

Summary Report



The Impact
of Epilepsy on
Canadians

About Epilepsy

Funded by UCB Canada Inc.



Conducted by Leger Marketing



www.legermarketing.com

One in 100

The number of Canadians living with epilepsy ¹

38

The number of Canadians everyday who learn they have epilepsy ²

2nd

After headaches, epilepsy is the most common neurological disorder ³

60%

The percentage of newly diagnosed patients with epilepsy who are either young children or senior citizens ⁴

3rd

Among seniors, epilepsy follows dementia and stroke as being the most common neurological disorder ⁵

30%

Percentage of people living with epilepsy who don't respond to any currently available treatment ⁶

¹ José F. Tellez-Zenteno, Margarita Pondal-Sordo, Suzan Matijevic, Samuel Wiebe (2004), National and Regional Prevalence of Self-reported Epilepsy in Canada, *Epilepsia* 45 (12), 1623-1629.

^{2,4,5} Epilepsy Canada - www.epilepsy.ca

³ World Health Organization and World Federation of Neurology. (2004). Atlas: country resources for neurological disorders. Geneva. World Health Organization.

⁶ National Institute of Neurological Disorders and Stroke - www.ninds.nih.gov

We are grateful to the many Canadians from St. John’s to Victoria who shared their experiences living with epilepsy through this important survey. Their insights confirm that many are still struggling to live well with epilepsy, and importantly, they point to where changes are needed most across the country to improve lives.



In my role as President of the Canadian Epilepsy Alliance (CEA), I strive to fulfill the mission of the organization in addressing the issues of national importance to Canadians living with the disorder. The CEA and its members strive to be a formidable voice for our community and a leading influence in the promotion of service innovation and excellence in epilepsy care across the country.

One of the CEA’s core beliefs is that good health encompasses both social and emotional wellbeing. Through our collective efforts and those of our individual member organizations, we will act on the findings of *The Impact of Epilepsy on Canadians* survey to help ensure the good health of our community.

This survey is the first of its kind in Canada to reveal the impact on the life and health of adults living with epilepsy. We hope its insights provoke thought and action among individuals and governments that will make a difference to the lives of all people touched by the disorder.

As you read through this summary, you will hear the voices of the hundreds of people living with epilepsy who contributed to this survey. Think about what they are saying and consider joining us in advocating for change that will ensure each and every person with epilepsy experiences the same chances, opportunities and respect that many Canadians enjoy and take for granted.

One thing we know to be true is that we cannot bring about the changes needed for the epilepsy community without your support. Stand with us as we ask our governments, and indeed all Canadians, to help us break down the barriers identified by the voices speaking through this survey.

With thanks,

Gail Dempsey, President, Canadian Epilepsy Alliance

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Breaking down the barriers

The survey findings clearly highlight the urgent need to address the many barriers people with epilepsy face – social isolation; employment battles; and lack of access to specialized care, treatments and government services. Educating Canadians about epilepsy will help to reduce stigma and bring greater recognition and understanding of the challenges people living with epilepsy face every day.

Improving care and support options

A gap in knowledge among healthcare providers and patients alike results in epilepsy diagnosis taking considerably longer than is safe or acceptable, compounding health problems. The earlier epilepsy can be diagnosed, the faster quality care can be provided.

Increased access to specialist care must be a top priority, as should access to social services and government disability programs, which are in high demand, but short supply. The CEA wants those with epilepsy to demand the best possible specialized care, treatment and social support, and urges all governments to work with the epilepsy community to develop and implement epilepsy guidelines and standardize care.

Better control for seizures

It's time for Canadians to take a stand in support of those living with epilepsy.

It can be a manageable condition. With access to specialized care and treatment, many people living with epilepsy can achieve seizure control. With the right support, those with the condition can lead more fulfilling and productive lives.

The Canadian Epilepsy Alliance encourages:

- All Canadians to eliminate the stigma facing those living with epilepsy by supporting greater public education and awareness about the disorder
- All levels of government to ensure access to all safe and effective treatment options for optimal seizure control
- All Canadians living with epilepsy to expect and demand the best possible specialized care, treatment and social supports

The first of its kind in Canada, *The Impact of Epilepsy on Canadians* survey was conducted to provide an in-depth look at how Canadian adults living with epilepsy are impacted by the condition in terms of their quality of life, health, and access to care and treatment.

Epilepsy is one of the most common neurological disorders affecting approximately 300,000 Canadians, or one in 100. Despite its wide reach, there is currently a lack of awareness and knowledge about epilepsy, which often leads to social isolation, work barriers and relationship issues. The general public and all levels of government require a better understanding of the impact of epilepsy in order to ensure the correct and best care can be provided to those living with the condition.

This summary provides an overview of the survey findings relating to:

- **The impact of epilepsy on daily life** providing insight into how those living with epilepsy believe job choices and prospects are affected by the disorder, as well as their thoughts and experiences with stigma and discrimination
- **Difficulties faced in accessing specialized care and government services** detailing survey respondents' experiences in receiving a diagnosis of epilepsy, waiting times to see epilepsy specialists, and experiences accessing social services in their community and government disability programs
- **Challenges of seizure control and the health impacts of seizures** highlighting the frequency of seizures, how they are managed, and the health impacts people experience as a result of having epilepsy

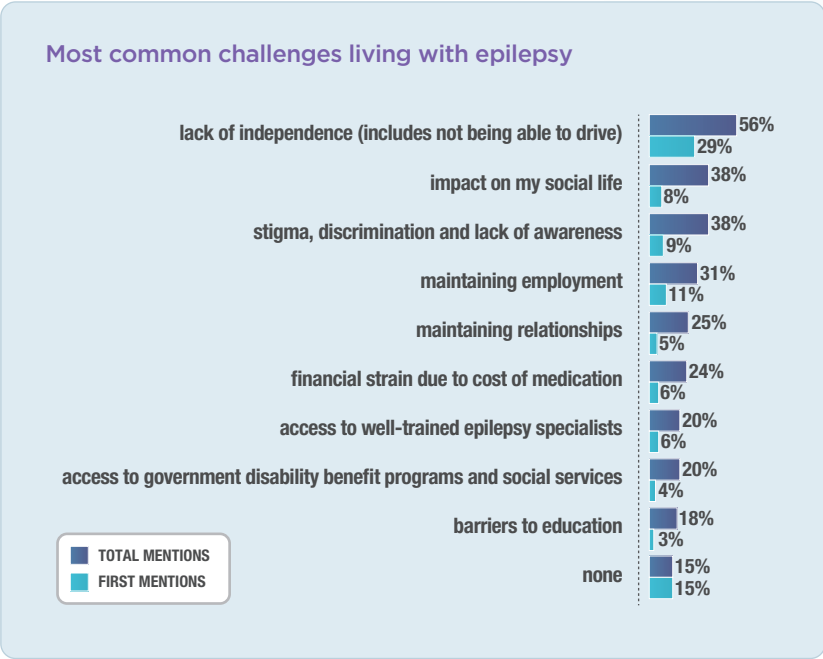
The survey was conducted by Leger Marketing, a leading market research and polling firm. It was completed by 671 adults with epilepsy in both official languages online or on paper between August 9 and October 14, 2011. A probability sample of the same size would yield a margin of error of +/-3.8%, 19 times out of 20.

The survey was funded by UCB Canada Inc., a global biopharmaceutical company focused on the discovery and development of medicines and solutions to transform the lives of people living with severe diseases of the immune system or of the central nervous system.

Challenges of epilepsy on daily life

Living with epilepsy presents many daily challenges. Many Canadians who participated in the survey reported experiencing social isolation, work barriers and relationship issues. Three of the top challenges revealed by *The Impact of Epilepsy on Canadians* survey include:

1. Over half of those surveyed say that restricted independence due to epilepsy is their number one challenge
2. Stigma, discrimination and a lack of awareness about epilepsy is cited by 38% as the number two challenge, along with the impact of the condition on their social life
3. Maintaining employment is cited by 31% as the third major challenge, with half stating their job choices are restricted and just under 40% unable to get a job if they disclose their condition

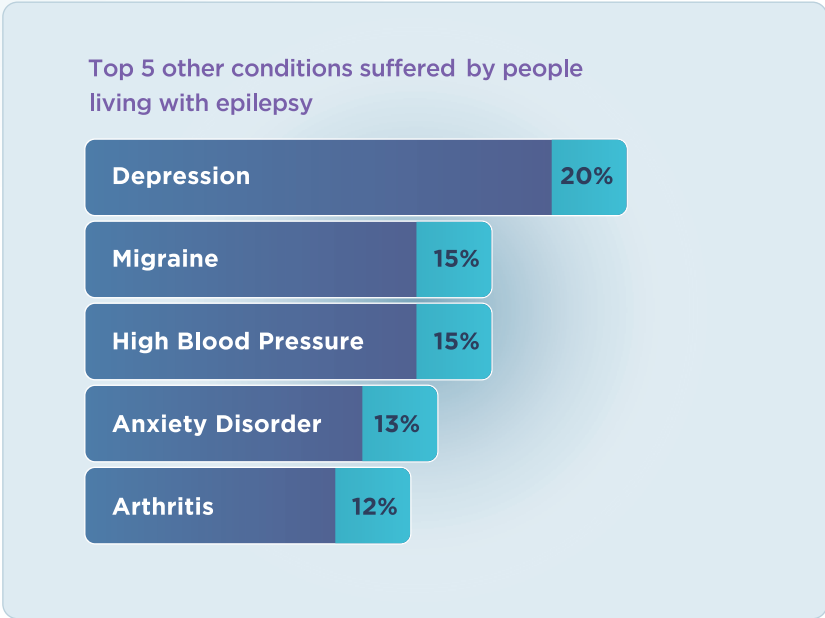


People with uncontrolled epilepsy are much more likely to have lower incomes, many having to get by on less than \$20,000 a year.

“I find it hard to keep a job for long periods of time. Fatigue sets in after a while, as I can’t sleep all that well most nights. I start missing work or becoming frequently late. Also, if I have a seizure, I lose my driver’s license for a period of time.”

Survey respondent

Most people living with epilepsy have also been diagnosed with at least one other condition such as depression, migraines or high blood pressure. For 51%, their condition has been linked to another such as stress, trauma or injury.



“I go through different stages of acceptance. Sometimes I’m angry; sometimes I grieve for things I have lost; sometimes I’m depressed; and sometimes I’m in denial . . . I need to change how I cope based on how I feel at the time.”

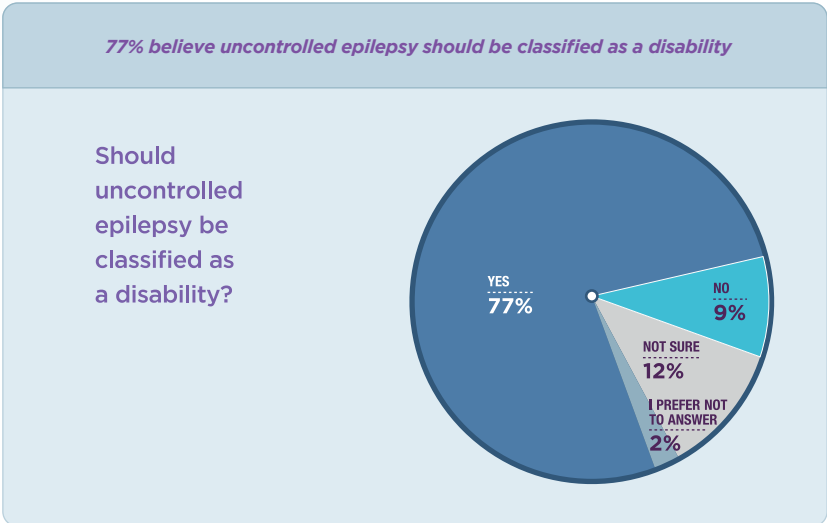
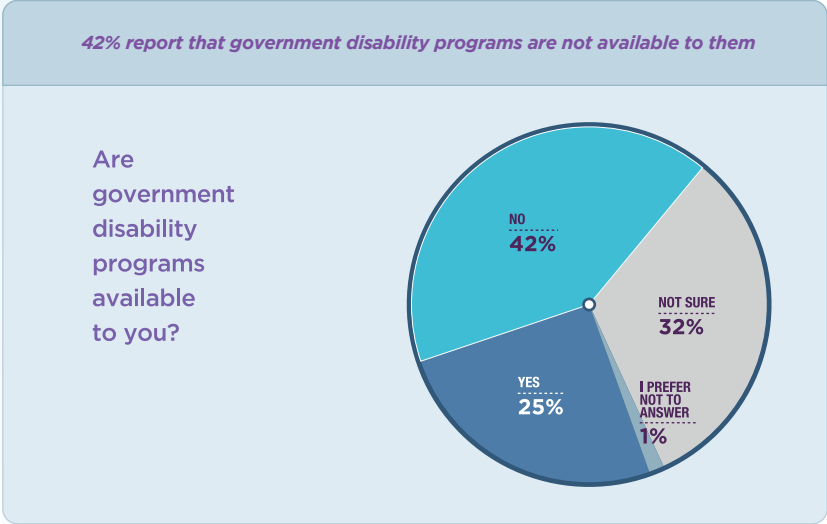
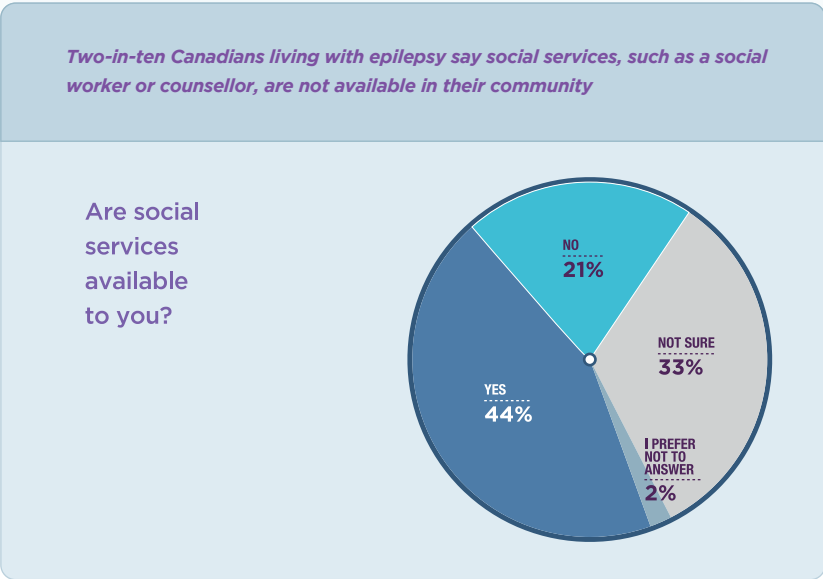
Survey respondent

Access to specialized care and government support

This survey clearly indicates that starting with diagnosis and throughout life, those living with epilepsy require improved access to specialized medical care to maintain a productive and healthy life.

- On average, survey respondents reported waiting nearly four years to be diagnosed with epilepsy, and almost one year to be seen by an epilepsy specialist
- 40% say they see only their General Practitioner (GP) or family doctor regularly, and only 30% have had a consultation with an epileptologist – a neurologist who specializes in epilepsy
- About 60% of the respondents who were candidates for surgery waited up to five years

The survey also shows that access to community-based government support services and disability programs is lacking.

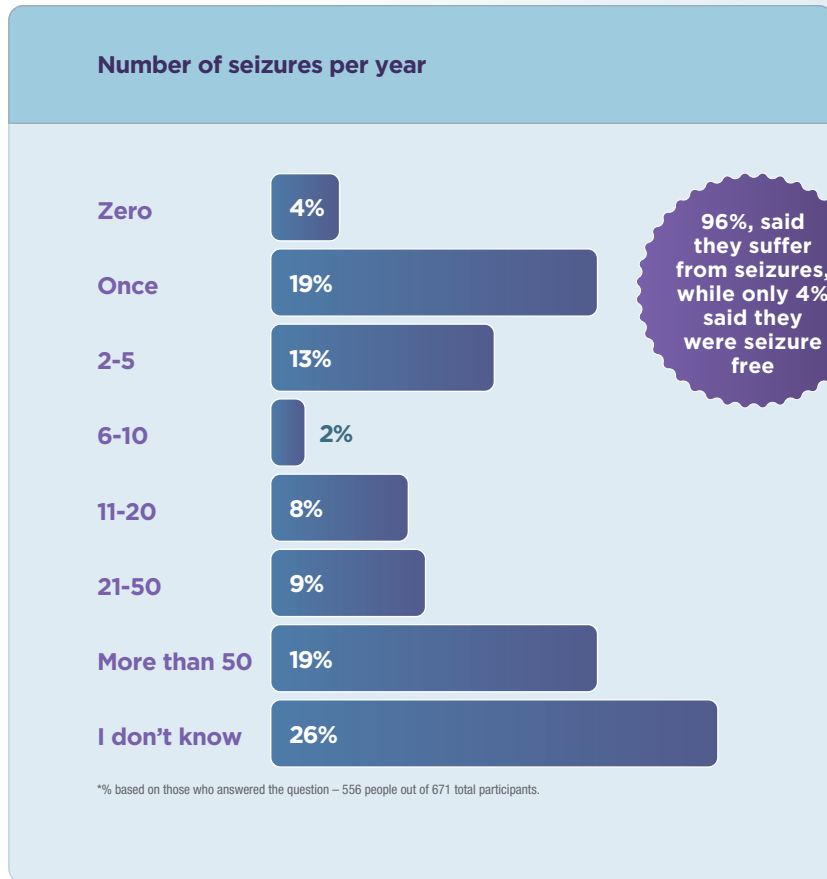


"I only recently heard of epileptologists, but I don't know of any, and cannot find one where I live."

Survey respondent

Seizure control and associated health impacts

The majority of Canadians living with epilepsy continue to endure seizures, which have profound psychological and emotional consequences.



“Until my epilepsy was controlled, I was afraid to go out anywhere because I was afraid of having a seizure. When that happens, people treat you like you are a freak.”

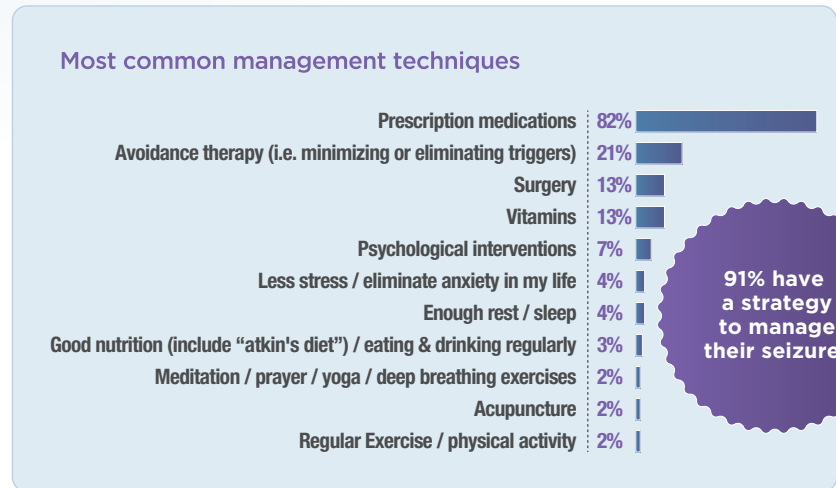
Survey respondent

The survey also underscores that access to new and better treatment options is needed to minimize the impact epilepsy has on those with the disorder.

A very high percentage (82%) of those living with epilepsy said they rely on medications to manage their seizures. Those respondents also reported being prescribed an average of four different drugs since diagnosis to help manage their seizures.

The top four negative health impacts reported by those with epilepsy include:

- medication side effects – 63%
- memory impairment – 60%
- injuries – 44%
- learning difficulties/cognitive decline – 40%



“I am not sure if it’s the medication or the effects on my brain from having seizures, but I have a hard time remembering events and names of people. My confidence level in my ability to do things is undermined because of epilepsy.”

Survey respondent



West

- Westerners (23%) are more likely to pay out-of-pocket for their medication vs. Quebec (8%)
- People living with epilepsy in Western Canada (61%) are less likely to indicate that they're getting the best possible care vs. Quebec (82%)
- Western residents are least likely to have seen a neuropsychologist vs. Quebec and Ontario (12% in the West vs. 21% in Ontario and 23% in Quebec)



Quebec

- Quebec residents are more likely to be seeing a specialist regularly (84%) – especially a neurologist (68%). On average, 68% of Canadians regularly see a specialist for treatment, the most common being a neurologist (53%)
- Quebecers are most likely to indicate that government disability benefit programs are not available to them (70% vs. 33% in the West, 31% in Ontario and 15% in Atlantic Canada)
- At 70%, Quebec residents are least likely to believe that uncontrolled epilepsy should be classified as a disability. (80% in the West and Ontario and 83% in Atlantic Canada)



Ontario

- Ontarians are more likely to agree that they cannot get a job if they disclose they have epilepsy vs. Quebec (46% vs. 30% respectively)
- People in Ontario are more likely to mention the biggest challenge they face is lack of independence (61% vs. 48% in the West and 51% in Quebec)
- Ontarians living with epilepsy have been prescribed a higher number of drugs in the past (4.3 vs. 3.6 for those in the West and Quebec)



Atlantic

- It took Atlantic Canadians much longer, on average, to be diagnosed with epilepsy, relative to those living in any other region (6.8 years vs. 2.8 in Quebec, 3.3 in Ontario, and 3.5 in the West)
- Atlantic Canadians are less likely to have seen a neuropsychologist (8% vs. 12% in the West, 21% in Ontario and 23% in Quebec)
- Atlantic Canadians are more likely to drive more than 100 km to see an epilepsy specialist vs. Quebec (30% in Atlantic Canada vs. 11% in Quebec)



For more information
and for local support:

Canadian Epilepsy Alliance
1-866-EPILEPSY (374-5377)
www.epilepsymatters.com

**The Impact of Epilepsy on Canadians survey and the production of this
summary booklet was funded by UCB Canada Inc.**