



PARENT/CAREGIVER EPILEPSY NEEDS ASSESSMENT SURVEY RESULTS

OCTOBER 2021

Report Prepared By
BC Epilepsy Society



About Our Survey

Caregivers of people living with epilepsy can encompass a wide variety of individuals, including parents, legal guardians, spouses, partners, children, siblings, other family members, friends, neighbours, etc.

All caregivers, regardless of the relationship they have to the person they care for, would do almost anything to ensure that the needs of the person that they care for are met. Because of this, their own needs may be lost in the process, as their focus is primarily geared towards the needs of another person.

However, it is immensely important for the caregiver to also prioritize their own care and well-being as they only have the capacity to care for others when their own needs are being taken care of.

In June 2021, the BC Epilepsy Society released the Parent/Caregiver Epilepsy Needs Assessment Survey so that we could find out what parents and caregivers of people with epilepsy need to ensure that we can best help them and the people that they care for through our programs and services.

WHAT IS EPILEPSY?

Epilepsy is a neurological disease that causes recurring seizures. A seizure is the sudden, brief and temporary disturbance of electrical activity in the brain.

According to the International League Against Epilepsy (ILAE), someone is considered to have epilepsy when they have at least two unprovoked seizures occurring more than 24 hours apart or one unprovoked seizure and an increased risk of future unprovoked seizures.

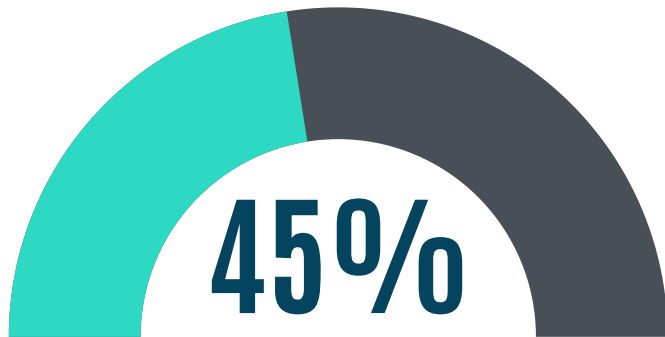
Epilepsy is one of the most common neurological diseases, affecting about 1% of the global population. There are over 65 million people living with epilepsy worldwide; over 3.2 million people living with epilepsy in the United States; over 380,000 people living with epilepsy in Canada; and over 50,000 people living with epilepsy in BC.

Epilepsy and seizures are very common. It has been found that 1 in 12 people will experience a seizure during their lifetime and that 1 in 100 people will develop epilepsy during their lifetime.

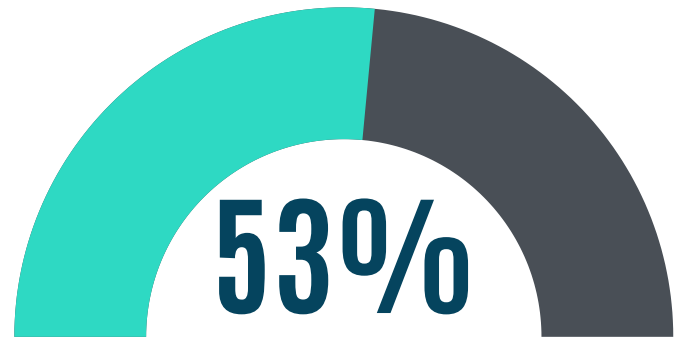
Epilepsy does not discriminate. Epilepsy can be developed at any time by any person of any age, stage of life, gender, race, ethnicity, religion, sexual orientation, socioeconomic status or geographic location.



Who Took Our Survey?



of respondents were the parent or caregiver to a child or youth with epilepsy

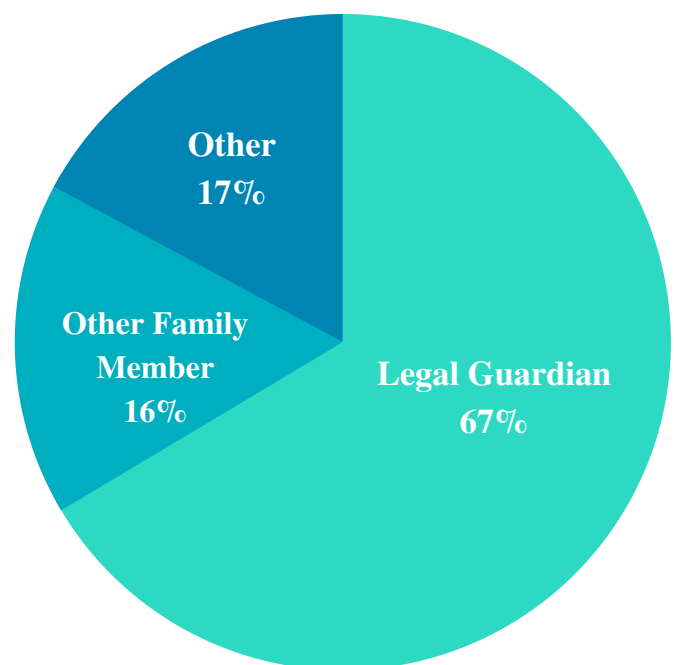


of respondents were the parent or caregiver to an adult with epilepsy

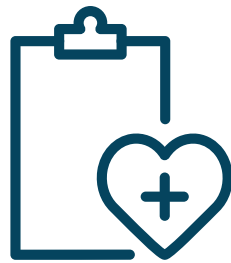


of respondents were the parent or caregiver to a senior with epilepsy

What is your relationship to the person you care for?

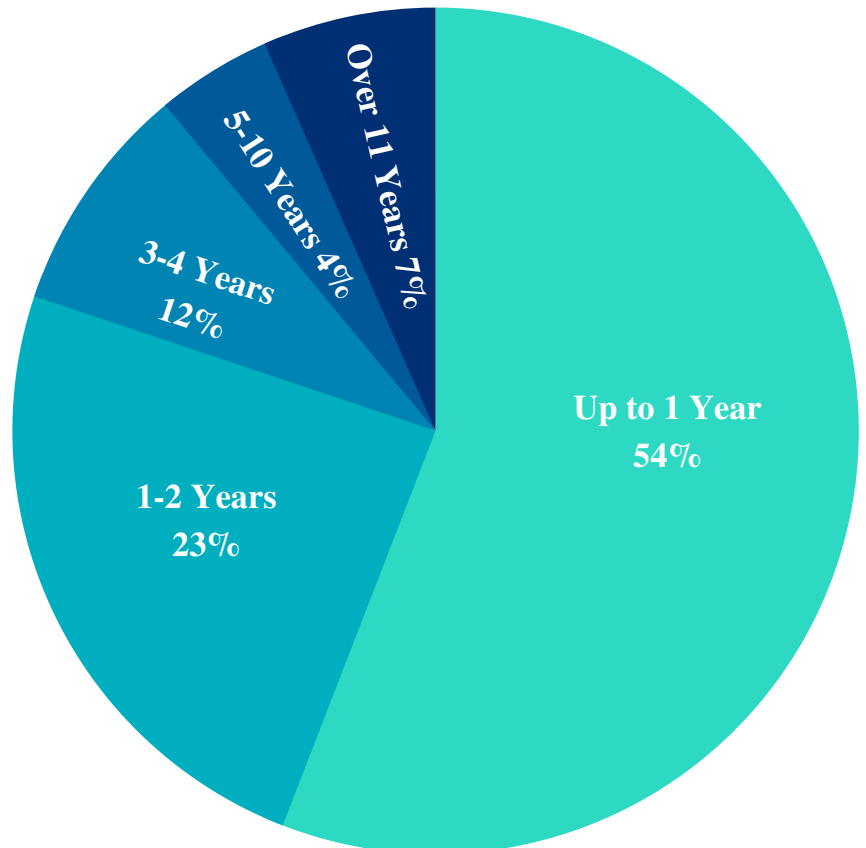


DIAGNOSIS



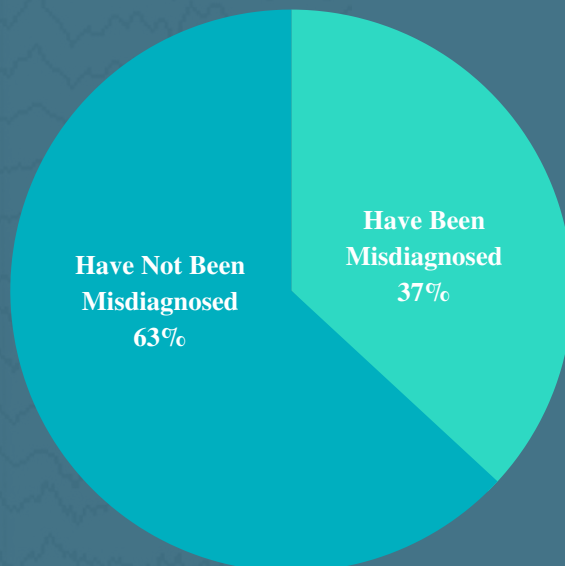
46% OF RESPONDENTS REPORTED THAT IT TOOK OVER 1 YEAR FOR THE PERSON THAT THEY CARE FOR TO GET A CORRECT DIAGNOSIS OF EPILEPSY

HOW LONG DID IT TAKE TO GET A CORRECT DIAGNOSIS?



Misdiagnosis

For most people, their journey with epilepsy begins with being misdiagnosed. While epilepsy is one of the most common neurological diseases, it is still often misdiagnosed. There are many conditions that people may be incorrectly diagnosed with, such as Psychogenic Non-Epileptic Seizures (PNES), Tourette's Syndrome, meningitis, encephalitis, migraine, sleep disorders, brain injury, various mental health conditions, etc., before they are correctly diagnosed with epilepsy.



37%

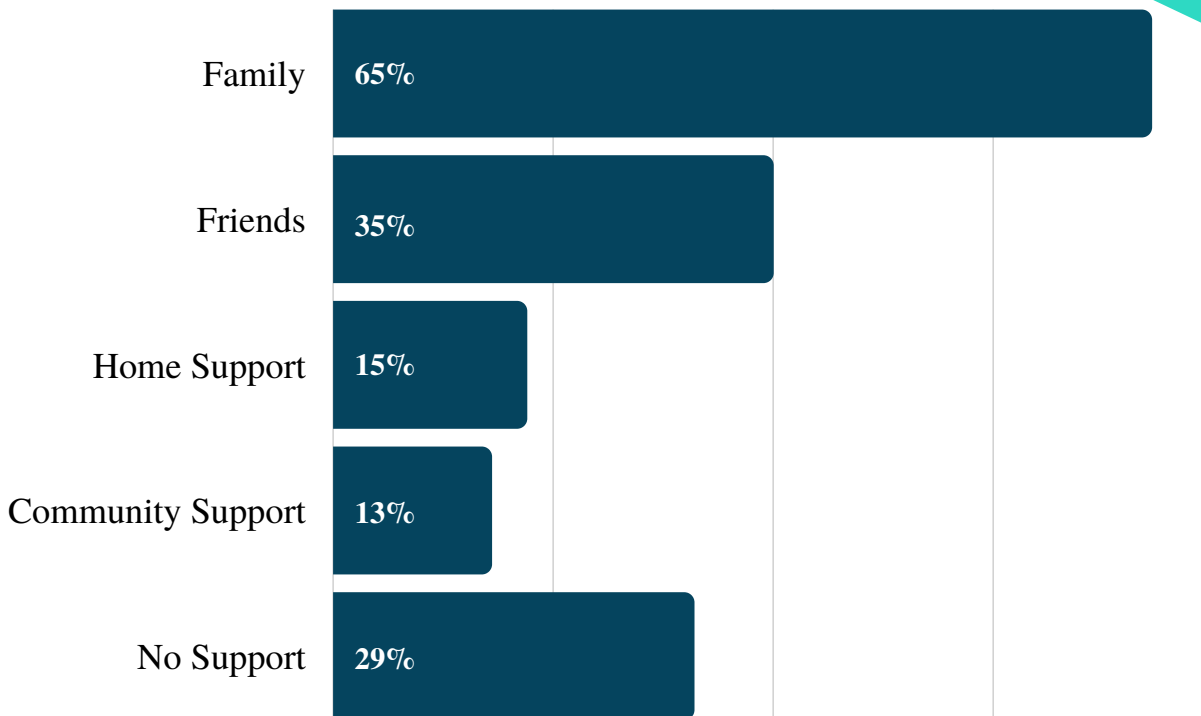
OF RESPONDENTS INDICATED THE PERSON THEY CARE FOR HAD PREVIOUSLY BEEN MISDIAGNOSED

63%

OF RESPONDENTS INDICATED THE PERSON THEY CARE FOR HAD NOT BEEN MISDIAGNOSED

Due to the fact that a parent/caregiver answered this question, we believe that the person living with epilepsy may have a different answer.

What Support Network(s) Do You Have?



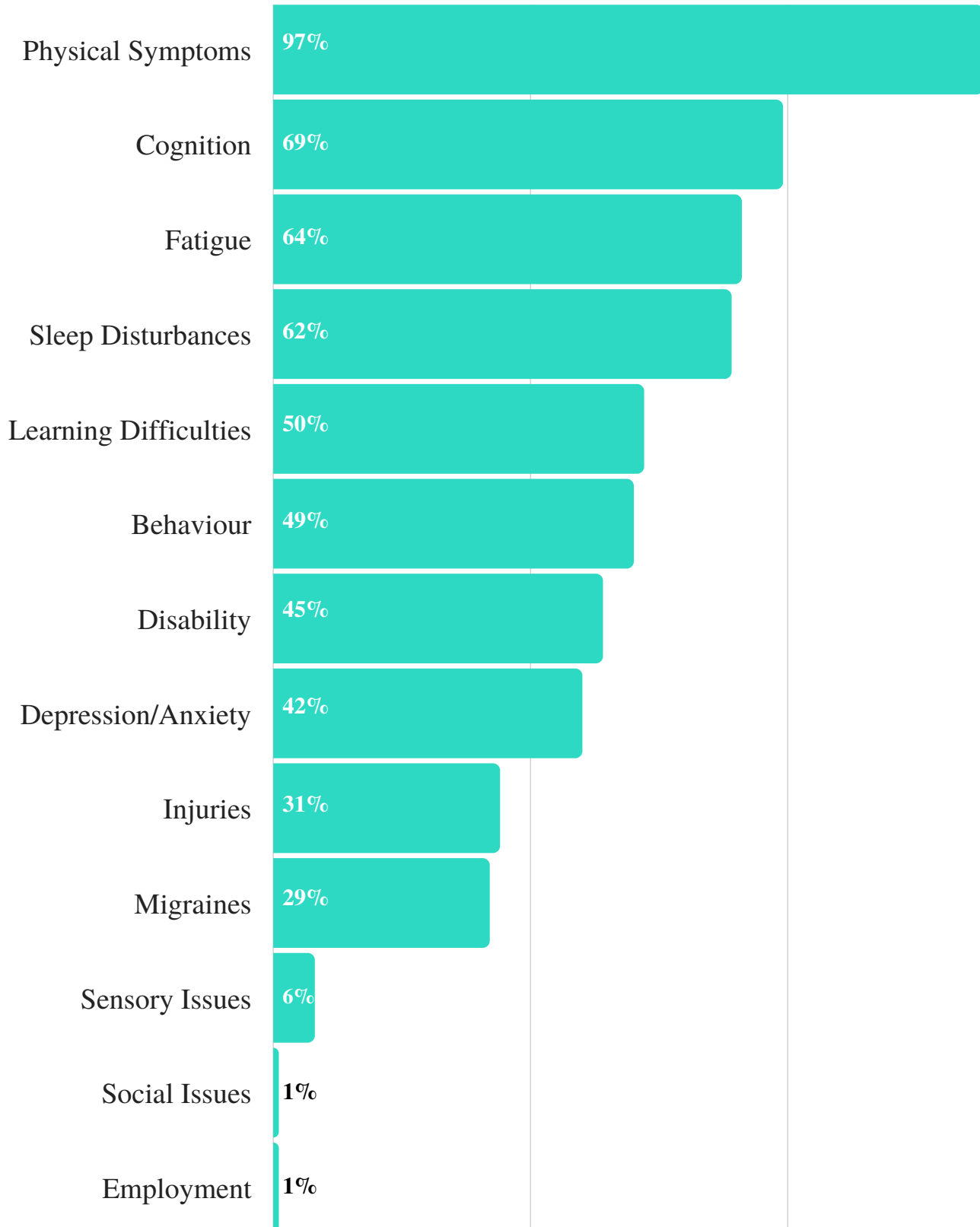
"DUE TO COVID, MY SOLE SOURCE OF SUPPORT HAS BEEN MY CHILD'S OTHER PARENT."

"I NO LONGER HAVE RESPITE SUPPORT BECAUSE OF COVID."

"MY HUSBAND AND I ARE OUR ONLY SUPPORT NETWORK."

EPILEPSY ... More Than Just Seizures

WHAT SYMPTOMS OR HEALTH EFFECTS DOES THE PERSON YOU CARE FOR EXPERIENCE DUE TO THEIR EPILEPSY?



HE NEEDS A FRIEND SO BADLY TO HELP LIGHTEN THE BURDEN OF BEING AND FEELING ALONE.

SOME THINGS EXISTED BEFOREHAND BUT NOW HAVE BECOME NOTICEABLY WORSE/ELEVATED.

HAS MULTIPLE DISABILITIES ... THE SEIZURE DISORDER IS JUST ONE PART.

IN ADDITION TO SEIZURES, EXPERIENCES HEADACHES, BLURRY VISION, NUMBNESS/TINGLING IN BODY, NAUSEA AND APHASIA.

NEUROLOGICAL REGRESSION. SENSORY DISTURBANCES. POST SEIZURE PARALYSIS.

I DO NOT HAVE SUPPORT.

WAITING TO SEE AN EPILEPTOLOGIST - 9 MONTHS!

WE ARE ON THE WAITLIST FOR OTHER SUPPORTS

I DID NOT REALIZE THERE WAS AN ADULT EPILEPSY PROGRAM TO TRANSITION INTO ...

WOULD LIKE TO SEE OTHER HEALTH CARE PROFESSIONALS BUT THERE IS A SHORTAGE IN BC.

INJURIES FROM FALLS DUE TO SEIZURES CAN INCLUDE BROKEN BONES, CHIPPED TEETH, CONCUSSIONS AND OTHERS.

WE WENT TO MONTREAL FOR SCOPE BRAIN SURGERY BECAUSE IT WAS NOT AN OPTION IN BC.

SUSTAINED A BRAIN INJURY DUE TO A POST-OP STROKE.

EXPERIENCES SOCIAL ISSUES.

MY SON AND I HAVE BEEN ON OUR OWN WITHOUT A HEALTH CARE TEAM TO SUPPORT US!

IT TAKES US OVER 6 HOURS TO GET TO THE EPILEPSY CLINIC.

MY KIDS SITUATION IS SUPER SEVERE ...

I DIDN'T KNOW GOING TO THE EPILEPSY CLINIC WAS AN OPTION!

HE CAN'T WORK.
MY HUSBAND AND I ARE OUR SUPPORT SYSTEM.

GOING TO THE EPILEPSY CLINIC WITH A 2 HOUR FLIGHT AND HAVING TO STAY IN A HOTEL ROOM IS EXPENSIVE.

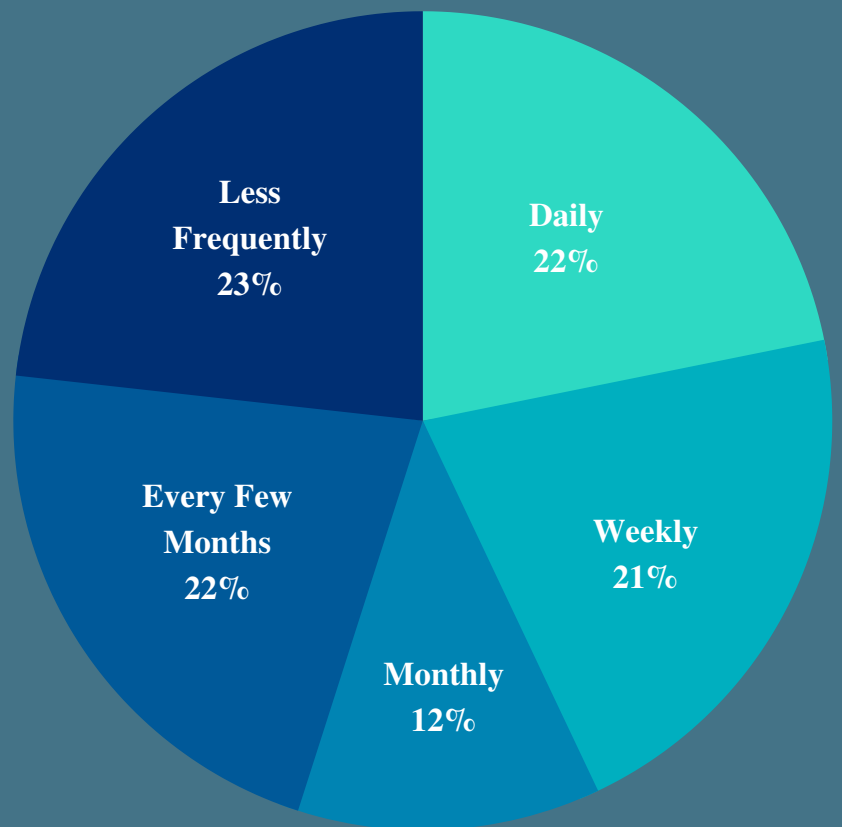
GETTING TO THE EPILEPSY CLINIC DEPENDS ON TRAVEL PLANS: FLIGHT OF 3 HOURS. DRIVE OF OVER 18 HOURS.

WE ARE 1100 KM AWAY FROM THE EPILEPSY CLINIC!

Crisis Mode

"CRISIS MODE" WAS DEFINED IN THIS SURVEY AS THE PARENT OR CAREGIVER FEELING OVERWHELMED AND DESPERATE WHILE THE SYMPTOMS OF THE PERSON THAT THEY CARE FOR WERE OUT OF CONTROL

How often do you enter crisis mode?



77% OF RESPONDENTS
reported entering crisis mode on a regular basis



Epilepsy Clinics in BC

There are two epilepsy clinics in BC: a pediatric epilepsy clinic at BC Children's Hospital in Vancouver, BC and an adult epilepsy clinic at Vancouver General Hospital in Vancouver, BC.



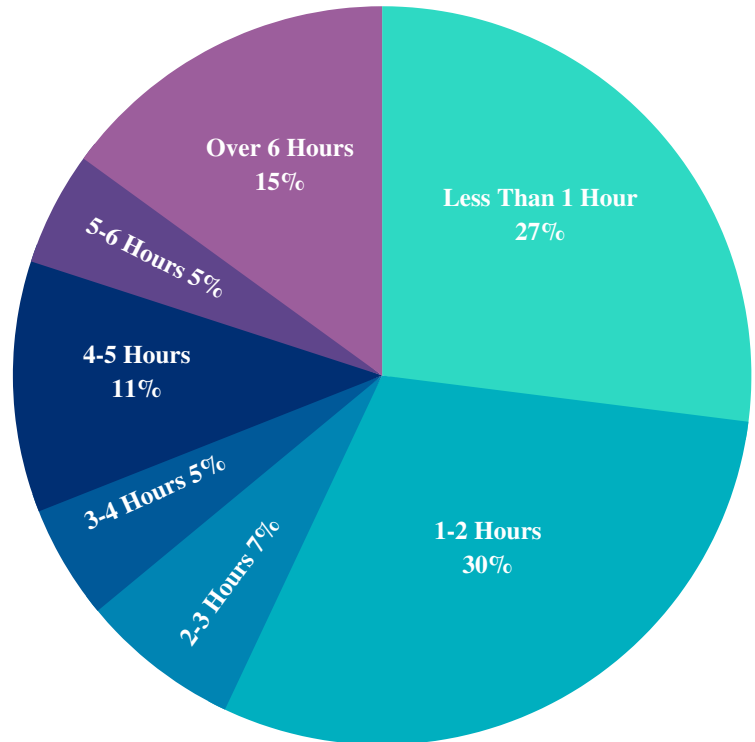
Travel & Medical Services



65%

of respondents reported the person with epilepsy that they care for had been seen at either the pediatric or adult epilepsy clinic in BC

How Long Did You Have To Travel To Get There?



"A FLIGHT OF 2 HOURS AND THEN HAVING TO STAY IN A HOTEL ROOM OVER PERIOD OF TIME ... IT IS EXPENSIVE."

"IT DEPENDS ON OUR TRAVEL PLANS: FLIGHT IS 3 HOURS AND DRIVE IS OVER 18 HOURS."

"WE LIVE 1100 KM AWAY!"

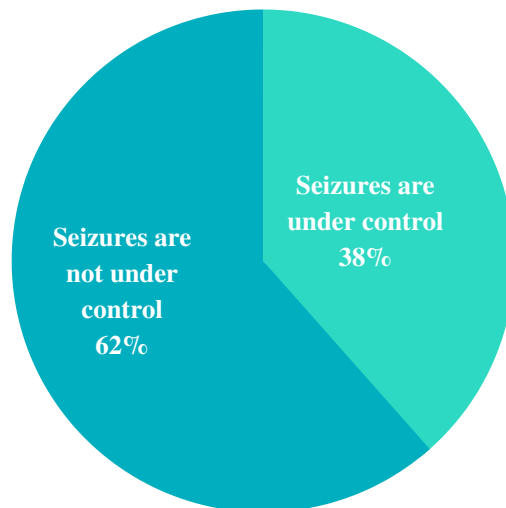




Seizure Control

It has been found that **65% of people living with epilepsy** live with **drug-controlled epilepsy**, meaning that they are able to achieve optimal seizure control through the use of Anti-Epileptic Drugs.

The remaining **35% of people living with epilepsy** live with **drug-resistant epilepsy** meaning that Anti-Epileptic Drugs do not work to control their seizures and they continue to live with uncontrolled seizures, leading to immense health challenges for them and burdens on their parents or caregivers.



38%

OF RESPONDENTS INDICATED THE PERSON THEY CARE FOR HAS ACHIEVED SEIZURE CONTROL

62%

OF RESPONDENTS INDICATED THE PERSON THEY CARE FOR DOES NOT HAVE THEIR SEIZURES UNDER CONTROL

44%

of respondents were not familiar with programs and services provided by the BC Epilepsy Society





Our Programs and Services:

- In-Person and Online Support Groups
- Epilepsy Friends Forever (EFF)
- BC Epilepsy Parents Network (BCEPN)
- BCES Men's Circle
- BCES Women's Circle
- BCES Young Adult Circle
- Partners in Teaching Program
- Clinic Support Services Program
- Epilepsy Surgery Peer Connection Program
- Bursary Program
- Summer Camp Subsidies Program
- Women in Mind Program
- International I AM A VOICE for Epilepsy Awareness™ campaign
- What If ... Documentary Series
- Voice Epilepsy™ Podcast Series
- Educational Events
- Multilingual Resources
- Lending Library of Resources
- Regular Blogs and E-Newsletters

ABOUT THE BC EPILEPSY SOCIETY

The BC Epilepsy Society is a provincially incorporated non-profit organization and a federally registered charitable organization dedicated to serving the over 50,000 people living with epilepsy in BC and their families, friends, and loved ones.

MISSION:

To empower, educate and support British Columbians living with epilepsy and their families, and support research to make their lives easier.

VISION:

Improving Lives. Inspiring Courage.

WE WANT EVERYONE TO HEAR THIS PLEA FROM ONE OF OUR RESPONDENTS: 'HE NEEDS A FRIEND SO BADLY TO HELP LIGHTEN THE BURDEN OF BEING AND FEELING ALONE' AND KNOW THAT THE ALL OF US AT THE BC EPILEPSY SOCIETY ARE HERE TO HELP YOU AND YOUR LOVED ONES.



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