

# Community • • • • • Pathways

for people with seizures and epilepsy



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Jasmine's epilepsy diagnosis was described as devastating to her family. The lack of information provided led to multiple trips to the emergency department by ambulance. Her mother shares their journey to find educational resources and community support.

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# Clinic To Community<sup>®</sup> is a new referral program for individuals with a seizure disorder or a diagnosis of epilepsy.

## The goals of the program are:

- Provide individuals and their family with information about seizures, seizure first aid and epilepsy
- Provide individuals and their family with a network of support services to help everyone in the family to live well with a diagnosis of epilepsy
- Reduce the burden of epilepsy on the family, the health care team and the Ontario economy

## The Four Components of the Clinic To Community Program

### 1) 60 minute education sessions:

Individualized appointments with a Clinic To Community Educator who is specially trained to support individuals and families living with epilepsy.

The Clinic To Community Educator will provide an overview of seizures, epilepsy, risk management including SUDEP and seizure first aid to the entire family.

2) Instructions on how to use a seizure log to document lifestyle, medication adherence and seizure activity.

3) A network of services including support groups, peer to peer linkages, recreation programs, and school and workplace assistance.

4) A series of information sheets filled with strategies to help the person with epilepsy to best manage their condition.

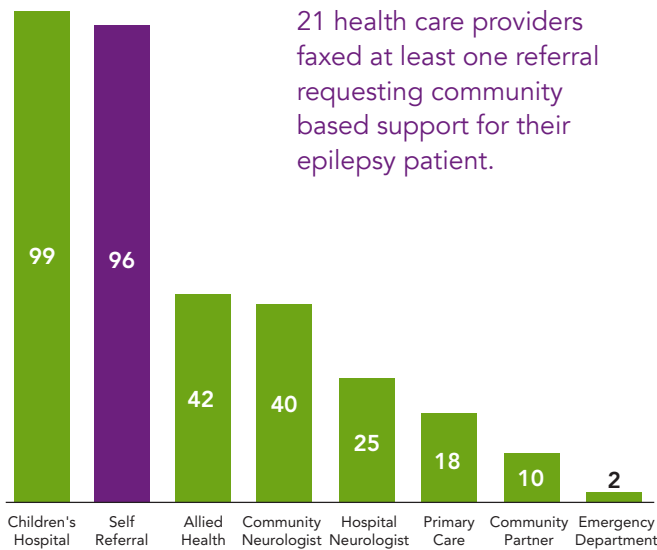


🌱 The program is currently offered to individuals and families who live in the Southwest and Erie St. Clair LHIN.

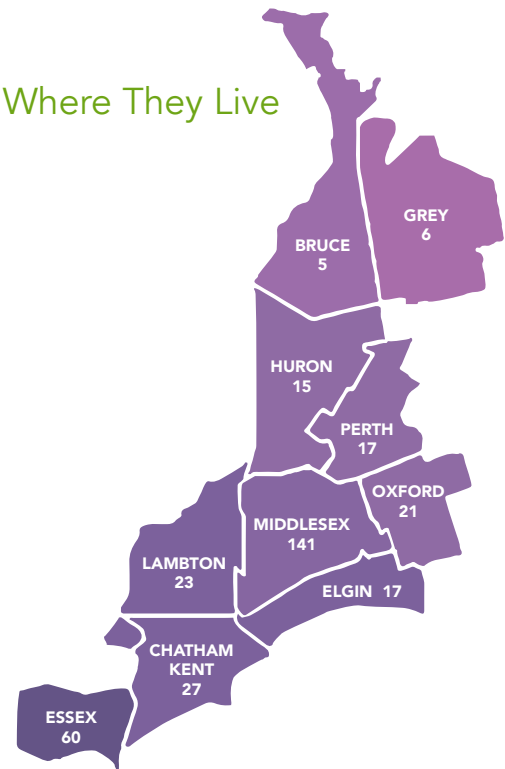
# Year 2 Progress Report

We sent information packages to health care providers in LHIN 1 and LHIN 2 offering to provide education, system navigation, and ongoing support to their epilepsy patients.

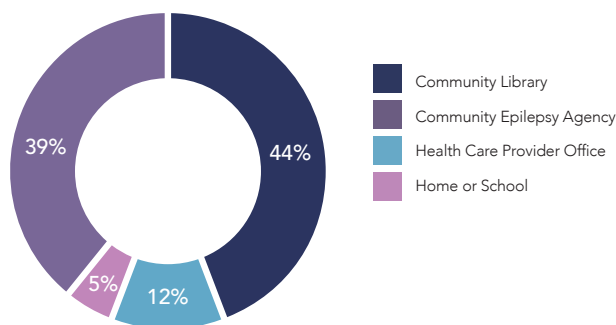
## Referral Pathway



## Where They Live



**332 + 498 = 830**  
 New Clients      Family Members      People have received a 60 minute education session



We offered to meet with the individual living with epilepsy and their family at the clinic or in their community.

88% requested their education session be in the community. Participants commented that it was more convenient and more cost effective. They did not want to pay for clinic or hospital parking, they did not want to feel rushed, they wanted the option of having the appointment in the evening and they wanted to be able to invite other family members to attend.

**98% stated that they wanted the meeting to be in person instead of over the internet or by phone.**

**Face to face interactions enable the patient to verbalize their worries and fears about epilepsy.**

*Cole and Gaspar, 2015, Pascual et al, 2015, Noble et al, 2016*

*"Face to face is best because it is an emotional subject and you can't ask questions to a piece of paper."*

*"I had pamphlets to manage but zero for coping."*

*"It should be an automatic referral after the first seizure."*

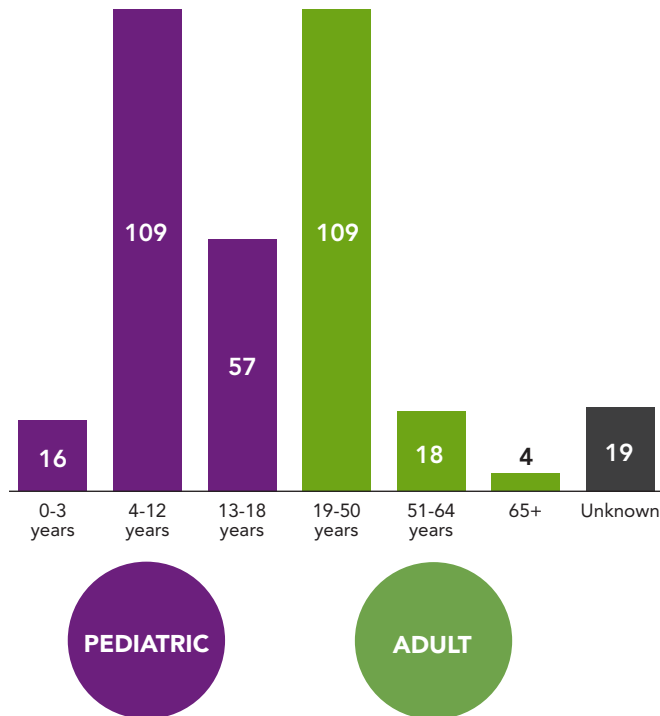
*"It needs to be mandatory."*

*"Now I understand what to look for and feel supported."*

*"Made me realize what to look for and how to handle the diagnosis."*

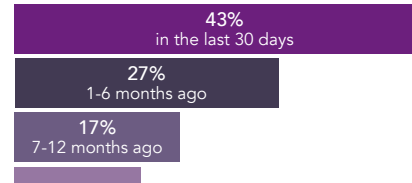
# Profile of 332 Clients

## Ages



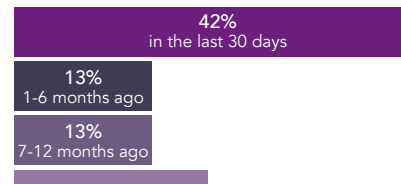
## Seizure Frequency

### Pediatric



87% have active epilepsy

### Adult



68% have active epilepsy

**Active epilepsy:** currently taking medication to control seizures plus 1 or more seizures in the past year.

*In a pediatric population even those children with a single seizure had a reduction in their quality of life compared to those without a history of epilepsy.*

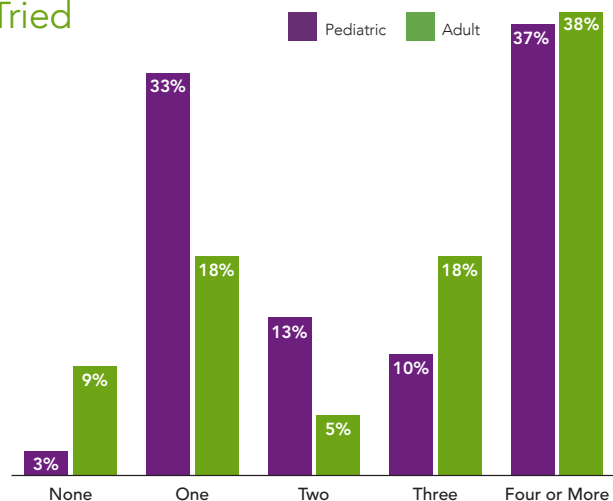
Modi et al, 2009

## Total # of Anti-Seizure Medications Tried

A component of the 'Clinic To Community' program is to help persons living with epilepsy to understand their treatment options which may include special diets or surgery.

"Patients should be educated about the essential role they play in decision making and be given effective tools to help them understand their treatment options and the consequences of their decisions. They should also receive the emotional support they need to express their values and preferences and be able to ask questions without censure from their health care providers"

*IOM Crossing the Quality Chasm: A New Health System for the 21st Century*

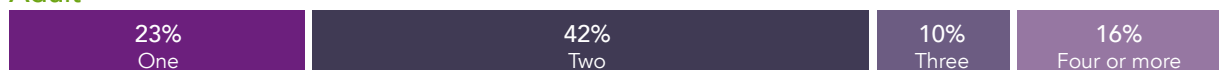


## Current # of Daily Medications

### Pediatric



### Adult



# Jasmine's Story

*Continued from page 1.*

When our son was diagnosed with Type 1 Diabetes we spent the next two weeks meeting with the diabetes interdisciplinary team: Endocrinologist, Diabetes Nurse, Social Worker, Psychologist and Dietitian. We had so much support, we could contact the diabetes team 24 hours a day if we had questions. We were given books, videos, and 'how to' guides. We were referred to the Juvenile Diabetes Research Foundation for ongoing community support. Our extended family members were trained to do injections, count carbs and to test blood sugars. Nurses went to his school to support his teachers.

**When our daughter was diagnosed with epilepsy there was no information and no support.** She was discharged from hospital with a prescription for an anti-seizure medication and a referral to see a pediatric neurologist in 6 months. We were not given any books, videos or 'how to' guides. We were not referred to Epilepsy Southwestern Ontario for ongoing community support. Our extended family members were not trained to recognize a seizure, to provide seizure first aid or to know when a seizure was a medical emergency. No one went to her school to support her teachers. We were in crisis.

**In the 6 months that we waited to see the pediatric neurologist our daughter Jasmine returned to the emergency department by ambulance 5 times.** She had a seizure on the school bus and it was a nightmare. The bus driver called the fire department and the ambulance, the kids were crying and scared. After this event, we were told we had to drive her to school until her seizures were controlled. We tried to enroll her in camp but she was denied (they did not think they could keep her safe because of the number and length of her seizures). Even her friends treated her differently because they were scared.

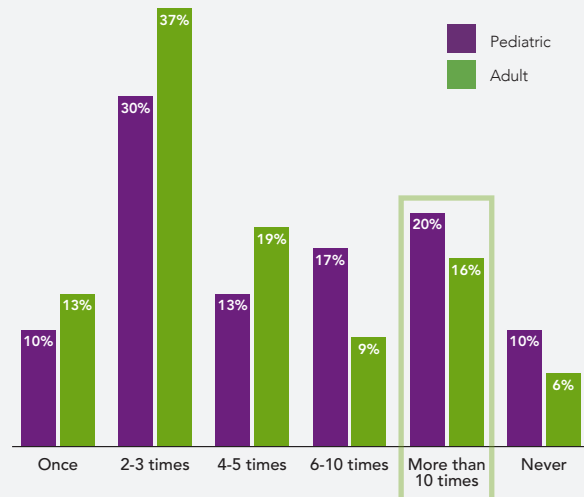
It was easy to cope with our son's Diabetes but our daughter's 'Epilepsy' was devastating our family. A friend told us about Epilepsy Southwestern Ontario. We walked into their office to meet with an epilepsy educator. They provided us with an overview of seizures, treatment pathways and seizure first aid. They met with Jasmine's teachers and gave her class a 45 minute education session about epilepsy. When they became involved with our family everything changed - **we went from crisis to calm, from panicked to proactive.** Epilepsy Southwestern Ontario provided us with educational resources that made much more sense than all of our Google searches. We were able to link with families who could provide support. We were given the information we needed to advocate for our daughter.

**Had we known about Epilepsy Southwestern Ontario from day one...our hospital visits and constant EMS calls could have been avoided.** We were ill equipped to educate teachers and coaches resulting in our child being segregated instead of included. We have helped in the design and delivery of the 'Clinic To Community' program and believe that the program should be funded by the Province and accessible to every newly diagnosed child or adult with epilepsy in Ontario.

Josie Swan-Merrison - Jasmine's Mom



## Emergency Department Use



In Ontario, persons living with epilepsy use primary care and emergency hospital services at significantly higher rates than for other comparable chronic conditions (Ng et al, 2015, Bowen et al, 2012). In a US study, 60% of persons with epilepsy had multiple clinically unnecessary visits to emergency departments each year (Noble et al, 2013). A retrospective chart review of London, Ontario emergency departments identified that 36% of visits with a billing code for 'epilepsy' or 'seizure' were potentially deferrable (Kapoor et al, 2005). In our demonstration project: 20% of the 'Clinic To Community' parents had gone to an emergency room for their child's seizures more than 10 times.



**"After we met with the educator we all felt that we had a better understanding of what to do"**

# Parent Evaluation of Clinic To Community<sup>®</sup> Program

Did meeting with the 'Clinic To Community' educator make you **feel less anxious** about your child's epilepsy diagnosis?



To what extent did the education session help you to **manage** your child's seizures?



Several studies have looked at the health related quality of life (HRQOL) in children with new onset epilepsy and have identified that seizure type, frequency, and epilepsy severity did not have a significant impact on a child's HRQOL.

These studies did find that potentially modifiable factors including parent and family stress, parental fears and concerns, co-morbid learning disabilities and ADHD and perceived stigma were identified as negatively impacting child HRQOL above and beyond seizure control.

*Speechley et al, 2012; Ferro et al, 2013; Wu et al, 2014*

*"Since we are on the mild spectrum, it has alleviated future anxiety for us and our child"*

*"I felt very confused by the limited information, time and explanation's provided by the neurologist and their staff. After I met with the Centre, I felt that I came away with a much deeper understanding, with my questions answered and better able to manage."*

*"I feel more confident and knowledgeable and I don't stress as much."*

Did the education session help you to feel confident that you know **when a seizure is a medical emergency and when it is not?**



Poor self-management leads to frequent, clinically unnecessary and costly emergency visits to the hospital. *Noble et al, 2012*

Outpatient education reduces emergency room use by patients with epilepsy. *Pascual et al, 2015*





Do you feel that the information about night time and water safety in the 'Clinic To Community' program will help you to **prevent an injury** to your child during a seizure?



A component of the program is to provide anticipatory guidance to help families to understand what to expect in the first year after a diagnosis of epilepsy. Parents who receive anticipatory guidance including information about potential co-morbidities (depression, learning challenges, ADHD) and offers of advocacy support for their child at home and school may feel more prepared and comfortable requesting early intervention support services. They may also feel more capable of communicating with their child's teacher and their healthcare team. Engaging families early in the care of their children could improve shared-decision making and health related quality of life outcomes.

*Modi et al, 2009; Ferro et al, 2013; Wu et al, 2014*

Do you feel that the information about **Sudden Unexpected Death in Epilepsy (SUDEP)** should be included in the 'Clinic To Community' education session?



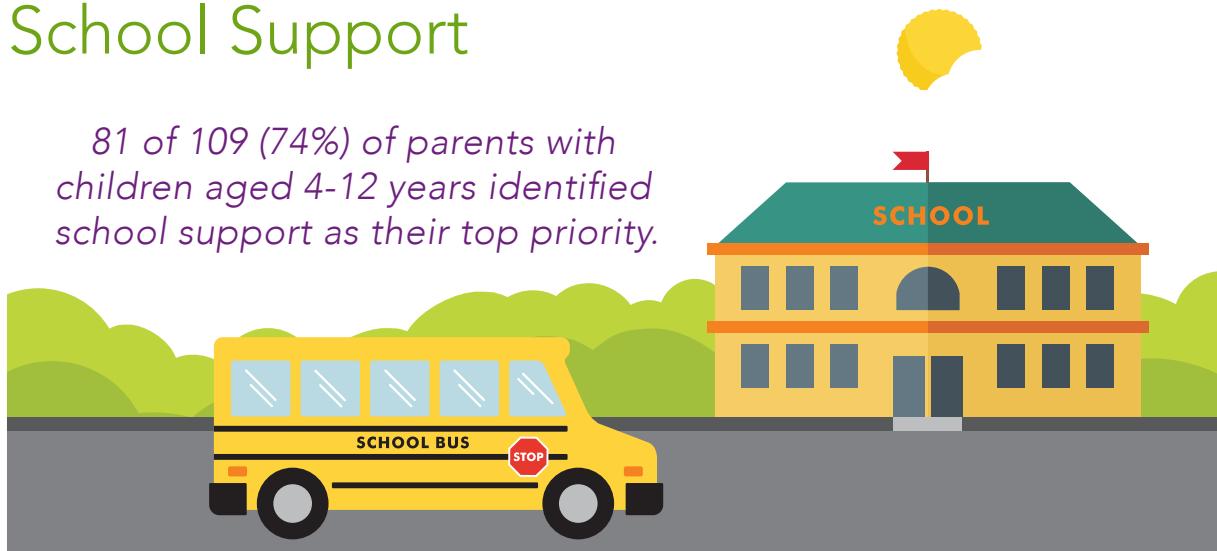
Surveys of neurologists found that 5-7% discussed SUDEP all of the time and 67 - 68.5% discussed it with a few or none of their patients. Sharing accurate information about SUDEP can optimize epilepsy self-management, reduce anxiety and distress and engage the person with epilepsy as a partner in their own care.

*Friedman D., Donner, EJ, Stephens, D, et al. Sudden Unexpected death in epilepsy: knowledge and experience among US and Canadian neurologists, Epilepsy Behav 2014;35: 13 -18.*

**95,000 persons in Ontario have epilepsy. Each year 6,500 new cases are diagnosed. There are currently 28,500 adults and children in Ontario experiencing seizures that do not respond to treatment with two or more appropriate anti-seizure drugs.**

# School Support

*81 of 109 (74%) of parents with children aged 4-12 years identified school support as their top priority.*



Website analytics showed parent downloads of strategy sheets by priority: ADHD (54%); learning challenges (52%); and memory (52%).

Parents identified that teachers placed restrictions in gym, recess, field trips and computer use citing safety concerns or to discipline behaviour.

43% of the parents requested a 45 minute presentation to their child's class and 32% had the Clinic To Community educator attend a parent-teacher school meeting to support the development of an Individualized Education Plan and/or a seizure safety protocol.

The results clearly identify the need for school support as part of a comprehensive plan of care for children with epilepsy.

*"They have been a voice to help support me and my son during school meetings, they have also been an ear for me to talk to"*

*"It's a great program and even the school mentioned how they were impressed with their involvement in making a safety plan"*



Does your child with epilepsy have **challenges with learning, behaviour, or memory?**



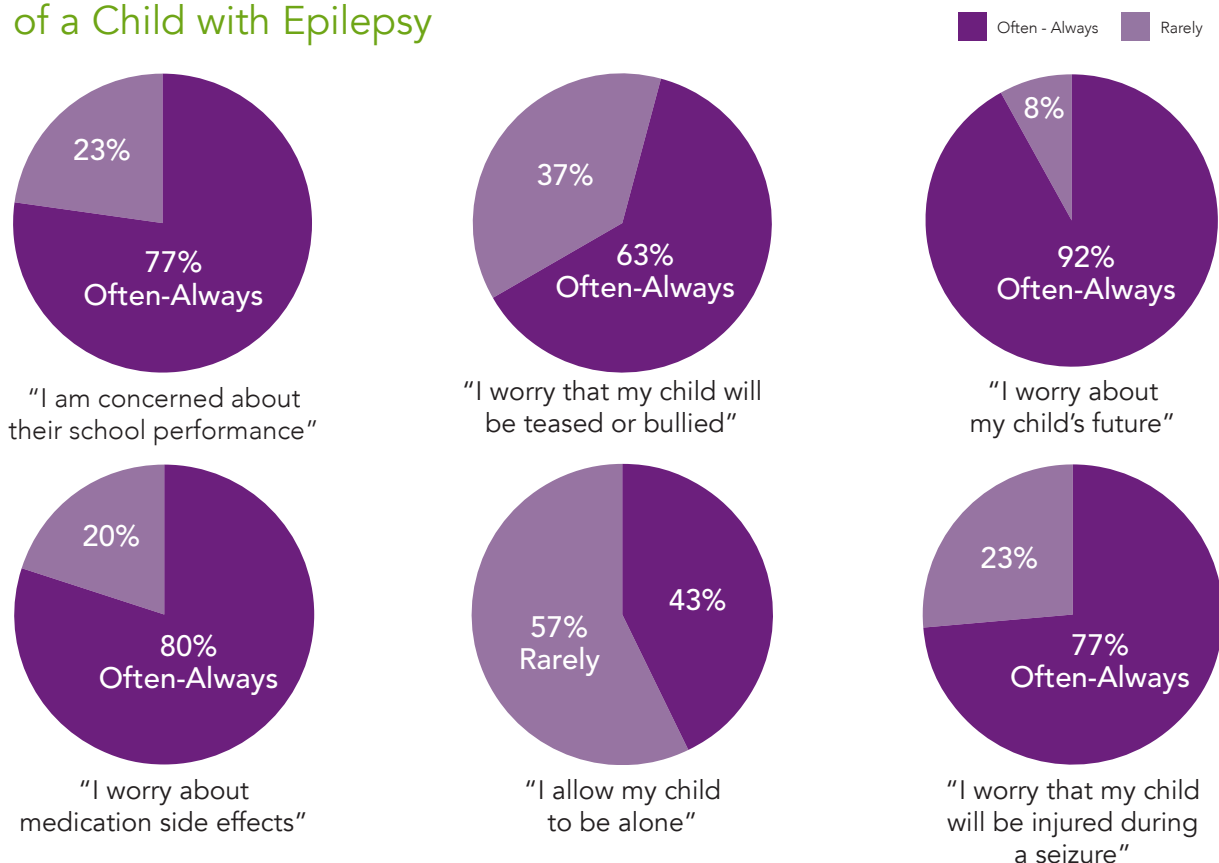
**Early intervention is possible.** 69% of the children under age 3 in our program already have at least one identified co-morbidity. 47% of children with epilepsy have a learning disability that can impact school performance. *Prasad et al, 2014*



# Use of Community Resources

Mandatory 60 minute education session	100%
Game ON recreation program	18%
Peer to peer support (Parent Facebook group, support groups, matched with another parent)	39%
'Clinic To Community' strategy sheets and/or website	54%
Presentation to child's class	43%
Presentation to child's teachers	39%
Support in developing a seizure safety protocol or individualized education plan (IEP)	32%
Purple Day for Epilepsy	43%
Staff Contact (email, telephone, in person, Facebook)	39%
Special event (Seize the Day Run, workshops, Gala, volunteering)	30%
Summer Camp	11%
We have not used any additional programs	25%

## How It Feels to be a Parent of a Child with Epilepsy



# The Top 3 Priorities of our Adults by Age Group

## Age 19-50

1 - Financial Aid & Drug Benefits **67%**

2 - Help with Depression **62%**

3 - Employment Support **62%**

N = 109

## Age 51+

1 - Financial Aid & Drug Benefits **86%**

2 - Help with Depression **50%**

3 - Employment Support **45%**

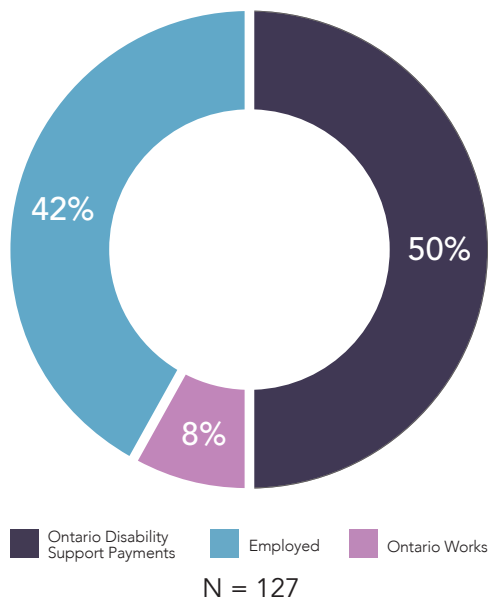
N = 18

In the program we administer the Neurological Disorders Depression Inventory for Epilepsy (NDDI-E), a 6-item questionnaire validated to screen for depression in people with epilepsy.

Occurring at a rate between 32% and 48% among people with epilepsy (Jones et al., 2003), depression is the most frequent co-morbid psychiatric disorder.

*Hermann, Seidenberg & Bell, 2000; Kanner, 2003; Kanner & Balabanov, 2002*

# Having a Diagnosis of Epilepsy Contributes to Financial Insecurity



**80,000** adults in Ontario have epilepsy.

**50%** of Canadian adults diagnosed with epilepsy reported that they did not have a job or were permanently unable to work.

*2011-2012 SLNCC data, Stats Canada*

Indirect economic costs due to working-age disability will increase. These costs are greatest in traumatic brain injury followed by epilepsy (from **\$2.5 billion in 2011 to \$2.8 billion in 2031**).

*Mapping Connections: An Understanding of Neurological Conditions in Canada, Stats Canada, PHAC*

Persons with epilepsy are not evenly distributed across neighbourhoods by income: **23.6%** live in the lowest-income neighbourhoods in Ontario.

*Brain Disorders in Ontario: Prevalence, Incidence and Costs from Health Administrative Data*

**"Lost wage-based productivity associated with epilepsy is nearly equal to combined wage losses associated with diabetes, depression, anxiety and asthma together."**

*Libby et al, 2012*

**There is a need for a provincial epilepsy strategy that goes beyond the medical and surgical management of seizures.**

## Benefits of Referring your Patients

The program will reduce visits to primary care and non-urgent use of emergency departments.

The program is designed to help the person living with epilepsy to understand their diagnosis, to know when a seizure is a medical emergency, to document what may trigger a seizure and to plan for their health care appointments.

The program will help the entire family to cope with the unpredictability and stigma associated with this misunderstood disease.

The program will link the person living with epilepsy to a network of community support.

The program helps parents to keep their children in school where they can learn and socialize.

The program reduces isolation for the person living with epilepsy and their care providers.

The program helps persons who do not have seizure control to access specialist care at a District or Regional Epilepsy Surgery Centre.

The program gives individuals living with epilepsy the tools to self-manage their condition.

## Three Easy Steps to Coordinated Care

- 1 Get patient permission to link them to the Clinic To Community Educator in their area.
- 2 Fax a referral form to Epilepsy Southwestern Ontario.
- 3 A Clinic To Community Educator will contact your patient within one week of receiving the referral to set up an education session.

## Contact Us

Epilepsy Southwestern Ontario  
690 Hale St - London, ON N5W 1H4

Fax: 519.433.4079  
Email: [info@clnictocommunity.ca](mailto:info@clnictocommunity.ca)  
Website: [www.clinictocommunity.ca](http://www.clinictocommunity.ca)



Thames Valley - 519.433.4073  
Huron Perth - 519.433.4073  
Grey Bruce - 519.433.4073

Sarnia/Lambton - 519.433.4073  
Chatham-Kent - 519.365.5131  
Windsor/Essex - 519.890.6614

epilepsy  
southwestern  
ontario



ONTARIO  
BRAIN  
INSTITUTE

Ontario  
Trillium  
Foundation



Fondation  
Trillium  
de l'Ontario



## Referral Form

Please fill out and return to Epilepsy Southwestern Ontario:

E-mail: info@clinictocommunity.ca

Phone (519-433-4073) Fax (519-433-4079)

Mail (690 Hale St. London, ON N5W 1H4).

Referral Date: \_\_\_\_\_

Name: \_\_\_\_\_ Date of Birth: \_\_\_\_\_

Address: \_\_\_\_\_

City: \_\_\_\_\_ Postal Code: \_\_\_\_\_ E-mail: \_\_\_\_\_

Phone: \_\_\_\_\_ Seizure Type(s): \_\_\_\_\_

**Reason For Referral** (check all that apply):

- |   |   |
|---|---|
| <input type="checkbox"/> New Diagnosis / Coping Strategies      | <input type="checkbox"/> School/ Workplace Support      |
| <input type="checkbox"/> Seizure Education / First Aid Training | <input type="checkbox"/> Volunteering / Social Programs |
| <input type="checkbox"/> Parent and Family Support              |   |
| <input type="checkbox"/> Other _____                            |   |

Referral Made By: \_\_\_\_\_

Phone: \_\_\_\_\_ Fax: \_\_\_\_\_

Consent to Contact (client / guardian signature): \_\_\_\_\_