



2020 Pre-Budget Submission to the Government of Ontario

Submitted January 2020

epilepsy
ontario

Over 95,000 people in Ontario live with epilepsy, with 6000 new cases diagnosed every year. Epilepsy can impact every part of a person's life, including their family, mental health, education, and employment, yet Ontario does not fund community epilepsy health education and support programs. While Ontario's 14 Community Epilepsy Agencies provide education and support programs that improve quality of life and reduce healthcare costs, these agencies rely on charitable fundraising and do not serve nearly as many people as they could if they had the proper resources. Entire parts of Ontario do not have a local epilepsy agency serving them.

By not funding these programs, the province is incurring needless healthcare costs through unnecessary Emergency Department (ED) usage, inpatient stays, and physician costs associated with poor mental health. **An investment of \$3 million per year, for four years, to fund programs at Ontario's Community Epilepsy Agencies will not only pay for itself in reduced healthcare costs, it will contribute an additional \$9.5 million in net savings by the 2023/24 budget year.** This modest investment will produce savings for the province's ledger, and improve the quality of Ontario's healthcare system by:

- **Cutting unnecessary hospital usage and reducing hallway healthcare.** Over 50% of Emergency Department visits for epilepsy are likely unnecessary and can be avoided with basic epilepsy education programs. Even a modest reduction in the nearly 20,000 annual ED visits for epilepsy will achieve millions in savings. As well, patients who have received epilepsy education have fewer and shorter inpatient admissions, saving additional money, freeing up hundreds of bed spaces per year and reducing the hallway healthcare crisis.
- **Improving mental health.** 35.5% of people living with epilepsy will have a mental health disorder in their lifetime compared, to 20.7% for the general population, and up to 55% of people with uncontrolled seizures are affected by depression. Basic mental health interventions, such as Cognitive Behavioral or mindfulness therapy, that can be delivered by trained staff at Community Epilepsy Agencies, or remotely, have been shown to reduce depression scores in people with epilepsy. This approach not only improves quality of life but saves the healthcare system money; even moderate reductions in depression are known to reduce other healthcare system costs, like GP visits.
- **Contributing to Ontario's Autism Strategy and supporting patients with complex needs.** Epilepsy is associated with above average rates of other serious conditions. Up to 30% of people with autism also live with epilepsy, compared to less than 1% of the general population. The Ontario Autism Program Advisory Panel recommendations emphasized that co-occurring conditions can have a multiplier effect on people and families affected by autism. Likewise, older adults who are diagnosed with epilepsy are at an increased risk of being diagnosed with dementia. By ensuring that epilepsy-specific supports exist through Community Epilepsy Agencies, those families impacted by both epilepsy and other serious medical conditions have access to the right resources to address complex needs.

By providing Community Epilepsy Agencies with \$11.9 million over 4 years, Ontario can pay for the program, produce additional savings towards its deficit elimination goal, reduce hallway healthcare, supplement mental health, dementia, and autism services, and ensure people with epilepsy receive the right care in the right place.

Epilepsy Education and Support Program Summary

Total Cost of Program: \$11,965,438

Number of frontline positions funded: 38

Total Clients Seen: Education Program-22,187; Mental Health and On-going Support Programs-11,537

Gross Savings \$21,464,730 by 2023/24

Net Savings (beyond program cost): \$9,499,292 by 2023/24

Background: The State of Epilepsy Community Care in Ontario

Over 95,000 people in Ontario live with epilepsy, 30% of whom do not have effective seizure control. While recurrent seizures are the most obvious effect of uncontrolled epilepsy, epilepsy can impact all parts of a person's life, including their family, education, employment, and mental health. It is also often associated with other conditions, like autism, at a significantly higher rate than the general population.

Like many other chronic diseases, such as Alzheimer's or diabetes, an important component of epilepsy treatment is education and support, outside of the clinical environment, in the community; however, unlike other chronic diseases, community-based education and support programs have not been integrated into Ontario's medical system. This comes despite the government's own guidelines for epilepsy care recognizing that Community Epilepsy Agencies, and the programs they provide, play an integral role in effective epilepsy treatment.

Across Ontario, 14 Community Epilepsy Agencies do the same work as many health charities that receive government funding, providing key information to patients, families, and the community about how to manage a disease, recognize when a situation is, and is not an emergency, and how to respond appropriately. Larger agencies provide support groups and first-line mental health assistance through counselling programs. Yet, these agencies are in a consistently precarious financial situation, relying on charitable fundraising efforts and short-term grants. This means agencies are chronically under-resourced and many parts of the province do not have a local agency serving their community.

Ontario's Community Epilepsy Agencies are recognized by the *Provincial Guidelines for the Management of Epilepsy in Adults and Children*, published by Critical Care Services Ontario, as a key component of the post-diagnosis care plan for people with epilepsy, particularly where there is a new diagnosis or where anti-epileptic medications have not been effective at controlling seizures. The primary intervention delivered by the Community Epilepsy Agencies is a basic epilepsy education program for individuals, and their families, that covers the topics listed in the *Guidelines* that are key to proper management of epilepsy. These topics include:

- Basic seizure First Aid, including when a seizure is not a medical emergency and can be properly managed by family or other individuals, and when it needs to be escalated to contacting 911 or going to an Emergency Department;
- Understanding medications, their possible side-effects, and the importance of adhering to treatment regimes to reduce or control seizure frequency and prevent medical emergencies;

Ontario Health Teams and Epilepsy

Community Epilepsy Agencies have been reaching out to the Ontario Health Teams being formed across the province. While many have expressed interest in epilepsy programs and how they could support the work of the OHTs, a key barrier to integrating Community Epilepsy Agencies into the new model has been the lack of funding from the Ministry of Health, which limits the ability of Agencies to guarantee service levels. This is especially unfortunate given how closely epilepsy programs align with the priorities of many OHTs, such as supporting patients with complex needs, mental health challenges, seniors, and reducing unnecessary ED usage.

- Lifestyle management to better control seizures and reduce safety risks; and
- Broader issues of living with epilepsy, including increased rates of mental health issues and specific challenges that may be faced at school or in the workplace.

These education sessions are typically delivered by qualified staff, such as social workers or health educators, and should be provided to every individual who has been diagnosed with epilepsy and, where appropriate, their family, and people in their classroom or workplace. Sadly, this is not the case in Ontario, as physicians do not have the capacity to deliver a 60- to 90-minute education session and the lack of formal integration of Community Epilepsy Agency programs into the Ontario healthcare system means most patients are not referred to their local agency. A study at Epilepsy Southwestern Ontario found participants in its Clinic to Community epilepsy education program had, on average, been diagnosed nearly 10 years before taking part in the education session.¹ That is nearly a decade of under-management of their epilepsy, with consequence for Ontario's healthcare system and spending.

Community Epilepsy Agencies also provide on-going support programs, particularly to those clients who have complex needs and comorbidities. These supports include facilitated peer groups, advocacy and system navigation, intervention in schools and workplaces and, where the capacity exists, individual and group counselling for mental health issues. These on-going support programs are especially critical for individuals and families impacted by multiple comorbidities, such as autism or depression. Despite this, the service capacity of agencies varies significantly across the province.

With funding for these programs, Epilepsy Ontario and the province's Community Epilepsy Agencies can sustain and increase their service levels, and in the parts of Ontario without a community organization in place, introduce local programs and staff or create networks for remote service delivery, all while reducing healthcare costs for the province.

Reducing Hospital Usage and Costs Through Epilepsy Education

A key component of epilepsy education programs involves seizure first aid training and better knowledge of when a seizure might be considered a medical emergency. A typical seizure, once someone has been diagnosed with epilepsy, is not a medical emergency unless other factors such as an unusually long seizure, injury, or complications such as pregnancy, diabetes, or water are present. Yet thousands of unnecessary Emergency

Community Epilepsy Agencies are vital for continuity of care for patients with epilepsy. More often than not, epilepsy has a significant adverse impact on the psychosocial life of patients, and their families. In order to address this co-morbid aspect of epilepsy care community-based education and support services as provided by the Community Epilepsy Agencies in the Province are an integral part of Ontario's Comprehensive Epilepsy Care system. It is a tribute to the resilience and dedication of these Community Epilepsy Agencies that they have been able to provide these services without core funding to date. I am convinced that provision of sufficient resources from the Ministry of Health to the Community Agencies will enhance the support that they provide to those Ontarians, both adults and children, across the province.

Dr. O. Carter Snead III
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Department visits following a seizure take place annually, contributing to hospital overcrowding.

Of the approximately 20,000 visits every year to Emergency Departments (ED) in Ontario where the main diagnosis is epilepsy², 64% had no medical intervention, including supplemental testing, after arriving at the ED, 73% had no other diagnosis, and only 20% resulted in hospital inpatient admission.³

This situation is especially startling given that a majority of ED visits for epilepsy are made by a minority of patients. Across the province, between 2015 and 2018, 33% of patients going to the ED for epilepsy accounted for 67% of visits. This top 33% made 4 times as many ED visits over almost twice as many years, when compared to the bottom 67%. The unscheduled inpatient admission rate by these high-usage patients was also 50% higher than the average for all unscheduled admissions.⁴

This data demonstrates the potential for saving through epilepsy education programs, especially by focusing a majority of program resources on those high-use patients most in need of education and support. By better educating people with uncontrolled epilepsy, and those around them most likely to call 911, about when a seizure is (and is not) a medical emergency, thousands of potentially unnecessary ED visits can be avoided. Thousands of people with epilepsy in Ontario have been living with uncontrolled seizures, and making unnecessary ED visits, for years because they have not received basic epilepsy education. Even a modest reduction of 33% in the number of ED visits after people take part in epilepsy education programs would save millions in ED costs.

Epilepsy education programs can also impact the hallway healthcare crisis by reducing and shortening unplanned inpatient admissions from the ED. A UK study of similar epilepsy education programs found that patients who were admitted from the ED following a seizure visit did so less frequently and, if they were admitted, remained in hospital for less time if they had participated in the education program. The costs of their admission were 79% lower than if they had not taken part in the program.⁵ Applied to the Ontario system, and again primarily targeting those high-usage clients, would result in over \$1.5 million in annual savings and, more importantly, open up hundreds of inpatient bed spaces per year at a time when hospitals are facing the on-going problem of hallway healthcare.

While epilepsy education programs will be weighted heavily towards the tens of thousands of people in Ontario with uncontrolled seizures who have disproportionately high healthcare usage, a portion will be targeted towards those newly diagnosed individuals and families who are searching for initial assistance and information. As 30% of epilepsy diagnoses are eventually recognized as uncontrolled seizures, these education sessions will help ensure reduced system costs in the future.

Mental Health, Autism, and Other Comorbidities- Supporting People with Complex Needs

While the challenges associated with seizures are often manageable with proper education, many people living with epilepsy also face other difficult medical conditions that are co-occurring with epilepsy, including mental health issues, autism, migraines, and ADHD. These comorbidities are extensive, but by providing community-based supports, patients and families can receive the resources required to manage a portion of their complex health needs.

Autism is also one of the most common co-morbidities associated with epilepsy. Between 10 and 30% of people with autism also live with epilepsy, compared to less than 1% of the general population. The Ontario Autism Program Advisory Panel recommendations emphasized that co-occurring conditions can have a multiplier effect

on people and families affected by autism and that those families affected by these complex needs must have access to the services appropriate to those conditions.

People with epilepsy have an increased likelihood of developing dementia⁶ and seniors are one of the age groups most likely to develop epilepsy. This, combined with the fact that the type of seizures that are typical of new epilepsy diagnoses in seniors can be mistaken for confusion or dementia,⁷ means that proper information about epilepsy is critical for both patients and their support systems.

Mental Health issues are especially common for people with epilepsy. Depression, the most prevalent mental health issue amongst people with epilepsy, affects up to 55% of people with uncontrolled seizures. Anxiety disorders occur at double the rate compared to the general population, and psychosis at 7 times the rate.⁸ The completed suicide rate by people with epilepsy is 30 times that of the general population.⁹

Apart from the obvious impact mental health disorders can have on individual and family life, the financial costs of issues such as depression have on the healthcare system is well documented. People with epilepsy and mild-to-moderate depression make more than twice as many MD and psychiatric visits compared to people with epilepsy and no depression. This number continues to increase if the depression level goes from moderate to severe: the number of MD visits increases by another 59% and psychiatric visits goes up by 570%.¹⁰

Fortunately, the effectiveness of mental health interventions for people with epilepsy is well documented.¹¹ Group and individual counselling, with either Cognitive Behavioral Therapy or mindfulness-based therapies, have received the strong recommendation of the International League Against Epilepsy Psychology Task Force for treating depression and other psychological co-morbidities with epilepsy.¹² With even modest improvements in depression scores by people with epilepsy, such as moving depression scores from severe to mild-to-moderate, healthcare system costs can be reduced.

By ensuring community Mental Health and On-Going Support Programs exist through Community Epilepsy Agencies those families impacted by multiple conditions that may require additional resources have access to the supports necessary to address part of a complex need.

Appendix 1: Program Delivery and Cost/Savings Overview

		2020-21	2021-22	2022-23	2023-24	Total
	FTE Staff	Clients Seen				
High-Usage Clients (top 33%)	20	4000	4250	4500	5000	17,750
New Diagnosis Clients	5	1000	1063	1125	1250	4438
On-going/Mental Health Support	13	2600	2762	2925	3250	11537
Annual Program Cost		\$2,946,861	\$2,976,329	\$3,006,093	\$3,036,154	
Program Cost to Date		\$2,946,861	\$5,923,191	\$8,929,284	\$11,965,438	\$11,965,438
ER Savings ¹³		\$1,311,990	\$2,760,099	\$4,350,919	\$6,178,306	
Inpatient Savings ¹⁴		\$1,410,517	\$1,498,674	\$1,586,832	\$2,038,164	
Mental Health Savings ¹⁵		\$74,191	\$78,828	\$83,465	\$92,739	
Year Gross Savings		\$2,769,699	\$4,337,602	\$6,021,217	\$8,309,210	
Gross Savings to Date		\$2,796,699	\$7,134,302	\$13,155,519	\$21,629,344	\$21,464,730
Net Savings to Date		-\$150,161	\$1,211,110	\$4,226,235	\$9,499,292	\$9,499,292

Appendix 2: Program Budget

	2020-21	2021-22	2022-23	2023-24	Total	% of Budget
Salary & Benefits						
Frontline Program Staff (38 FTE)	\$2,538,338	\$2,563,721	\$2,589,359	\$2,615,252		
Central Program Coordinator	\$71,508	\$72,223	\$72,945	\$73,675		
Data & Information Management Support	\$14,898	\$15,046	\$15,197	\$15,349		
Salary & Benefits Total	\$2,624,744	\$2,650,991	\$2,677,501	\$2,704,276	\$10,657,511	89%
Infrastructure						
Office & Telecom	\$90,673	\$91,579	\$92,495	\$93,420		
Equipment	\$19,950	\$20,150	\$20,351	\$20,555		
Infrastructure Total	\$110,623	\$111,729	\$112,846	\$113,975	\$449,173	4%
Other						
Supplies	\$19,344	\$19,537	\$19,732	\$19,930		
Travel	\$40,299	\$40,702	\$41,109	\$41,520		
Administration	\$151,852	\$153,371	\$154,905	\$156,454		
Other Total	\$211,495	\$213,610	\$215,746	\$217,903	\$858,754	7%
TOTAL	\$2,946,861	\$2,976,330	\$3,006,093	\$3,036,154	\$11,965,438	

1-Includes MERC and benefits at 18% of salary.

2-Includes responsibilities for training, evaluation, and related functions.

Endnotes

- 1 Living With Epilepsy: Voices From the Community, Epilepsy Southwestern Ontario.
- 2 Here epilepsy INCLUDES a visit with a Main Diagnosis code of Epilepsy (G40), or a visit with a Main Diagnosis code of Seizure NOS (R568) IF the patient also had a Main Diagnosis of G40 during the same review period. It EXCLUDES visits with a Main Diagnosis code of Status Epilepticus (G41).
- 3 Per Intellihealth Database
- 4 Ibid.
- 5 Noble AJ, McCrone P, Seed PT, Goldstein LH, Ridsdale L (2014) Clinical- and Cost-Effectiveness of a Nurse Led Self-Management Intervention to Reduce Emergency Visits by People with Epilepsy. PLoS ONE 9(3): e90789. doi:10.1371/journal.pone.0090789
- 6 Sen, Arjune et al. "Cognition and dementia in older patients with epilepsy." *Brain : a journal of neurology* vol. 141,6 (2018): 1592-1608. doi:10.1093/brain/awy022
- 7 Acharya, Jayant N, and Vinita J Acharya. "Epilepsy in the elderly: Special considerations and challenges." *Annals of Indian Academy of Neurology* vol. 17,Suppl 1 (2014): S18-26. doi:10.4103/0972-2327.128645
- 8 Salpekar, Jay A., and Marco Mula. "Common psychiatric comorbidities in epilepsy: How big of a problem is it?" *Epilepsy & Behavior* 98 (2019): 293-297.
- 9 Abraham, N.; Buvanaswari, P.; Rathakrishnan, R.; Tran, B.X.; Thu, G.V.; Nguyen, L.H.; Ho, C.S.; Ho, R.C. A Meta-Analysis of the Rates of Suicide Ideation, Attempts and Deaths in People with Epilepsy. *Int. J. Environ. Res. Public Health* 2019, 16, 1451. .
- 10 The impact of comorbid depression on health resource utilization in a community sample of people with epilepsy. Cramer, Joyce A. et al. *Epilepsy & Behavior*, Volume 5, Issue 3, 337 - 342
- 11 Michaelis R, Tang V, Wagner JL, Modi AC, LaFrance Jr WC, Goldstein LH, Lundgren T, Reuber M. Psychological treatments for people with epilepsy. *Cochrane Database of Systematic Reviews* 2017, Issue 10. Art. No.: CD012081. DOI: 10.1002/14651858.CD012081.pub2.
- 12 Michaelis R, Tang V, Goldstein LH, et al. Psychological treatments for adults and children with epilepsy: Evidence-based recommendations by the International League Against Epilepsy Psychology Task Force. *Epilepsia*. 2018;59:1282–1302. <https://doi.org/10.1111/epi.14444>
- 13 The Intellihealth Database reports an average of 1.32 ED visits per year for the top 33% most frequent (high-usage) patients between 2015 and 2018 and an average of 0.659 annual visits for the bottom 67% (low-usage) patients. Cost/visit reductions use an average cost of Emergency Department visits for epilepsy of \$594.13 per visit in 2016 dollars (and adjusted for inflation for future years). The reduced visit number assumes that 80% of education program clients will be in the high-usage client category, with an average reduction in ED visits per patient per year of 33%, and that 20% of clients will be newly diagnosed, with 30% assumed to be in high-usage client category and 70% in the low-usage category (based on the average rates for uncontrolled and controlled epilepsy). The ED visit reduction is calculated by multiplying the number of clients in the high- or low-usage category by the annual average visit and multiplying the result by 33%. The calculation assumes that the reduction will continue in subsequent years. Cost estimates are derived from a CIHI supplied 2016 reference cost per Main Diagnosis of epilepsy visit, plus estimates of OHIP physician and ambulance billing based on IntelliHealth data and OHIP benefits schedule. CIHI generated average ED cost for patients with epilepsy G40 (2016); excludes physician billing: \$394.65 Physician Assessment Billing Avg, assuming a partial assessment and adjusted for date and time using 2016 as reference year: \$20.71; Consultation Billing Avg, based on average of billing costs for 1st consultations for all G series, using 2016 as a reference year: \$28.03; Ambulance (\$195 per ambulance call, adjusted to reflect 77.3% of G-series ER visits by ambulance): \$150.74. Total (2016): \$594.13. Inflation adjusted costs- 2020-21-\$641.59, 2021-22-\$654.42, 2022-23-\$667.51, 2023-24-\$680.86
- 14 Inpatient cost calculation are based on an average of 0.172 discharges from unplanned admissions per ED visit, per year amongst the high-usage cohort(2172 discharges per 12601 visits), with a median Resource Intensity Weight of 1.461 per discharge (based on IntelliHealth inpatient data) and multiplied against the Cost of a Standard Hospital Stay (2017/18) of \$5,460 . While the UK study notes a cost reduction rate of 79% after participation in an education program, the study also notes a higher ratio of Inpatient admissions to ED visits than Intellihealth notes for Ontario hospitals. The cost reduction calculation has been adjusted to reflect this lower ratio, with an effective cost reduction of 15%. Per Noble AJ, McCrone P, Seed PT, Goldstein LH, Ridsdale L (2014) Clinical- and Cost-Effectiveness of a Nurse Led Self-Management Intervention to Reduce Emergency Visits by People with Epilepsy. PLoS ONE 9(3): e90789. doi:10.1371/journal.pone.0090789
- 15 Based on a cost of \$77.20 and \$20.10 for MD and Psychological visits respectively, per The Schedule of Benefits: Physician Services is a schedule under Regulation 552 of the Health Insurance Act and a reduction in depression severity from Severe to Mild/Moderate Depression, corresponding with a reduction in visits rates from 12.3 to 7.7 per person per year for MD visits and from 4.4 to 0.77 visits for psychological treatments, with a NNT of 5 amongst participating patients and assuming a 1-year only reduction. Assumes 33% of client-load take part in a multi-week group-based CBT or mindfulness therapy program or equivalent. Per Noble AJ, Reilly J, Temple J, et al Cognitive-behavioural therapy does not meaningfully reduce depression in most people with epilepsy: a systematic review of clinically reliable improvement *Journal of Neurology, Neurosurgery & Psychiatry* 2018;89:1129-1137.



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.

Epilepsy Ontario works in partnership with Ontario's Community Epilepsy Agencies:

Epilepsy Durham Region

Epilepsy Niagara

Epilepsy North Bay

Epilepsy Ottawa

Epilepsy Peterborough & Area

Epilepsy Sault Ste Marie

Epilepsy Simcoe County

Epilepsy South Central Ontario

Epilepsy South Eastern Ontario

Epilepsy Southwestern Ontario

Epilepsy Sudbury

Epilepsy Toronto

Epilepsy York Region

Seizure & Brain Injury Centre (Cochrane-Timiskaming)

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