



THE IMPACT OF EPILEPSY ON CANADIANS SURVEY

Background Information

What is the *Impact of Epilepsy on Canadians* survey?

The *Impact of Epilepsy on Canadians* survey, the first of its kind in Canada, was conducted to provide an in-depth look at how Canadian adults living with epilepsy are impacted by the disorder with respect to quality of life, health and access to care and treatment. The survey was completed by 671 respondents in both official languages on-line 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 conducted by Leger Marketing by funds received from UCB Canada Inc.

Why is the *Impact of Epilepsy on Canadians* survey important?

Epilepsy is one of the most common neurological disorders affecting approximately 300,000 Canadians (or 1 in 100). Despite the wide reach of this debilitating condition, there is currently a lack of awareness and knowledge about epilepsy, leading to social isolation, work barriers and relationship issues. The general public, all levels of government and those living with the disorder require a better understanding of the impact of epilepsy in order to properly care for those living with the condition.

What are the key findings of the *Impact of Epilepsy on Canadians* survey?

Impact on daily life:

- Just over half of respondents say their independence is restricted – 56% mentioned it as their #1 challenge
- Stigma, discrimination and the lack of awareness about epilepsy among Canadians was mentioned as the #2 challenge faced by 38% of respondents, along with the impact of the disorder on their social life
- Half of respondents say their job choices are limited, and just under 40% say they can't get a job if they disclose that they have epilepsy
- 77% believe uncontrolled epilepsy should be classified as a disability

Specialized care and government support:

- On average, respondents report waiting nearly four years to be diagnosed with epilepsy, and almost one year to be seen for the first time by an epilepsy specialist
- 40% see only their GP or family doctor regularly for treatment for epilepsy, and only 30% have had a consultation with an epileptologist (a neurologist who specializes in epilepsy)
- Two in ten Canadians with epilepsy say social services are not available in their community, and 41% say government disability programs are not available to them

Seizure control and health impacts:

- Nearly all (96%) of those who responded to a question about seizure frequency reported that they suffer from seizures, with only 4% reporting being seizure free
- Of the 60% who were able to calculate their seizure frequency, 16% have more than 50 seizures a year (one seizure per week)
- Negative health impacts of epilepsy include medication side effects (63%) and memory impairment (60%), followed by injuries (44%) and learning difficulties/cognitive decline (40%)
- Most (82%) say they depend on medications to manage seizures and have been prescribed an average of four since diagnosis, so more options are needed



What are the regional disparities found in the *Impact of Epilepsy on Canadians* survey?

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)

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)

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)

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)

What can be done to improve the lives of people with epilepsy?

The Canadian Epilepsy Alliance (CEA) 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 options for optimal seizure control
- All Canadians living with epilepsy to expect and demand the best possible specialized care, treatment and social supports

Please visit www.epilepsymatters.com for more information and to locate your community epilepsy support organization.

**The survey, conducted by Leger Marketing, the largest solely Canadian owned polling and market research firm, was completed on-line or on paper between August 9 and October 14, 2011. 671 respondents participated in the survey in both official languages. A probability sample of the same size would yield a margin of error of +/-3.8%, 19 times out of 20.*