



Pre-Budget Submission to the Government of Ontario

epilepsy
ontario



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What is Epilepsy?

Epilepsy is a chronic neurological condition affecting over 95,000 people of all ages in Ontario. Anyone who has had 2 or more unprovoked seizures, one seizure with a high probability of having another, or has been diagnosed with an epilepsy syndrome, has epilepsy.¹

Seizures are sudden bursts of electrical activity in the brain that cause a temporary disturbance in the way brain cells communicate with each other. Seizures can have different appearances depending on where and how much of the brain the seizure affects, including convulsions, strange behaviour, or a lack of awareness.

Epilepsy is treated in a number of ways, typically with antiepileptic medications. However, of the over 6000 people diagnosed with epilepsy every year in Ontario, nearly 2000 will have refractory epilepsy, meaning they won't respond to two or more antiepileptic drugs.² Other treatment options include surgery, modified diets, and neurostimulation. Of people with refractory epilepsy, 12% will die in the first two years following their diagnosis.³

Epilepsy can be a life-long condition. 85% of people living with epilepsy are diagnosed before age 40.⁸

As a result, epilepsy has significant social and quality of life impacts, greater than in many other chronic conditions. It impacts education, employment, and mental health. People with epilepsy are 71% more likely to have a mental health disorder in their lifetime,⁴ with the unemployment rate for people with epilepsy more than 4-times the national average.⁵ Stigmatization and loss of independence are common, and this broader burden is particularly felt amongst individuals who do not have complete seizure freedom,⁶ with over 80% feeling a loss of independence.⁷

People with epilepsy in Ontario are more likely to suffer from social isolation and other mental illness, and they are less likely to be able to work.

(Health Quality Ontario).⁹

Unlike many conditions, epilepsy extends to all aspects of a person's life. The constant fear of having a seizure, social stigmatization, uncertainty about how epilepsy can impact employment, school, relationships, and family can have a profound effect on those living with the condition.

Epilepsy care includes a significant role for patient education, health-coaching, and self-management, with factors ranging from nutrition and fatigue, to depression and stigmatization, involved in controlling seizures and maximizing quality of life.¹⁰

Epilepsy Care in Ontario

Individuals living with epilepsy receive treatment from a variety of medical practitioners, from local family physicians and community neurologists to neurosurgeons at the province's regional and district epilepsy centres. The province recently increased funding to 5 Ontario regional epilepsy surgery centers, generating exciting results; however, fewer than 1% of Ontarians with epilepsy ultimately have surgery.¹¹ The Ministry of Health Critical Care Services Epilepsy Implementation Task Force produced guidelines for comprehensive epilepsy care in the province that recommend the provision of community-based epilepsy education and support as part of the service continuum. Successful seizure management requires informed patient participation in

self-care.

However, the medical community has identified a lack of coherence in the province's epilepsy care, particularly outside the clinical environment, to support the broader social and mental health impacts of epilepsy.

According to the Ontario Health Technology Advisory Committee “people with epilepsy have lower quality of life, family function, and social support as compared to other chronically ill individuals” yet “there is no organized system of care in Ontario for patients with epilepsy, no support system for the patients and their families.”¹² The lack of infrastructure is so significant that participants taking part in the Clinic To Community epilepsy education pilot program had, on average, been diagnosed with epilepsy 9.7 years before entering the program.¹³

Community Epilepsy Agencies across Ontario are working to fill that gap.

In its Provincial Guidelines for Regional Epilepsy Surgery Centres the Epilepsy Implementation Task Force of Critical Care Services Ontario recognized the importance of Community Epilepsy Agencies in the creation of a comprehensive care model for epilepsy:

Because patients with medically-refractory epilepsy almost always suffer from a number of psychosocial comorbidities, social work evaluations, a neuropsychological assessment, and liaison with Community Epilepsy Agencies for support and advocacy are also required...

Community Epilepsy Agencies provide a range of support services to persons with epilepsy and their families. These services include epilepsy information, seizure first aid training, support groups, social opportunities, employment counseling and school advocacy.¹⁴

Across Ontario there are 14 Community Epilepsy Agencies supporting the epilepsy community with varying levels of staff, programs, and resources. However, the need for community epilepsy support does not vary and community epilepsy agencies receive no government funding for core education and counselling services.

Ontario's Community Epilepsy Agencies

Community Epilepsy Agencies throughout the province play a critical role, picking up where the medical system leaves off, creating a support system for when patients leave the hospital or clinic. Their expertise in health-coaching means more thorough epilepsy education than medical practitioners provide, with more flexibility for support outside a clinical environment. Patients continually report the importance of support based in the community, allowing them to receive support where they need it; 87% of Clinic To Community epilepsy education program participants requested that their education presentation take place in the community.¹⁵

That in-depth epilepsy education and health coaching has a significant impact, for patients, their family, and the health care system:

The most formalized epilepsy education program in Ontario to date has been Clinic To Community, a pilot project developed and implemented by Epilepsy Southwestern Ontario. Based on the Alzheimer's First Link Program, this health education program for patients with epilepsy and their families teaches seizure information and self-management. The program also collected significant data about the effectiveness of early intervention.



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- Safety education and first aid training reduce injuries and unnecessary trips to the Emergency Room, easing pressure on hospitals.
- Medication information and seizure reduction plans help manage side-effects, improve medication adherence, and decrease the risk of seizures and the potential dangers of not following medication plans. Self-management education has been shown to be effective, reducing seizure frequency and fear, and improving epilepsy knowledge.¹⁷
- Social and mental health education help identify strategies to minimize the impact of epilepsy on family, education, and employment, and how to address the comorbidities common to living with seizures, particularly the markedly higher rate of mental health disorders in people with epilepsy.¹⁸
- Epilepsy education programs also present the opportunity to identify and work with those patients who may benefit from on-going support through peer-group meetings, one-on-one counselling, and epilepsy education interventions in school or the workplace.

20% of parents and 16% of adults living with epilepsy in the Clinic To Community program had used an emergency department 10 or more times.¹⁶

Ontario's Community Epilepsy Agencies are already struggling to provide these services, with levels varying by community, while receiving no core government funding for education and counselling, relying principally on grants and creative fundraising efforts. This leaves these fundamental services in a precarious situation, open to the shifting mandates of granting organizations and the fluctuations of private fundraising.

By way of comparison, the number of individuals living with Alzheimer's and dementia in Ontario is approximately 33% greater than the number of individuals living with epilepsy, yet the province's Alzheimer's Society chapters receive nearly 45 times the amount of government funding, 93% of which comes from the provincial government.¹⁹ There is no doubt that Ontario's Alzheimer's Society chapters are making a real difference in the lives of the people they serve with programs like Alzheimer's First Link; properly-resourced Community Epilepsy Agencies will make a similar impact in the lives of people living with epilepsy.

An investment in epilepsy education and support programs of this kind through Ontario's Community Epilepsy Agencies will have a major effect on the lives of patients living with epilepsy, putting their needs first, and supporting broader policy goals, including faster and more effective access to education and information, providing integrated support in the community, and reducing unnecessary hospital system usage.

Recommendation 1

An investment of \$3 million per year will fund Ontario's Community Epilepsy Agencies to provide comprehensive epilepsy education programs across the province, including in currently under-served areas, with approximately 1 staff position per 2200 persons living with epilepsy.²⁰

Rationale:

Providing Critical Health Education and Information

Ontario's current healthcare system does not provide comprehensive epilepsy education in a timely fashion, instead Community Epilepsy Agencies serve as a core provider of epilepsy education and health-coaching in Ontario.²¹ Yet due to lack of resources and integration with the broader health system, agencies only serve a fraction of the province's epilepsy patients.

Helping to Sustain the Health Care System by Reducing Unnecessary Usage

Of the major neurological conditions, epilepsy is second only to Alzheimer's/dementia in total direct health-care costs,²² a number that may be unnecessarily high; one study has found that 60% of persons with epilepsy had multiple clinically unnecessary visits to emergency departments each year.²³ These unnecessary visits can be reduced through proper seizure education; of individuals participating²⁴ in the Clinic To Community Epilepsy Education program, 60% had gone to the Emergency Room following a seizure because of fear, while only 20% went because someone else had called an ambulance. Following participation in the program 86% of participants felt more confident about when a seizure is a medical emergency and when it is not.²⁵

Recommendation 2

An additional investment of \$1 million per year would provide longer term counseling and support positions to assist those individuals requiring additional social and mental health services, with approximately 1 staff position per 2000 persons with intractable seizures.

Rationale:

Managing the Chronic Nature of Epilepsy with Coordinated Care in the Community

Epilepsy is not only a chronic condition, it is a complex one, potentially impacting every aspect of a person's life. That's why it is critical that patients receive community-based coordinated and integrated support to meet their needs. 73% of parents with children living with epilepsy in the Clinic To Community program requested follow-up school support.²⁶ Amongst adults living with epilepsy, 64% accessed further support services from the local Community Epilepsy Agency, including programs for employment, mental health, and/or disability supports.²⁷

Ontario's Community Epilepsy Agencies are providing needed community-based education and support to people living with epilepsy, filling a gap in the current healthcare model. With an investment from the provincial government, these services can be solidified and expanded. Well resourced Community Epilepsy Agencies will provide people living with epilepsy faster access to education and information, in the community, and protect the public health system by reducing unnecessary usage.



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- 1 Provincial Guidelines for the Management of Epilepsy in Adults and Children, Critical Care Services Ontario (CCSO)
- 2 Ibid.
- 3 Burneo JG, Shariff SZ, Liu K, Leonard S, Saposnik G, Garg AX. Disparities in surgery among patients with intractable epilepsy in a universal health care system. *Neurology* 2016;86:1-7.
- 4 Tellez-Zenteno, J. F., Patten, S. B., Jetté, N., Williams, J. and Wiebe, S. (2007), *Psychiatric Comorbidity in Epilepsy: A Population-Based Analysis*. *Epilepsia*, 48: 2336–2344. doi:10.1111/j.1528-1167.2007.01222.x
- 5 Mapping Connections: An understanding of neurological conditions in Canada/Statistics Canada unemployment data.
- 6 Report of the OHTAC Expert Panel on a Provincial Strategy for Epilepsy Care in Ontario (August 2011)
- 7 The Impact of Epilepsy on Canadians Leger Marketing, March 27, 2012
- 8 Canadian Community Health Survey–Mental Health, 2012. <http://www.statcan.gc.ca/pub/82-003-x/2016009/article/14654/c-g/c-g01-eng.htm>
- 9 OHTAC Recommendation: Care for Drug-Refractory Epilepsy in Ontario, Ontario Health Technology Advisory Committee, Health Quality Ontario July 2012, p5.
- 10 Self-management in epilepsy: Why and how you should incorporate self-management in your practice
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- 11 Burneo JG, Shariff SZ, Liu K, Leonard S, Saposnik G, Garg AX. Disparities in surgery among patients with intractable epilepsy in a universal health care system. *Neurology* 2016;86:1-7.
- 12 OHTAC Recommendation: Care for Drug-Refractory Epilepsy in Ontario, Ontario Health Technology Advisory Committee, July 2012.
- 13 Living With Epilepsy: Voices From the Community, Epilepsy Southwestern Ontario.
- 14 Provincial Guidelines for Regional Epilepsy Surgery Centres, Critical Care Services Ontario (CCSO) pgs 17, 25.
- 15 Ibid.
- 16 Living With Epilepsy: Voices From the Community, Epilepsy Southwestern Ontario.
- 17 *Shaw EJ, Stokes T, Camosso-Stefinovic J, Baker R, Baker GA, Jacoby A. Self-management education for adults with epilepsy. Cochrane Database of Systematic Reviews 2007, Issue 2. Art. No.: CD004723. DOI: 10.1002/14651858.CD004723.pub2.*
- 18 Tellez-Zenteno, J. F., Patten, S. B., Jetté, N., Williams, J. and Wiebe, S. (2007), *Psychiatric Comorbidity in Epilepsy: A Population-Based Analysis*. *Epilepsia*, 48: 2336–2344. doi:10.1111/j.1528-1167.2007.01222.x
- 19 Based on 2016 CRA filings.
- 20 Based on \$72,762 per FTE position, derived from LHIN record detailing funding for Alzheimer’s Society education programs.
- 21 Living With Epilepsy: Voices From the Community, Epilepsy Southwestern Ontario.
- 22 Mapping Connections p39
- 23 Noble et al, 2013
- 24 Includes adults, and parents of children, with epilepsy.
- 25 Living With Epilepsy: Voices From the Community, Epilepsy Southwestern Ontario.
- 26 Living With Epilepsy: Voices From the Community, Epilepsy Southwestern Ontario.
- 27 Ibid.

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Epilepsy Ontario is the voice of epilepsy in the province. Since 1956, we have been serving the province as a registered health charity incorporated under the statutes of Ontario as a non-profit and non-governmental organization. We aim to raise public awareness and improve education through publications, conferences, outreach initiatives and our website.

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