact on men's sexuality, antiepileptic drugs can have sexual side effects (sexual dysfunction). Some antiepileptic drugs cause impotence. More often, they lead to a low sexual drive.

The important thing to remember is that there's no such thing as a normal sexual drive. All men are different. It's up to you to figure out if there's a problem with your sexual appetite.

If you are in a relationship, it's important to discuss this issue. Your partner may feel rejected if your sexual desire has diminished. It takes two to tango, especially when it comes to sexuality!

If you experience sexual dysfunction...

Don't be ashamed to face sexual problems. They can affect any man – with or without epilepsy. If you encounter sexual difficulties, don't automatically blame epilepsy or your medication.

Above all, don't assume that there's nothing you can do to improve your condition. Your doctor may have solutions – a change in medication or prescription for anti-impotence drugs. But to do so, your doctor will have to know about your problem. The only risk of talking about sexual dysfunction with your doctor is your situation may get better.

Fatherhood and family

As fathers, men with epilepsy are as good as anybody else.

A lot of men planning to have a child wonder if epilepsy will be passed to their son or daughter. The good news is that it's very unlikely to happen. Fathers with epilepsy have about the same chances of having a child with epilepsy as fathers without epilepsy: not much!

What about child safety?

Having seizures is not a barrier to safely raising children. You just have to take some precautions – an extension of normal childcare.

Here are a few safety tips:

- If you're feeding a baby, sit on the floor. If you always fall on the same side during a seizure, position yourself to prevent you from falling on the baby.
- You can dress, change and sponge bathe a baby on the floor. Don't bathe a baby in a tub, if you're alone.
- Teach older children how to care for younger siblings during your seizures.
- Fix safety brakes on the baby's stroller, so it won't roll away, if you have a seizure while out for a walk.
- If you have an infant, catch up on sleep, whenever possible. Fatigue can trigger seizures.

What happened to daddy?

As they grow, your children will probably have questions about your seizures. A seizure occurring without warning and followed by no explanation may leave your children scared or perplexed.

It's important to discuss epilepsy with your children. Keep it simple. Use words that your children understand. Be calm and positive. Make it clear you won't be hurt but may need some help during a seizure.

Teach children how to react during a seizure. Show them how to call 911 – in case you're unconscious after a seizure. When children are older, you can add details about your condition.

Get moving!

There's no reason for epilepsy to keep you from playing sports – as long as you take some commonsense precautions. An active lifestyle benefits everyone, and men with epilepsy are no exception. Regular exercise brings better sleep and decreases stress – improving seizure control. Sports are good for physical and mental health. At sporting events, you can gather with friends and lead a fruitful social life. Don't deprive yourself of such a valuable part of your life!

Sports

Before you get involved in a sport, take the following things into account:

- The type, severity and frequency of your seizures.
- Your known triggers, e.g., stress, excitement and more. In very rare cases, playing a sport can trigger seizures, possibly through hyperventilation.
- The presence of a warning (aura) before a seizure
- The risks of playing the sport: scuba and sky diving, mountain climbing, bungee jumping, car racing, hand gliding, parachuting and other sports are risky for anybody, especially if you have epilepsy. If you want to play these sports, be cautious. Use your common sense. The rule is if loss of consciousness or a seizure could endanger or threaten your life as you play a sport, it's wiser to avoid it.
- How much supervision is available? Some sports are moderately risky and must be practiced under good supervision, e.g., swimming, skiing, canoeing, hockey, tennis, cycling and weightlifting.

Tips

- Talk to your doctor before you begin a new sport, especially if it has some risk.
- Tell your coach or team mates about your epilepsy to ensure they know how to help during a seizure.
- Play sports with a friend who knows about your epilepsy and your first aid needs. It's safer and friendlier than playing sports alone.
- Always wear protective gear, especially head protection.
- If you lose or gain weight substantially, tell your doctor. Changes in weight can alter the blood level of your medication and a dosage adjustment may be necessary.
- When swimming, inform the lifeguard to keep an eye on you, because you have epilepsy.

Tough sports for wise men

Men with epilepsy can still participate in some contact sports. However, always wear head protection and tell your team mates how to react to a seizure. If you do, you'll probably be able to play contact sports, such as football, hockey or rugby. An exception is boxing. It has a greater risk of head injuries.

Leisure and social life

What's stopping you from leading a normal social life and enjoying leisure activities? Nothing! You may have to choose your activities more carefully, but your choices still depend mainly on your interests. You have to consider how you act during a seizure and how it affects your safety. If you like an activity, ask yourself if you can do it safely, despite your seizures. Most of the time, your answer will be "yes".

Shedding light on photosensitivity

Photosensitivity is a condition that makes people with epilepsy react to natural and artificial light, leading to seizures. Photosensitive seizures are triggered by video games, flashing lights or sunlight reflecting on leaves or wet surfaces. The most common trigger is television. Only 3% to 5% of all people with epilepsy are photosensitive. There's a higher proportion of photosensitivity among women.

Photosensitivity and Leisure

Television

If you're photosensitive, follow these tips:

- Watch television well away from the set. Sit at a distance of 2.5 meters or more from the screen, depending on screen size.
- Watch television in a well-lit room.
- Use a remote control.
- If you have to approach the television cover one eye with the palm of your hand.

Computers

A very low scan frequency (below 60 seconds) could trigger seizures in photosensitive men. However, very few computer screens flicker that slowly.

Video games

Half of men with photosensitive epilepsy are sensitive to patterns in some video games. If you play video games and are photosensitive:

- Read the instructions and warnings on your game packs.
- If you're tired, avoid playing.
- Take frequent breaks and rest between games.
- Quit playing if you feel dizzy or have blurred vision.

Nightclubs

Strobe lights and lights flashing at a certain speed can trigger photosensitive seizures. If you feel a seizure coming on, try to cover one eye with your hand.

Cinema

It's very rare for a movie to trigger a seizure, but it can happen during scenes with flashing lights. You may – but won't always – get a warning.

Theme parks

Rides with flashing lights may pose some risk, if you have photosensitive epilepsy.

Travel tips

- Plan to carry extra medication and prescriptions.
- Find out what your travel insurance will pay, if you have to see a doctor in another country.
- Get enough sleep before and during your trip. A lack of sleep and jet lag can trigger a seizure.
- Wear an epilepsy ID bracelet or necklace.
- Make sure you take your medication at regular intervals when traveling through time zones.
- Take your insurance card and the names and phone numbers of your doctor and pharmacist with you.
- Ask your doctor if immunization shots can interfere with your medication.
- Carry medicines in your handbag or carry-on luggage. Keep your pills in their original bottle.
- Ask your doctor for the chemical or generic name of your medication, because the drugs you take may have different trade names in different countries. Carry a list of these medications.

Alcohol

Some men can drink alcohol in moderation without increasing the risk of a seizure. For others, the smallest amount of alcohol triggers a seizure almost every time – so they avoid drinking completely.

Determining whether to drink or not is a very personal issue. Sometimes, the decision depends on what type of medication you take.

Drinking alcohol along with epilepsy medication can worsen the effects of alcohol and side effects of antiepileptic drugs. Alcohol can make your medication less effective.

Heavy drinking is never a good idea. Binge drinking is likely to lead to a seizure – and more likely to make you forget to take your medication. Changes in lifestyle that sometimes come along with drinking may affect your seizure threshold. Sleep deprivation and late nights, missed meals and forgetting pills are seizures triggers for many men.

Drinking or not is a decision to discuss with your doctor – the best person to know what can happen if you drink alcohol while taking a specific medication. With this information, you can make a well-informed decision.

Other drugs and seizures

Marijuana: There's no conclusive evidence that marijuana provokes seizures. Some say that it helps to control certain types of seizures – if taken in moderation – while others say the opposite – that it may trigger seizures.

Ecstasy: Taking ecstasy increases the amount of some chemicals in the brain that cause over-stimulation. It can provoke seizures. And, ecstasy is often taken while dancing all night long, leading to dehydration and making seizures more likely to occur.

Heroin: Heroin can cause seizures.

Amphetamines (speed, pep pills, uppers): At abnormally high doses, these drugs can trigger seizures. Side effects, such as lack of sleep, increase the risk of seizure.

Cocaine: It causes seizures, lack of sleep, poor nutrition and missed medication.

Solvents: They cause brain damage, leading to or worsening epilepsy.

Steroids: There's no evidence these drugs lead to seizures.

Tobacco: Smoking doesn't seem to trigger seizures. However, nicotine preparations intended to help you quit smoking may cause convulsions (as can bupropion).

Caffeine: Drinking coffee, tea or soft drinks as part of everyday life does not usually cause seizures.

Any drug can interfere with your medication. If you take some of these drugs it should be discussed with your doctor.

Safety at home

Most seizures won't hurt you, but there's some risk of injury when they occur in certain places or during certain activities. Some hazards are obvious – in the water or heights – but some are in places you don't suspect – bathrooms or kitchens. These dangers are not something to fear; they are something to prevent. Often, minor adjustments reduce the risk of injuries. The trick is: think and plan ahead.

General safety tips

- Pad tables and furniture to cover sharp edges. If you have nocturnal seizures, include your bed.
- Forced air heating instead of exposed elements, such as radiators, reduce the chances of injuring yourself if you fall.

Bathroom safety

- Leave the bathroom door unlocked, so people can enter if you need help.
- Take showers rather than baths. They reduce the risk of having a seizure in water and drowning.
- Use a shower seat or tub with non-skid strips to prevent falling in case of a seizure.
- Turn cold water on first, adding the hot gradually. Adjust the water temperature, so it's not hot enough to cause burns if a seizure or blackout occurs.
- Put padding and bathroom carpeting on the floor.

Kitchen safety

- Microwave cooking is safer than using an electric or gas stove.
- If you use a stove, use the back burners as often as possible.
- Use plastic plates and drinking cups instead of glass or porcelain.
- Serve hot meals on plates rather than serving from saucepans or frying pans at the table.

A warning for handymen

Mowing the lawn, changing a light bulb or fixing a broken toaster is routine for many men. Doing repairs around the house may be one of your official family duties. Some of these activities carry some risk. Be cautious.

You'll have to evaluate the dangerousness of these chores, should a seizure occur. If you're likely to have a seizure that could injure you, it's better to adapt the chore, postpone it or ask someone else to do it.

Safety tips for handymen

- Use a lawn mower that stops running if you stop holding the handle.
- Use power tools with hand protection and that stop automatically when you aren't holding them.
- Wear protection gear – goggles, helmet, safety gloves – whenever necessary.
- Avoid heights, e.g., ladders, roof repairs, or at least, wear a harness to prevent falls. Never do these chores alone!
- Fire is dangerous. It may be safer to let someone else light fires or clean ashes from a fireplace. Ask someone else to grill food on the BBQ. If you have to weld, wear a mask. Never work with fire alone!

Epilepsy is in your head!

How epilepsy affects your life is partially a matter of perception and attitude. Epilepsy can interfere with your life – if you let it. Of course, epilepsy imposes limitations. So what! Everyone faces limits of some kind for different reasons. Change your perspective, and you'll find obstacles become challenges – defining what you can and cannot do. Take control. Don't let epilepsy get in the way of a satisfying life.

Men are strong, competitive, independent, proud and persevering. If you can avoid the traps of taking unnecessary risks and being too proud to ask for help, epilepsy won't limit your enjoyment of life.

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