

YOU ASKED, WE ANSWERED:

CURRENT EVIDENCE ABOUT EPILEPSY AND SEIZURES



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EPLINK
THE EPILEPSY RESEARCH PROGRAM
OF THE ONTARIO BRAIN INSTITUTE

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Background

In 2020, a Priority Setting Partnership for epilepsy was undertaken by EpLink, the OBI, the James Lind Alliance and our national partners to identify and prioritize unanswered questions relating to the cause, diagnosis, treatment and management of epilepsy and its comorbidities. This is the first such initiative for epilepsy in Canada. Canadians came together to identify their top 10 priorities for epilepsy research, which can be found in the [published journal article](#) and accompanying [report](#).

However, during the course of this PSP, hundreds of questions related to the treatment and management of epilepsy were submitted that are fully or partially answered by current scientific evidence. These questions, while not considered evidence uncertainties, provide insight into knowledge gaps that need to be addressed. More work is needed to effectively translate existing knowledge to the epilepsy community, and this report aims to contribute to that effort. Based on current evidence, this report provides brief answers to some of the most frequently asked questions about epilepsy and seizures.

While information in these areas continues to evolve, the questions in this report are considered “answered” because the evidence is strong enough for researchers to reach a consensus. The goal of knowledge translation is to ensure that research can be used to inform and empower. We hope that the information in this report and the additional resources listed can help Canadians living with epilepsy to make informed healthcare decisions and become equal partners in their care.

Resources for support and more information can be found at the end of this report.



Information and Support: The Canadian Epilepsy Alliance

The Canadian Epilepsy Alliance (CEA) is a Canada-wide network of grassroots organizations dedicated to the promotion of independence and quality of life for people with epilepsy and their families, through support services, information, advocacy and public awareness.

Community epilepsy agencies provide disease management and psychosocial support for an epilepsy diagnosis. Referrals for community support can occur at diagnosis or at any point during the treatment pathway.

Community epilepsy agencies can*:



Provide epilepsy education and first aid training to family, friends, employers and other relevant groups.



Provide counseling for anxiety/depression, stress management, problem-solving, self-esteem etc.



Facilitate connections to peer supports and support groups based on needs identified.



Advocate for patients and their families at schools, workplaces and other community agencies where they are experiencing stigma and discrimination relating to epilepsy.



Assist patients with accessing and navigating community resources (applying for disability, respite, Trillium Drug Program etc.).

*Note that not all agencies provide all services.

Call **1-866-EPILEPSY** to reach the agency nearest you for help and assistance.

<https://www.canadianepilepsyalliance.org/>



20 Commonly Asked Questions

1. Does stress/excitement/alcohol trigger seizure onset? Do legal substances (e.g. alcohol, cannabis) impact the effectiveness of anti-seizure drugs?

Samples of submitted questions:

- What role does stress play as a seizure trigger?
- Are emotions related to seizures?
- Does the consumption of alcohol directly impact the medications Tegretol, Keppra and Clobazam?

There are multiple factors that may trigger a seizure in a person with epilepsy and in those with a lower-than-normal seizure threshold. Experiencing a **stressful situation or becoming upset** may cause a seizure to occur. Seizures may also be triggered by drinking **alcohol**, particularly if alcohol is consumed in higher amounts or if the drink has a higher percentage of alcohol. In addition, a seizure may occur in the event of alcohol withdrawal, in extreme situations, known as 'delirium tremens'.

Alcohol misuse may also affect how well a newly diagnosed person with epilepsy responds to anti-seizure drugs (ASDs). Specifically, alcohol may affect the rate at which the liver breaks down ASDs, which reduces the levels of the drug in the blood and may affect seizure control.

The effects of occasional or long-term use of **cannabis** on epilepsy are not fully understood. Cannabidiol (CBD), a compound found in cannabis, has been recommended as a potential therapy for certain epilepsy syndromes, including Dravet and Lennox-Gastaut syndrome. However, studies show that CBD may **interact** with certain ASDs. For example, taking CBD with valproic acid, a commonly used ASD, may result in liver damage. Also, the combination of CBD and clobazam may lead to an increase in clobazam levels in the body, which can cause adverse effects such as fatigue. Cannabis use should be closely monitored by a doctor to avoid the risks associated with these interactions.

2. Environmental toxins (e.g. chemicals, pollution, pesticides, heavy metals, etc.) and seizures

Samples of submitted questions:

- What environmental factors are important in the development of epilepsy?
- What effects do mercury and aluminum have on the brain? Is there a relationship between mercury/aluminum and seizures?
- What types of secondary or external factors can cause epilepsy?

There are certain environmental toxins that may cause seizures or contribute to the development of epilepsy. For example, exposure to **toxic levels of heavy metals**, such as lead, arsenic or mercury, may cause brain damage leading to seizures. If herbal medicine is taken at excessive doses for long periods of time, there may be potential contamination of the herbal preparations with heavy metals and these could be toxic to the brain.

Different pollutants that can be found in the air may also cause seizures, such as methane, carbon monoxide, nitric oxide, nitrogen dioxide, particulate matter and non-methane hydrocarbons. Studies have found that **air pollution** may be linked to an increase in hospital admissions for epilepsy, although more research is needed to further support this finding. Air pollutants may trigger inflammation and toxic effects in the brain, increasing the risk for seizures.

Exposure to **pesticides** might also increase the risk of developing epilepsy since studies have shown higher rates of epilepsy in areas of greater pesticide use.





3. How should rescue medications be used in community settings?

Samples of submitted questions:

- *What should be done at the time of an actual epileptic seizure?*
- *What needs to be done physically with the patient?*
- *What medicine and dosage should be given during the episode?*

When a seizure occurs in a school or community setting, the following steps should be taken:

1. Clear away any unsafe objects
2. Time the seizure
3. When it is safe, roll the person onto their side and put something soft under their head
4. Never put anything in their mouth or hold them down during a seizure

If the seizure lasts for more than five minutes, then rescue medication should be administered. In a community setting, the first-line treatments that should be given are 1 mg sublingual lorazepam, 5 mg intranasal midazolam, 10 mg of buccal midazolam (the syrup can be placed in the mouth between the gum and the cheek), or 10–20 mg of rectal diazepam (according to an agreed administration protocol). This treatment, ideally administered by a caregiver, family member or clinician, will reduce seizure intensity or duration and avoid unnecessary hospital admission. In addition, the treatment will help to prevent status epilepticus (SE), a life-threatening seizure that lasts for more than 5 minutes or when someone has two or more seizures without becoming conscious between seizures. If someone is having SE, it may occur as convulsive (e.g. generalized tonic-clonic seizure) or non-convulsive (e.g. absence seizure, or focal unaware).

4. What are the strategies that can be implemented in schools to support students with seizures or epilepsy?


Samples of submitted questions:

- How can children with epilepsy get better support at school?
- Are there places that can educate schools about epilepsy?

In terms of supporting children with seizures or epilepsy at school, various strategies may be effective. These include having a nurse specialist on site, training school staff on how to effectively respond to students experiencing seizures, strategies to reduce stigma, epilepsy protocols for each patient at school made by his/her neurologist, and communication between schools and doctors about children living with epilepsy.

However, several studies suggest that while the training and information resources exist, teachers still lack important information about how to assist a student who is experiencing a seizure. Many agencies and provinces offer **educational programs or resources for teachers and students** (for example, the [Government of Alberta](#), [Epilepsy Maritimes](#), [BC Epilepsy Society](#) and [Epilepsy Toronto](#)). For educators seeking more information on how to support children with epilepsy at school, including videos, please see the teacher tool kit found at epilepsyforeducators.ca.





5. Stress management techniques and psychotherapy as methods of treating seizures and improving quality of life of people with epilepsy

Samples of submitted questions:

- *Is psychotherapy effective in improving quality of life or agency in patients with epilepsy?*
- *What is the role of trauma in epilepsy and is trauma release a possible solution for some people with seizure disorders?*
- *Does meditation work for managing stress?*

Receiving an epilepsy diagnosis can be difficult, and many aspects of living with epilepsy can be stressful. Recent studies have found that **mindfulness-based techniques, physical exercise and psychotherapy techniques** (e.g. counselling, cognitive strategies, and behavioural change strategies) can help to reduce stress and anxiety. Mindfulness-based techniques focus on noticing, recognizing and processing the emotions related to seizures to enable acceptance and coping. Techniques such as cognitive behavioural therapy, yoga or mindfulness-based interventions that focus on thought restructuring can be beneficial for stress reduction. Mindfulness, which often involves breathing techniques or guided imagery, focuses our awareness on the present moment and encourages acceptance of our thoughts, feelings and body sensations. These techniques can increase emotional well-being, reduce fatigue and improve quality of life.

Stress reduction is important in two ways: it may directly reduce epileptic activity in the brain and may also reduce the risk of stress triggering a seizure. Psychotherapy has also been recommended for patients with psychogenic non-epileptic seizures. Services may be offered in hospitals, in the community, or by a community epilepsy agency (CEA). Your medical team or local CEA can help connect you with service providers in your area.

6. How can children's seizures be managed, while still allowing them to experience "normal" childhood activities?

Samples of submitted questions:


- *As a mother of a child with epilepsy, how can I grant independence to a teenager while staying intellectually responsible for that child?*
- *How do parents of children with epilepsy balance caution and normal life in regards to their children's activities and health?*
- *How can you teach a child to detect seizures by themselves?*

For children living with seizures or epilepsy, there are different treatment options to help reduce the number of seizures, including medications, diet therapy, and surgery. However, compared to children without seizures they have an **increased risk of psychosocial issues**, including depression, anxiety and poor self-esteem. A child may also feel angry if they perceive that their epilepsy is preventing them from taking part in activities with their peers. If these comorbidities are not treated and stress is not managed, then a child may experience more seizures and a reduced quality of life.

To reduce this risk, there are some **self-management techniques** that a child may practice, including maintaining a normal sleeping routine, tracking seizures and taking seizure medications at the correct time. While a family member or caregiver should help the child develop the skills to carry out these techniques, it is also important that they avoid being too overprotective since the child may perceive themselves as vulnerable or incapable.

Unfortunately, there are other risk factors for poor seizure outcomes in children that may be outside of their control, such as caregiver unemployment, lack of family resources, and family socioeconomic status. To help a child achieve seizure freedom and improve their quality of life, experts recommend inclusion of the family in the management of their epilepsy, strengthening of the family unit and the family's ability to adapt to epilepsy, and having adequate social support. Some interventions that have been shown to strengthen the family unit include **family therapy and behavioural parenting interventions**. Community epilepsy agencies may also provide family support groups, educational resources and other tools or strategies.





7. Are people with seizures at increased risk of autism, ADHD, or developmental delays?

Samples of submitted questions:

- *My child also has severe autism, ADHD and Tourette's. Are these all related to, or an effect of seizures? I was told that absence seizures are very rare in autistic children, is this true and why?*
- *How are epilepsy and autism linked?*
- *What are the statistics of experiencing developmental disorders when seizures are well managed versus when seizures are unmanaged?*

Compared to the general population, people with epilepsy are more likely to have developmental delays, due to brain lesions associated with their epilepsy, genetic conditions or other abnormalities not yet identified. Studies have found that children with epilepsy have a higher risk of developing **autism spectrum disorder (ASD)** and **attention deficit hyperactive disorder (ADHD)** than children without epilepsy. ASD is a neurological disorder that is associated with impaired social interactions, communication skills, and behaviour patterns. Research suggests that early onset seizures may place infants at a higher risk of developing ASD, and this is also usually associated with intellectual deficits. Children with ASD have an increased prevalence of seizures, which is estimated to be 20–25% of the whole spectrum. In addition, the more severe the developmental delays, the more severe the epilepsy. Given this, it is recommended that children with epilepsy be screened for ASD upon diagnosis.

ADHD is characterized by symptoms of hyperactivity, impulsivity and attention deficits. Current research suggests that ADHD is seen in 30–40% of children with epilepsy. It is therefore important that family members or caregivers work with the child's doctor to determine the best treatment options and management of emotional or behavioural issues that may be associated with ASD or ADHD.

8. Are people with seizures at increased risk of mental health illnesses?

Samples of submitted questions:

- *How is obsessive compulsive disorder linked to my seizures?*
- *What research has there been in relation to a connection between epilepsy and Borderline Personality Disorder (BPD)?*
- *Can my schizophrenia be linked to my epilepsy?*

Mental health illnesses often co-occur in people with epilepsy. The most common are **depression and anxiety disorders**, which occur in 30–40% of people with epilepsy. This rate is much higher than in the general population. A person with epilepsy is also at an increased risk of suicidal behaviour, with suicides occurring in an estimated 5–14% of the epilepsy population.

It is important to note that epilepsy does not necessarily cause these conditions or vice versa. Mental health issues may be linked to the epilepsy itself or its treatment (such as certain anti-seizure drugs), reactions to an epilepsy diagnosis, changes in brain chemistry or structure, or they may be unrelated to epilepsy.

Some of the less common mental health illnesses that may occur in a person with epilepsy include personality disorders, alcohol abuse, or drug abuse. Around 5% of people with epilepsy have **interictal psychosis**. In this condition, a person may experience schizophrenia-like symptoms (e.g. hallucinations or delusions) that occur between seizures. These symptoms appear when a person is conscious, and do not immediately follow a seizure. Research suggests that someone with epilepsy is at greater risk of having interictal psychosis if they have focal impaired awareness seizures, generalized seizures, a family history of psychosis, or early age onset of epilepsy. For more information on mental health treatment options, it is recommended that you speak with your health care provider. Community epilepsy agencies may also provide support or other services.



9. Are people who experience seizures at increased risk of developing learning disabilities and cognitive deficits?

Samples of submitted questions:

- *What is the relationship between epilepsy and learning disabilities?*
- *Could we initiate research to better understand the correlation between epilepsy, learning disabilities and mental illnesses?*
- *How do epilepsy drugs impact children's cognitive ability and what could be done to mitigate the impact?*

Most children with epilepsy have the same intellectual capabilities as children living without epilepsy. However, about 30–40% of children with epilepsy have **learning disabilities** or **cognitive impairments**. Some neurological issues that these children may experience include learning challenges, language impairment and sleep problems.

Some anti-seizure drugs may also impact a child's cognitive abilities since many medications cause **drowsiness** and **impaired concentration**. In terms of learning challenges, studies have found that children with epilepsy may have significantly **lower language scores**, particularly in word knowledge and verbal comprehension. These issues are more noticeable in children with an earlier age of seizure onset and in those using the anti-seizure drug topiramate. Moreover, in the case of childhood-onset epilepsy, these cognitive deficits may remain throughout adulthood and have a negative impact on their quality of life.

In addition to anti-seizure medications, the underlying causes of cognitive impairments include more frequent seizures, uncontrolled or drug-resistant seizures or specific seizure types. For example, children may experience more cognitive difficulties if they have focal impaired awareness seizures, or feel a loss of time and more 'disconnected' if they have absence seizures. Given this, **early diagnosis and treatment of seizures in children** are important to help prevent developmental delay and potential cognitive impairments. Early treatments, including surgery, should be offered to minimize long-term effects of frequent seizures or high doses of multiple medications. It is also important that parents or caregivers discuss potential learning challenges with school personnel. Educational interventions and special assistance programs can help children and adults thrive in school and be productive members of their community.

10. Seeking information

Samples of submitted questions:

- *What research is being done into absences seizures and how can I access it?*
- *What measures are being taken to educate employers and schools about epilepsy?*
- *What is the best way to tell a boss/teacher about your epilepsy?*

Where to find research about epilepsy: Published scientific research papers are catalogued in specialized search engines. These articles have been published in established journals and have been peer-reviewed to ensure that the methods are rigorous, the conclusions are valid and that the science is of high quality.

To search for current research on a particular topic, some examples of free search engines include [Google Scholar](#) or [PubMed](#). While abstracts (a summary of the main points of the paper) are freely accessible, in some cases you may need to pay a fee to view the entire article.

Employers and disclosure of epilepsy: Studies have shown significant **discrimination against people with epilepsy in the workplace**. Unemployment or underemployment (where a worker's skills are underused) can reduce quality of life for a person with epilepsy. Stigma, type of seizures, and psychological factors such as motivation and self-esteem can all contribute to employment status. For example, frequent seizures are linked to lower rates of employment. However, many jobs can be safely performed by most people with epilepsy. Each province has standards and policies related to employment rights, discrimination, and employee accommodation (see examples here from the [BC Epilepsy Society](#), [Epilepsy Ontario](#), [Epilepsy Newfoundland and Labrador](#) and the [Epilepsy Association of Calgary](#)). Contact your nearest Community Epilepsy Agency for more information and to learn about your rights.



11. Epilepsy after traumatic brain injuries, strokes and tumours

Samples of submitted questions:

- Can a previous stroke or brain surgery be a cause for epilepsy or seizures?
- How common is the incidence/prevalence of epilepsy as a result of acquired brain injury?
- Does my brain tumour cause seizures?

While some epilepsies have no known cause, there are instances when epilepsy can result from a **brain injury**. Infections or trauma to the brain, such as stroke or an impact to the head, can cause seizures to develop days, weeks or even years later. This can happen in two ways: first, immediately following an injury, inflammation (swelling) and infections can cause damage to brain cells and disrupt electrical activity in the brain, leading to seizures. Secondly, over time, the presence of scar tissue or a buildup of damaging proteins can change the structure of brain cells and the way they fire, causing seizure activity. The more severe the injury, the higher the risk of developing epilepsy. For people who have suffered mild traumatic brain injuries, the risk of developing seizures is about 2%. This increases to 15% for severe head injuries.

Seizures are also commonly seen in people with **brain tumours**. Up to 60% of people with brain tumours may experience seizures following their diagnosis. Tumours can cause changes in electrical activity or brain chemistry that may trigger seizures. Overall, it's easier for doctors to identify the cause of seizures if abnormal brain tissue can be clearly seen with brain imaging, such as magnetic resonance imaging (MRI). However, in many cases, an MRI is normal and doctors may not be able to identify the cause.

In relation to epilepsy and stroke, it is not uncommon for these to occur together. Usually, epilepsy associated with **ischemic stroke** (caused by the blockage of a blood vessel supplying the brain) responds well to antiseizure medications. In addition to ischemic strokes, **brain hemorrhages** (bleeds) can also cause epilepsy.

12. Life expectancy of people with seizures and epilepsy

Samples of submitted questions:

- *Is my life expectancy shortened compared to those that don't have epilepsy?*
- *What is the average life expectancy of epileptics?*

****Please note that this answer contains sensitive information. Community epilepsy agencies can provide service and support for dealing with an epilepsy diagnosis. To find the agency nearest you, please call 1-866-EPILEPSY (1-866-374-5377)***

Most people with epilepsy live long and healthy lives. However, epilepsy is associated with an increased risk of premature death. Studies have shown that a person with epilepsy has a 2 to 3 times increased risk of premature death compared to the general population. The life expectancy of someone with epilepsy may be reduced by between 2 and 10 years.

The causes of premature death may or may not be related to epilepsy. The greatest reduction (up to 10 years) is seen in people who develop epilepsy as a result of a brain injury or structural abnormality in the brain. Epilepsy-related causes include status epilepticus, sudden unexpected death in epilepsy (SUDEP), drowning and accidents. Tragically, a person with epilepsy is more likely to commit suicide and may be at an increased risk of cardiovascular disease and cancer. Children with severe epilepsy may be at risk of breathing complications such as aspiration pneumonia due to underlying neurological impairments.

In addition, poorly controlled seizures increase the risk of premature death, including the risk of SUDEP. This means that the most important ways to reduce the risk of premature death are to work with health care providers to achieve seizure control, take all medications as prescribed and follow all treatment plans. Health care providers should also screen for, identify and treat any mental health issues in someone with epilepsy, including depression and anxiety. If you are in need of mental health support, please call 2-1-1 or see the following link for a list of mental health resources: <https://www.ontario.ca/page/find-mental-health-support>.





13. Major side effects of drug and non-drug treatments

Samples of submitted questions:

- *Are the issues with word recall from my epilepsy or my medications?*
- *What side effects of drugs will impact my child?*
- *If surgery is an option, what should I expect?*

Anti-seizure drugs: There are several different types, or classes, of antiseizure drugs (ASDs), and since they work in different ways, they have different side effects. The most common side effects of ASD therapy include: drowsiness, fatigue, dizziness, unsteadiness, blurred or double vision, difficulty concentrating, irritability and depression. Weight gain or weight loss and decreased bone mineral density can occur, especially with certain ASDs, such as carbamazepine and phenytoin. In some instances, serious side effects can occur, such as severe rashes or allergic reactions, but these are very rare. If you are experiencing side effects, talk to your medical team to see if lowering the dose or switching medications is an option for you.

Some ASDs may affect the health of unborn babies, so it's important that women of childbearing age be aware of these risks and how to reduce them, such as folic acid supplementation before and during pregnancy. If you are thinking of becoming pregnant, you can work with your doctor to develop a treatment plan.

Ketogenic diet therapy: The most common side effects of ketogenic diet (KD) therapy are gastrointestinal symptoms, including vomiting, constipation, diarrhea and abdominal pain. Other possible side effects include fatigue, gallstones or kidney stones, infections, weight loss, high cholesterol, status epilepticus, dehydration and rapid heart rate (known as tachycardia). Currently, researchers do not have enough information to draw conclusions about the long-term effects of KD therapy on heart function, bone health, height and growth. Due to possible side effects, not every person with epilepsy is a candidate for this treatment.

Surgery: Resective surgery involves removing the part of the brain where seizures start. For suitable candidates, there is up to an 80% chance of being seizure-free after surgery, depending on the source of the seizures. Possible side effects of surgery include infection or bleeding, difficulties with memory, language or vision, or impaired movement. There is also a risk of anxiety, depression or other mental health problems. Some side effects can resolve with time, while some may be permanent. The risk of side effects will depend on the location of the surgery and the extent of the surgery (which part of the brain is removed and how much is removed). However, some aspects of language, memory and mental health can also improve following surgery, and it's important to remember that uncontrolled seizures can also lead to language, concentration and memory problems. If you are a candidate for surgery, your medical team will discuss the potential risks and benefits that are specific to you.

Brain stimulation: There are different brain stimulation devices to help treat seizures, including vagus nerve stimulation (VNS) and deep brain stimulation (DBS). Responsive neurostimulation (RNS) is also available in the United States. VNS is most commonly used for the treatment of drug-resistant epilepsy and seizures. It involves implanting a device under the skin that delivers intermittent electrical stimulation to the vagus nerve (which communicates with the brain) to help reduce seizure activity. Possible side effects include change in voice or hoarseness, cough, shortness of breath, burning or tingling sensations, nausea, pain, headache and infection at the implantation site.



14. How do doctors select the most effective treatment option?

Samples of submitted questions:

- How is it known which medication to start with?
- How to explain the choice of drug?
- Why so many trials and errors?

There are dozens of anti-seizure drugs (ASDs) available, and it can be challenging for doctors to know which one to choose. Below are some of the most important factors to consider when selecting ASDs:

1. **The type of epilepsy.** For example, some drugs work better for focal epilepsy, such as carbamazepine, and some work better for generalized epilepsy, such as valproic acid.
2. **Doctors must consider age, sex and race.** Older individuals may be more likely to experience side effects or have co-existing conditions. In women who are pregnant or of childbearing age, some ASDs may be harmful to the fetus, and some methods of contraception can reduce the effectiveness of ASD treatment. Finally, some racial populations may be more likely to experience certain rare side effects based on their genetic profiles.
3. **Other medications and conditions:** doctors must consider possible drug interactions with other medications a person may be taking, and if the person has any co-existing conditions in addition to epilepsy (such as mental health issues).
4. Finally, doctors will consider **the possible side effects of the drug** and how they might impact daily functioning, employment, or pre-existing health issues. Despite these considerations, it is impossible to predict which drug at which dose will work for a particular person, because each case of epilepsy is unique. Doctors may not know the cause of the epilepsy or how a person will respond to a particular drug, which means that finding the right drug may be a trial-and-error process. If seizure control is not achieved with the first drug, doctors may switch to a second drug or a combination of drugs. If the second drug trial is not effective, a person is said to have drug-resistant epilepsy and should be referred to a comprehensive epilepsy centre to discuss other treatment options ([visit ontarioepilepsyguidelines.ca](http://visit.ontarioepilepsyguidelines.ca) for more information).

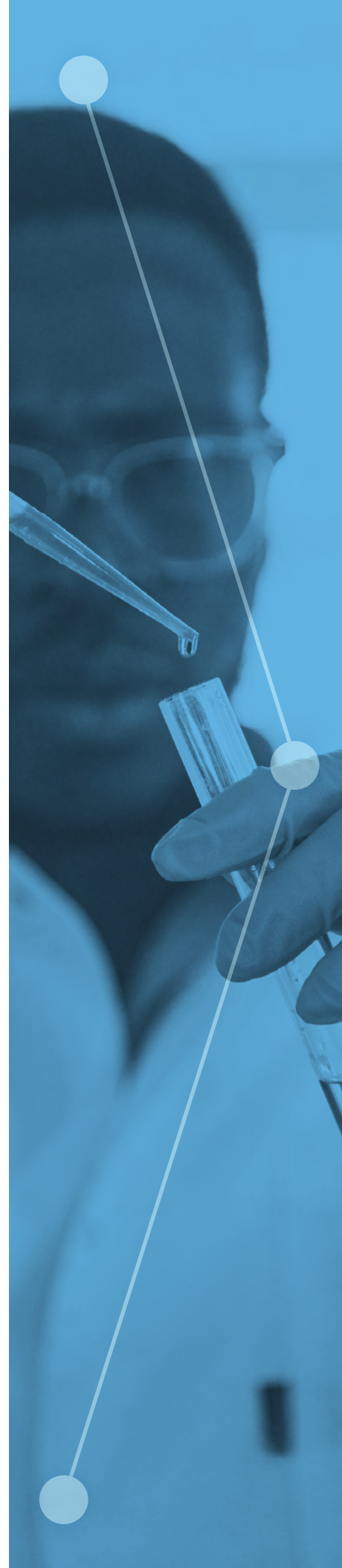
15. Stigma and seizures

Samples of submitted questions:

- *Why are we always hesitant to disclose our epilepsy to our friends, relatives and employer?*
- *Why is epilepsy still not discussed in public very often?*
- *Are children living with epilepsy bullied or avoided by their peers?*

Despite increased scientific knowledge and awareness about epilepsy, **stigma around seizures still exists**. There is a long history of legal discrimination against people with epilepsy such as restrictions on marriage, employment and driving. At one time, epilepsy was so misunderstood that people with seizures were isolated and placed in asylums for the mentally ill. Unfortunately, there are places around the world where those beliefs still exist. Old misconceptions of seizures as being contagious or related to demonic possession can still influence perceptions about epilepsy today. Unlike other medical conditions, epilepsy is difficult to conceal, and people often report feeling distressed when they witness someone having a seizure. Studies have shown that the more frequent a person's seizures are, the more stigmatized they feel. In turn, this stigma can cause someone with epilepsy to feel shame around their condition or attempt to hide it.

Since epilepsy is very rarely cured, the stigma may persist even for those who are seizure-free. However, **public perceptions of epilepsy are changing and are more positive than in the past**. Advances in scientific knowledge have made it clear that epilepsy is a medical condition and public education and awareness campaigns have helped to reduce stigma. Misinformation about epilepsy still represents a substantial problem, but with targeted efforts, both knowledge of epilepsy and attitudes toward epilepsy can be improved. **Sharing positive, education-focused messages** about epilepsy and approaches that emphasize inclusiveness can help shape attitudes. Using platforms like social media can help appeal to younger audiences, and targeted campaigns can support people with epilepsy in schools and workplaces. Importantly, those who are **better informed about their epilepsy** are less likely to feel stigmatized. For a person with epilepsy, joining support groups that allow participants to share ideas, experiences and strategies can be empowering. Health care providers and Community Epilepsy Agencies can offer support to those with epilepsy by providing information about their diagnosis, helping individuals and families cope with the fear of living with the unpredictability of seizures, and discussing ways to disclose their epilepsy to others.





16. Depression and anxiety

Samples of submitted questions:

- Are depression and anxiety directly linked to having epilepsy biologically or is it a side effect of medication?
- Do people get depression after epilepsy?
- Why do some patients seem more prone to depression and anxiety?

Epilepsy is strongly linked to mental health, and about **1 in 3 people with epilepsy will experience depression**. There is no single cause of depression in people with epilepsy, but there are many ways these conditions may be related. Someone with epilepsy may be prone to depression because of **genetics** (family history) or **changes in brain chemistry** due to seizures. Individual differences also play a role, such as **coping strategies, emotional responses or negative thought patterns**. Finally, factors such as stigma, lack of freedom, worrying about further seizures and side effects, a lack of social support, stress or past traumas can all lead to depression. Research shows that people who have depression are at a higher risk of developing epilepsy. This could mean that there is a genetic basis for both conditions, or that certain changes in brain structure or function can lead to both epilepsy and depression. In addition, depression and suicidal thoughts are possible **side effects of many different antiseizure drugs**, such as phenobarbital, primidone, levetiracetam, perampanel, vigabatrin and topiramate. These drugs help to control seizures but can also affect the mood centres in the brain.

Less is known about the relationship between anxiety and epilepsy, but research suggests that **anxiety disorders are common in people with epilepsy**. Anxiety is a less common side effect of antiseizure drugs but is sometimes seen with levetiracetam and brivaracetam. Anxiety can also be a response to a diagnosis of epilepsy, or a reaction to the fear and unpredictability of seizures. As with depression, the relationship goes both ways – seizures may trigger anxiety, and anxiety may trigger seizures through the release of stress hormones. Areas of the brain where seizures commonly start, such as the temporal lobes, are also involved with regulating emotions. In addition, some people may experience anxiety as part of their auras, or warning signs, before a seizure.

If you are suffering from depression or anxiety, there are treatments that can help. Please talk to your health care providers.

17. Support for people living with depression and anxiety

Samples of submitted questions:

- *How do I manage the depression/social anxiety that I developed as a result of the seizures?*
- *What is the best treatment for depression in those with epilepsy?*
- *Are there other forms of therapy other than prescribing medication to treat depression and anxiety?*

The first step to treating mental health conditions is a correct diagnosis. Ontario's epilepsy guidelines recommend that all **people with epilepsy should be regularly screened for depression**. Anyone diagnosed with depression should receive a referral to a mental health professional for treatment options; however, such resources are often limited. Depression and anxiety are typically treated the same way in people with epilepsy as in those without epilepsy. Antidepressant drugs are commonly prescribed to treat anxiety or depression. Some doctors may be reluctant to prescribe antidepressants due to fear that they will cause or worsen seizures. However, most **antidepressants can be safely used in people with epilepsy** without increasing the risk of seizures ([see the Epilepsy and Depression infographic here](#)).

As an alternative or complementary strategy to drug treatment, **approaches such as cognitive behavioural therapy (CBT) or psychotherapy can also be beneficial**. CBT is a type of treatment that aims to change thinking patterns through recognizing problematic thoughts, promoting understanding and acceptance, and providing behaviour change strategies. Some people find that mindfulness training helps them to manage negative thoughts and feelings. For those with anxiety, training in cognitive strategies can also help to restore a sense of control over seizures. Ontario's epilepsy guidelines (ontarioepilepsyguidelines.ca) recommend that supportive therapy, including psychoeducation provided by trained therapists, social workers, epilepsy nurse specialists, or other suitably trained professionals, should be provided to all newly diagnosed people with epilepsy and their families. Some community epilepsy agencies may offer support groups, counselling or other services to those dealing with anxiety and depression (see 'Resources' section on page 30).

18. How useful are EEGs as a seizure disorder/epilepsy diagnostic tool?

Samples of submitted questions:

- *Why do some people have negative EEG results?*
- *How is epilepsy diagnosed if EEG, MRI tests are normal?*

EEGs, or electroencephalograms, are an important tool for diagnosing and evaluating epilepsy and seizures. Using electrodes placed on the scalp, **EEGs detect and record electrical activity in the brain**, and particular patterns of abnormal activity can reveal whether epilepsy is present. These patterns can be seen during a seizure and in between seizures. An EEG can reveal whether seizures are starting in one part of the brain (focal seizures) or affect the entire brain (generalized seizures). EEGs can be used to **diagnose or confirm epilepsy, to learn more about the type of epilepsy or seizures, to determine if epilepsy surgery is an option or to make treatment decisions**. However, it is important to note that a normal EEG does not rule out epilepsy. It's estimated that only about one-third of initial EEGs are abnormal. EEGs are also less likely to show abnormal activity if they are done more than 24 hours after a seizure occurs.

There are ways to increase the chances that an EEG will detect abnormal activity, such as repeating EEGs over time, recording for longer durations or during sleep, sleep deprivation, hyperventilation, flashing lights, or recording directly from the surface of the brain rather than the scalp. However, **even if an EEG does not show any abnormal activity, epilepsy may be diagnosed through clinical information, such as a description of the seizure, medical history and a physical examination**. Other types of imaging, such as magnetic resonance imaging, and less commonly computed tomography (CT) scans, can be used to rule out structural changes in the brain or abnormal brain development that might be causing new onset seizures, such as strokes, tumours, scar tissue, or blood vessel abnormalities.

19. How can people who experience seizures best manage their own healthcare/seizures to achieve good quality of life?

Samples of submitted questions:

- *What can I do to manage my epilepsy?*
- *How can I encourage my child to both take responsibility for, and understand the seriousness of his epilepsy as he grows, particularly into the teenage years?*
- *Why do I feel poorly pretty much all the time and how can I remedy this to live the best life possible?*

Self-management describes a person's ability to manage the symptoms, treatments, lifestyle and day-to-day challenges associated with living with epilepsy. While self-management encourages a person with epilepsy to take an active role in managing their condition, they can only do so with sufficient skills and knowledge. Effective self-management of epilepsy requires **support and partnership from health care providers** and encourages **shared decision-making** about treatment decisions. These tools allow a person with epilepsy to build the skills and confidence needed to manage health problems and achieve their goals.

The interventions that provide self-management skills can be educational in nature or can involve psychotherapy. There are also **decision support tools** available that can help people with epilepsy and their health care providers to assess self-management needs and to identify strategies for improvement. This process allows a person with epilepsy to assess their own needs and behaviours related to lifestyle management, social functioning, seizure triggers, medication, safety and epilepsy information. These techniques also allow people with epilepsy to identify goals and select strategies to achieve those goals. Self-management programs may be offered online, via the phone or in-person. Contact your local community agency to learn more about which programs are available.



20. What community/government social programs can provide support for people who experience seizures?

Epilepsy is classified as a disability by the Canadian government, which means that financial assistance may be available to those who qualify. The [Canada Pension Plan \(CPP\) Disability Benefit](#) is available to those who have contributed to the CPP and have a disability that prevents them from being gainfully employed. [The Disability Tax Credit \(DTC\)](#) is available to those who have a severe mental or physical impairment because of their disability. More information about eligibility requirements can be found on the [Canada Revenue Agency's \(CRA\) web page for people with disabilities](#). Many children (and adults) who qualify for the DTC also qualify for the [Registered Disability Savings Plan \(RDSP\)](#). Assistance may also be offered through [Employment Insurance Sickness Benefits](#). Some provinces provide programs that offer financial aid, legal assistance, support for housing or employment, home or vehicle modifications, mental health and school supports and more, but these services vary by province. Contact your local Community Epilepsy Agency for more information.



Quick Facts

1. Are any contagious diseases associated with an increased risk of seizures?

Yes. Neurocysticercosis, bacterial meningitis, and encephalitis are examples of infections that can cause seizures and epilepsy. These diseases are most common in low- and middle-income countries.

2. Can using illegal drugs cause non-withdrawal seizures? (Illegal drugs do not include cannabis products or alcohol)

Yes. Consuming very high quantities of alcohol or taking illicit drugs such as crack or cocaine, opioids, quaaludes or amphetamines can cause seizures. Hallucinogenic drugs, such as PCP, can also induce seizures.

3. How often do misdiagnoses of epilepsy or seizure disorders occur?

It is estimated by the National Institute for Health and Care Excellence that misdiagnosis of epilepsy occurs in **5–30%** of cases.

4. Is there a relationship between autoimmune disorders and seizures?

Yes. Autoimmune disorders (where the immune system mistakenly attacks the body) such as lupus, Crohn's disease, and celiac disease, can cause seizures if the immune activity also affects the brain.

5. Does pregnancy impact the effectiveness of anti-seizure drugs?

Yes. Pregnancy can increase the elimination of anti-seizure drugs from the body, causing drug levels to decrease and increasing the risk of seizures. Regular sampling of drug levels in the blood can help to determine if dose adjustments are needed.

6. How effective are anti-seizure drugs?

Can any treatments “cure” seizures?

Anti-seizure drugs are effective at controlling seizures in about 70% of people with epilepsy. The remaining 30% of people may require alternative treatments, such as surgery, diet therapy or brain stimulation to achieve seizure control. In general, epilepsy is a lifelong condition; however, in some people who have undergone surgery to remove the part of the brain where seizures start, epilepsy may be considered to be cured.

7. Are people who experience seizures at an increased risk of having migraines?

Yes. The prevalence of migraines in people with epilepsy is higher than in the general population. There may be a common genetic basis for both conditions, or there may be changes in the brain that lead to the development of both migraines and seizures.

8. Are any pregnancy and birth-related factors associated with an increased risk of seizures?

Yes. Complications at birth, such as vacuum and forceps delivery, low gestational age, or low birth weight can increase the risk of seizures in babies. In addition, if the mother has diabetes, preeclampsia or develops an infection during labour, the chances of seizures in the infant are increased.

9. Which factors impact the effectiveness of surgery as a treatment for seizures?

While the effectiveness of surgical treatment is not possible to predict in a given individual, certain factors can improve the chances of success. These include a well-defined abnormality visible on magnetic resonance imaging (MRI) that aligns with electroencephalography (EEG) results, and complete surgical removal of the affected area.



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Resources

Emergency seizure management and using rescue medications in community settings, including schools

- [Video](#): Epilepsy and School Success
- [Video](#): How to Administer Emergency Medications to Students with Epilepsy
- Teacher Tool Kit found at epilepsyforeducators.ca
- Epilepsy Ontario article 'School life for children with epilepsy': <https://epilepsyontario.org/school-life-for-children-with-epilepsy/>
- Canadian Epilepsy Alliance article on seizure first aid for both convulsive and non-convulsive seizures: <https://www.canadianepilepsyalliance.org/about-epilepsy/epilepsy-safety/seizure-first-aid/>

SUDEP information and mental health support

- SUDEP Aware: <https://www.sudep.news/>
- Community epilepsy agencies can provide service and support for dealing with an epilepsy diagnosis. To find the agency nearest you, please call 1-866-EPILEPSY (1-866-374-5377)
- If you are in need of mental health support, please call 2-1-1 or see the following link for a list of mental health resources: <https://www.ontario.ca/page/find-mental-health-support>

Finding the most effective treatment options with your doctor

- 'Talking To Your Doctor' page: <https://ontarioepilepsyguidelines.ca/talking-to-your-doctor/>

Support for people living with depression and anxiety

- 'Epilepsy and Depression' [infographic](#)
- 'Information about Epilepsy and Antidepressants' [info sheet](#)
- UPLIFT – 'Using Practice and Learning to Increase Favourable Thoughts', mindfulness-based CBT program. Offered at [Epilepsy Toronto](#), [Epilepsy Ottawa](#), [Epilepsy Southwestern Ontario](#)
- Epilepsy Toronto, Adult Services: <https://epilepsytoronto.org/about-us/programs-and-services/adult/>

How can people who experience seizures best manage their own healthcare/seizures to achieve good quality of life?

- Preparing for the transition to adult care: <https://www.lhsc.on.ca/paediatric-epilepsy-program/transition-clinic-know-before-you-go>
- 'Diagnosis, Treatment, & Referral Pathway': <https://ontarioepilepsyguidelines.ca/referral-pathway-paf/>
- Patients Like Me: <https://www.patientslikeme.com/>
- Clinic to Community: <https://clinctocommunity.ca/>

For more resources:

- Visit the Ontario Epilepsy Guidelines site at ontarioepilepsyguidelines.ca
- Visit the EpLink site at eplink.ca and follow @EpLinkON on [Twitter](#) and [Facebook](#)
- Visit the Ontario Brain Institute site at braininstitute.ca and follow @OntarioBrain on [Twitter](#) and [Facebook](#)

Additional resources:

- Information on seizure types: <https://eplink.ca/types-of-seizures/>
- Information on ketogenic diet therapies: <https://www.matthewsfriends.org/>
- Spark sheets (available in English and French): <https://epilepsyontario.org/research-and-resources/spark-sheets/>
- Canadian League Against Epilepsy: <https://claegroup.org/>

About EpLink

EpLink is dedicated to reducing seizures and improving quality of life for people with epilepsy through research. We have over 25 researchers and dozens of collaborators from eight universities and hospitals across Ontario working to improve drug, diet and genetic therapies, surgical outcomes, brain monitoring and modulation, and quality of life for people with epilepsy. We work with industry partners, patients, caregivers, and community epilepsy agency representatives to bring our research to the community. We also host research talks and public education events to raise epilepsy awareness. For more information about our program, please visit www.eplink.ca.



About the Ontario Brain Institute

The Ontario Brain Institute is a provincially funded, not-for-profit organization that accelerates discovery and innovation, benefiting both patients and the economy. Our collaborative 'team science' approach promotes brain research, commercialization and care by connecting researchers, clinicians, industry, patients, and their advocates to improve the lives of those living with brain disorders. Welcome to Brain Central. Visit www.braininstitute.ca for more information. *Funding provided, in part by, the Government of Ontario.*



About the James Lind Alliance

The James Lind Alliance infrastructure is hosted by the National Institute for Health Research to provide the support and processes for Priority Setting Partnerships (PSPs). PSPs aim to help patients, caregivers and clinicians work together to agree which are the most important treatment uncertainties affecting their particular interest, in order to influence the prioritisation of future research in that area. For further information visit www.jla.nihr.ac.uk



For questions about the report, contact us at:

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