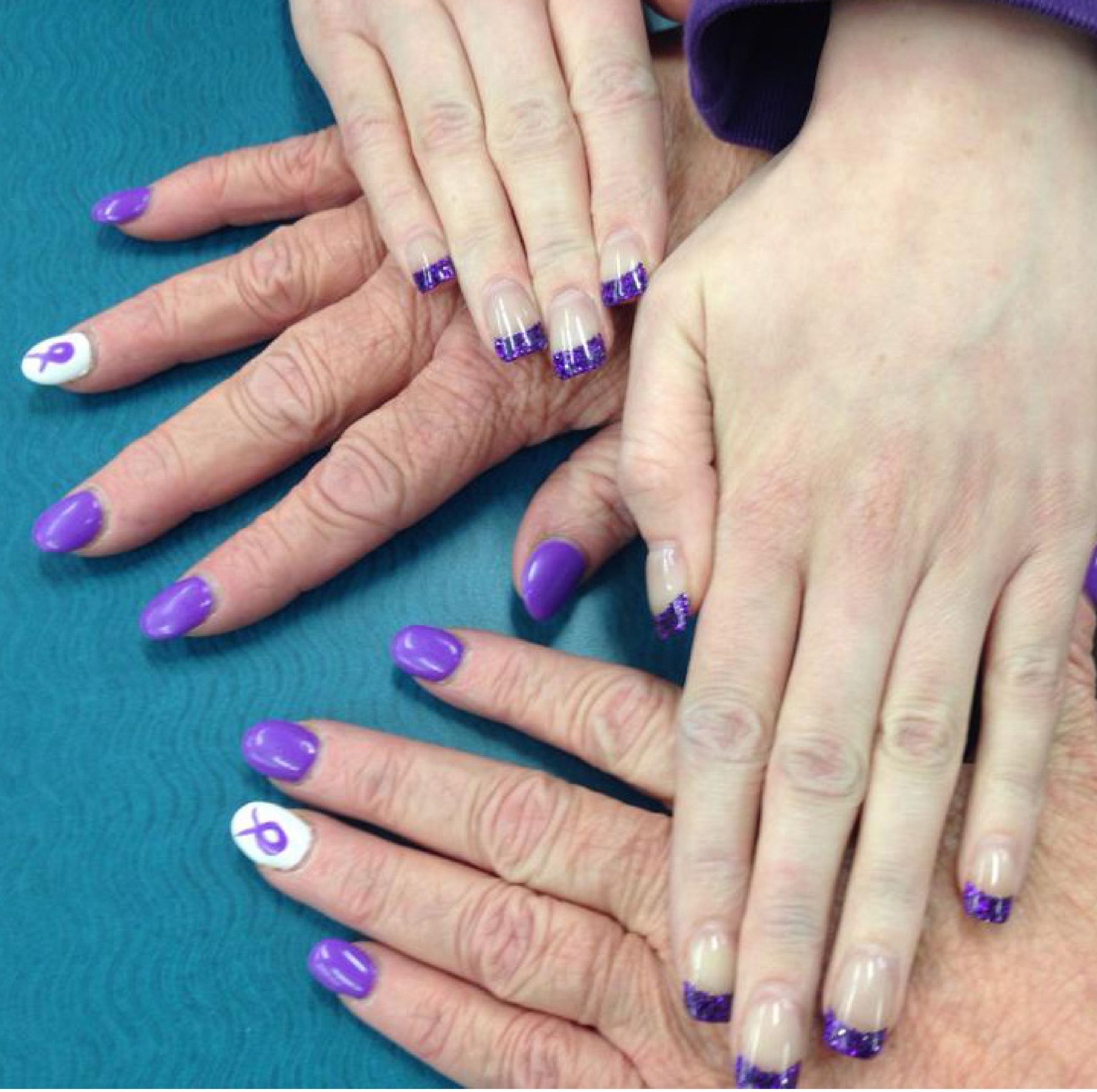

LIVING WITH EPILEPSY: VOICES FROM THE COMMUNITY

epilepsy southwestern ontario

ONTARIO BRAIN INSTITUTE

Ontario Trillium Foundation

Fondation Trillium de l'Ontario

EPLINK

Acknowledgments

Thank you to the families, parents, spouses and adults living with epilepsy who freely shared their opinions for the development of this report. We appreciate your input, time, expertise and valuable insight.

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Thank you to the paediatric neurology department at Children's Hospital of Western Ontario for piloting the program and helping us to collect research data in your clinic: Dr. Andrea Andrade, Kara Bigelow, Dr. Craig Campbell, Margo Devries-Rizzo, Whitney Edgeworth, Brad Ferris, Patti Geurtjens, Cara Gordon, Zena Jaworski, Dr. Simon Levin, Dr. Asuri N. Prasad, Kimberley Tiemens, and Laura Van Den Eynden.

Thank you to the Clinic To Community© Advisory Team:
Dr. Jorge Burneo, Dr. Nora Fayed, Dr. Hema Gangam, Michelle Hurtubise, Dr. Asuri N. Prasad and Dr. Kathy Speechley. Special thanks to Kim Bond for her commitment to the program.

Thank you to the Ontario Brain Institute for providing seed funding to evaluate the program and for being leaders in brain health in Canada. Your commitment to investing in people with brain conditions gives us hope that there will be earlier detection, better treatment, improved quality of life and a cure for epilepsy.

Thank you to the Ontario Trillium Foundation for providing funding to deliver the program in LHIN 1 and LHIN 2 allowing us to coordinate care with health providers to reach people with epilepsy as soon as they are diagnosed and to provide them with the information and support they need to live healthy, vibrant lives.

Contact Us

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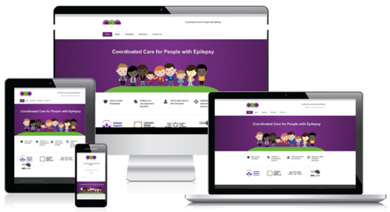


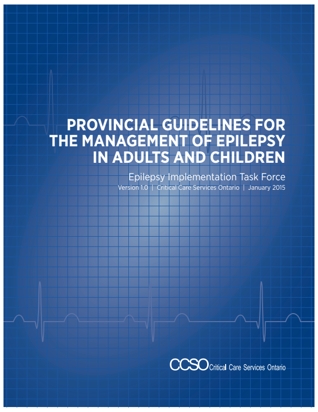
An agency of the Government of Ontario

Executive Summary with Recommendations

Community Epilepsy Agencies have a unique vantage point in that they provide information and support to persons with epilepsy across the continuum of the lifespan. They understand the fear after the first seizure and the misconceptions that newly diagnosed people share. They also see the stigma, despair and the erosion of hope when seizures persist, treatments fail or when surgery is not an option.

Community Epilepsy Agencies have been on the frontlines working to support children, youth, parents, adults and seniors living with epilepsy. As frontline workers we often see individuals and families seeking information and support during a crisis, after the loss of a job or after an injury or death of a loved one. **Our message is that we need to be proactive - to provide every newly diagnosed person with epilepsy with information and support before they are drug refractory and in crisis. This approach has the potential to reduce the burden of epilepsy on the individual, their family, the education and health care systems, and the Ontario economy.**

In January 2015, Critical Care Services Ontario published Provincial Guidelines for the Management of Epilepsy in Adults and Children. These guidelines were developed by the Epilepsy Implementation Task Force in an effort to standardize and improve epilepsy care across the province. We saw these guidelines as an opportunity to reach newly diagnosed persons living with epilepsy earlier to provide them with information about their seizures, system navigation and a network of community support services. We developed the Clinic To Community© program to give health care providers a tool to cover the epilepsy education checklist in these guidelines.



PROVINCIAL GUIDELINES FOR
THE MANAGEMENT OF EPILEPSY
IN ADULTS AND CHILDREN

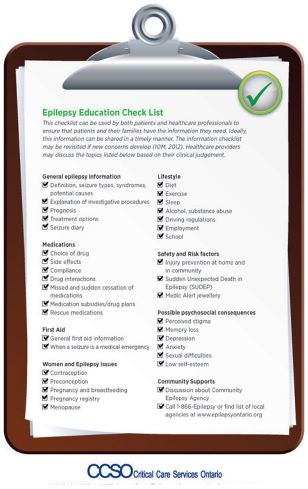
Epilepsy Implementation Task Force
Version 1.0 | Critical Care Services Ontario | January 2015

CCSO Critical Care Services Ontario

With a research grant from the Ontario Brain Institute and in partnership with the entire paediatric neurology team at London Health Sciences Centre, the Clinic To Community© program was piloted and evaluated by 50 parents of children with epilepsy. These parents provided feedback on what worked in the program and offered suggestions to improve the content and delivery of the program.

The Ontario Trillium Foundation provided funding to expand the pilot by offering the program to health care providers in Thames Valley, Essex, Kent, Lambton, Grey, Bruce, Huron and Perth Counties (Erie St. Clair LHIN 1 & South West LHIN 2).

Prior to the development of the Clinic To Community© program, the standard practice was for health care providers to recommend consumer health information to their patients with epilepsy (PWE). Depending on the provider, the PWE and their family may or may not have received a seizure first aid brochure, an epilepsy booklet, a parent package or a list of websites. The onus was on the PWE to educate themselves. There was no guarantee that they would read the materials or that they would understand the content or how the information related to their particular seizure type or syndrome.



Epilepsy Education Check List

This checklist can be used by both patients and healthcare professionals to ensure that patients and their families have the information they need. Ideally, this information can be shared in a timely manner. The information checklist may be revisited if new concerns develop (IOM, 2012). Healthcare providers may discuss the topics listed below based on their clinical judgement.

General epilepsy information
☑ Definition, seizure types, syndromes, potential causes
☑ Explanation of investigative procedures
☑ Prognosis
☑ Treatment options
☑ Seizure diary

Medications
☑ Choice of drug
☑ Side effects
☑ Compliance
☑ Drug interactions
☑ Missed and sudden cessation of medications
☑ Medication subsidies/drug plans
☑ Rescue medications

First Aid
☑ General first aid information
☑ When a seizure is a medical emergency

Women and Epilepsy Issues
☑ Contraception
☑ Preconception
☑ Pregnancy and breastfeeding
☑ Pregnancy registry
☑ Menopause

Lifestyle
☑ Diet
☑ Exercise
☑ Sleep
☑ Alcohol, substance abuse
☑ Driving regulations
☑ Employment
☑ School

Safety and Risk factors
☑ Injury prevention at home and in community
☑ Sudden Unexpected Death in Epilepsy (SUDEP)
☑ Medic Alert jewellery

Possible psychosocial consequences
☑ Perceived stigma
☑ Memory loss
☑ Depression
☑ Anxiety
☑ Sexual difficulties
☑ Low self-esteem

Community Supports
☑ Discussion about Community Epilepsy Agency
☑ Call 1-866-Epilepsy or find list of local agencies at www.epilepsyontario.org

CCSO Critical Care Services Ontario

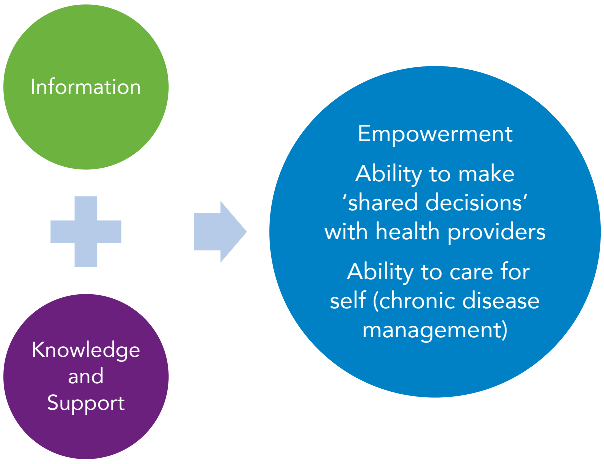
The Clinic To Community© program combines health information with patient education. Patient education is the process of influencing patient behaviour to produce changes in knowledge, attitudes and skills calculated to maintain and improve health. The strength of the Clinic To Community© program is that it is individualized to meet the identified needs of the PWE and their family. In the initial meeting (approximately 60 minutes), the Clinic To Community© educator is able to answer individual questions and cover the Epilepsy Education Checklist (page 29) as recommended in the Provincial Guidelines for the Management of Epilepsy in Adults and Children.

The Clinic To Community© educator develops a relationship with the PWE and becomes their patient navigator and care coordinator. The program helps the entire family to develop health management skills and this is empowering and transformative. The PWE and their family are able to ask all of their questions to a trained community based epilepsy educator in an empathic and supportive environment and they are able to re-engage with the epilepsy educator as often as needed.

This wrap around support can change the way that persons with epilepsy and their families manage and cope with this unpredictable and stigmatizing diagnosis.

During our demonstration project we collected data and feedback from 425 PWE and their families. We heard that the Clinic To Community© program should be a mandatory referral at diagnosis and that the program should be funded by the Ministry of Health and Long Term Care.

We heard that primary care providers did not have the time, interest or expertise to provide epilepsy patient education. We heard that when the PWE is given a brochure or a list of websites this is not enough to make them feel confident that they are capable of managing or to know when their seizure is a medical emergency and when it is not. We heard that epilepsy is an emotional diagnosis and that written materials are not effective in reducing fear or helping the family to cope with the day to day reality of living with unpredictable, embarrassing and stigmatizing seizures. More often than not, we heard that reading about epilepsy on websites perpetuated fear and feelings of discrimination and social isolation.



In our demonstration project we heard that PWE and their families want to speak with someone after they have been diagnosed. They want help to cope with the loss of control and the fear they experience. They want emotional support and system navigation to manage the cognitive, behavioural, social, emotional and psychiatric co-morbidities. They are seeking information, guidance and support on ways to disclose the diagnosis to others (family members, neighbours, teachers and employers). When offered this support in the clinic or in the community, 87% chose to receive patient education in their community where they could invite other members of their family to attend and

425 living with epilepsy + **638** family members = **1063** individuals

received a 60 minute Clinic To Community© education session where they could ask all of their questions without feeling time pressured and censured.

In our demonstration period, 75% of parents (177/236) used more than 2 programs offered by our Community Epilepsy Agency. We collected data to better understand the programming priorities of these parents who ranked school support for their child with epilepsy as their top priority followed by social programs and access to information.

For the adults in the demonstration project, 64% (121/189) used 2 or more programs offered by our Community Epilepsy Agency. On average, these adults had lived with epilepsy for 9.7 years. At the time of referral 53% identified that they were living on government income support programs, 20% were employed and 42% had epilepsy plus depression/anxiety. Sadly, we heard that adult life with epilepsy is unsatisfactory with high rates of unemployment, poverty, social isolation and poorly managed mental health. In our opinion, adults came to the program too late.

We asked PWE to tell us how many times they had used an emergency department after having had a seizure. The most frequent response was 2 – 3 times (30% of parents and 37% of adults) but 20% of parents and 16% of adults reported that they had used an emergency department more than 10 times. This is costly for the health care system and stressful for the entire family. This data suggests that we could be meeting PWE earlier if we had a partnership with local emergency departments. In our focus groups, we heard that the emergency department is not the right place to learn about epilepsy and that discharge instructions should include a direct referral to meet an epilepsy educator through the Clinic To Community© program. This direct referral would help the PWE and their family to feel comfortable knowing when a seizure is a medical emergency and when it is not. It would also help with system navigation (how to access specialist care) for persons who do not have seizure control after trying two anti-seizure medications. It would also link the PWE and their family to a network of information, knowledge, system navigation and community support.

Using tracking sheets, surveys, field notes, semi-structured interviews and focus groups we have evidence that the Clinic To Community© program:

- Improves the epilepsy knowledge of parents and adults living with epilepsy.
- Helps parents and adults living with epilepsy to know when a seizure is a medical emergency and when it is not.
- Helps to reduce injury in children with epilepsy.
- Develops coping and self-management skills in parents and adults living with epilepsy.
- Reduces anxiety and social isolation in parents and adults living with epilepsy.

We have demonstrated that the program develops skills in PWE and their families. We have positive feedback from 46 healthcare providers who referred 305 PWE to the program during the demonstration period that the program works to coordinate care. In other chronic conditions, patient education and training in self-care has been found to be associated with reduced health care service utilization. We are ready to spread the program to other regions in Ontario.

Our List of Recommendations:

☐ Referral forms should be available in health care provider databases.

☐ Referral should be mandatory at time of epilepsy diagnosis.

☐ Upon receiving a diagnosis of epilepsy, a one time meeting with a Clinic To Community© Educator should be covered by the Ministry of Health and Long Term Care (OHIP billable).

☐ Policy makers should look at indirect economic costs due to working-age disability in epilepsy and develop a strategy to reduce the public health burden of epilepsy in Ontario.

☐ Designated mental health funding should be available for persons with epilepsy who have high rates of depression and anxiety.

☐ The psychosocial support that is available to surgical candidates through the District Epilepsy Centres and the Regional Epilepsy Surgical Centres should be offered to non-surgical candidates. This includes psychological and neuropsychological testing.

☐ Core funding needs to be available so that every newly diagnosed person with epilepsy is provided with patient education and patient navigation regardless of where they live in Ontario. We have existing models that can be replicated for epilepsy (First Link for Alzheimer's and Diabetes Care Strategy).

☐ Outpatient education is a valuable tool to reduce emergency department use, which may, in turn cut down on health care costs and improve patient satisfaction.

☐ Emergency departments should provide a direct referral to the Clinic To Community© program.

☐ Core funding is needed to deliver school support for children with epilepsy and research is needed to determine to what extent school based intervention programs can improve the long term academic and social outcomes of children with epilepsy.

Living with Epilepsy: Voices from the Community is unique in Canada. It is the only report to document the community based needs and program preferences of 425 individuals and families living with epilepsy. The report concludes with recommendations of ways we can make investments that will reduce the burden of epilepsy on the individual, the family, the health care team and the Ontario economy.

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Published: March 2018

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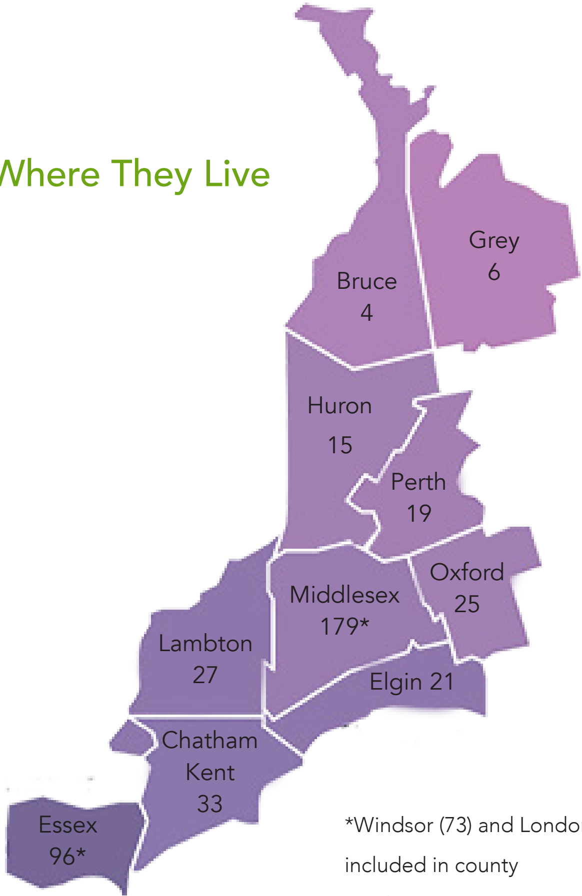
Where They Live



*Windsor (73) and London (157) included in county numbers.

425 living with epilepsy + **638** family members = **1063** individuals

received a 60 minute Clinic To Community© education session

Learning Health Care System

This report contains unique insight and recommendations on ways to coordinate and improve epilepsy care in Ontario.

The report summarizes the experience of 425 persons with epilepsy across the continuum of the lifespan. Collectively they have stated that living well with a diagnosis of epilepsy goes beyond the medical management of their seizures.

Our research shows that the Clinic To Community© program helped the person with epilepsy to know when a seizure is a medical emergency and when it is not. More research is needed to know if the Clinic To Community© program can reduce non-urgent use of local emergency departments.

Our research shows that this linkage program was ranked highly by persons with epilepsy who felt it improved their care.

Health care providers acknowledged that this linkage program was easy to use and valued by their patients with epilepsy.   They would like the referral forms to be available in their health care provider databases.

Persons with epilepsy are asking that the Clinic To Community© program be a mandatory referral at diagnosis and that it should be funded by the Ministry of Health and offered in both urban and rural Ontario.

Clinic To Community© is a referral program for individuals with a seizure disorder or a diagnosis of epilepsy.

The goals of the program:

One

Provide individuals and their family with information about seizures, seizure first aid and epilepsy.

Two

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.

Three

Reduce the burden of epilepsy on the individual, their family, the health care team and the Ontario economy.

The Components of the Clinic To Community© Program

1) Individualized appointments with a Clinic To Community© Educator who will provide an overview of seizures, epilepsy, risk management 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.

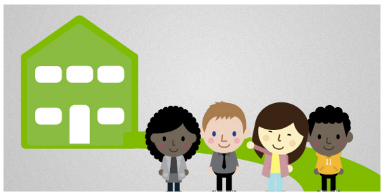
3) A network of services including support groups, peer to peer linkages, recreation programs, and school and workplace assistance.

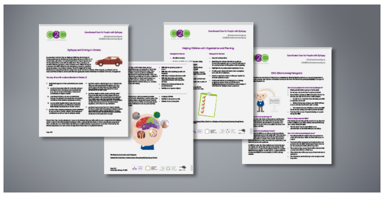
4) A series of strategy sheets filled with information to help the person living with epilepsy to best manage their condition.

5) A website with downloadable resources: www.clinictocommunity.ca

6) Community Pathways Newsletter for health care providers.

7) Private online parent group.





Health Care Providers

Our outreach to health care providers began in January 2015 with emails and phone calls to paediatric and adult neurologists, Family Health Teams, Community Health Care Centres, Community Care Access Centres and the Health Units in LHIN 1 and LHIN 2.

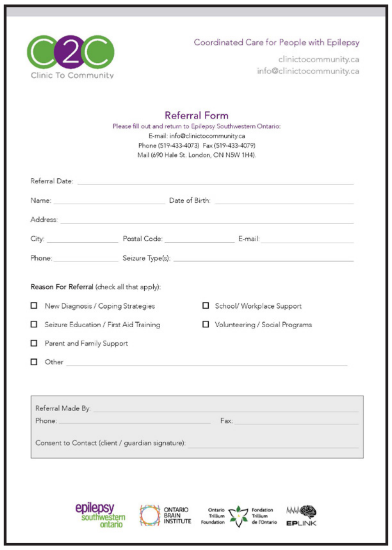
This outreach resulted in **28** presentations at staff meetings and during lunch and learn sessions, with **353** health care providers in attendance. On average, this professional development session was 30 minutes. We were able to provide an overview of the Provincial Guidelines For The Management of Epilepsy series with a focus on the psychosocial needs of persons with epilepsy.

The Results

This approach opened many doors. We were offered meeting space in one Community Health Centre to organize individual or group presentations with their epilepsy patients. Two family health teams offered us the opportunity to facilitate epilepsy groups semi-annually and agreed to mail invitations to their patients living with epilepsy. Community neurologists in Windsor and the CCAC in Chatham provided us with complimentary office space to meet with her epilepsy patients. The paediatric neurology team at Children's Hospital of Western Ontario invited our Clinic To Community© educator to join their multidisciplinary comprehensive epilepsy clinic. An adult epileptologist at London Health Sciences Centre invited our Clinic To Community© educator to join his 'new onset seizure clinic' to meet with newly diagnosed epilepsy patients.

46 health care providers referred **305** patients with epilepsy to the program during the demonstration period (January 2015 - July 2017)

We developed three steps to coordinate care:



Clinic To Community

Coordinated Care for People with Epilepsy
clinictocommunity.ca
info@clinictocommunity.ca

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):

☐ New Diagnosis / Coping Strategies
☐ Seizure Education / First Aid Training
☐ Parent and Family Support
☐ Other __________
☐ School/ Workplace Support
☐ Volunteering / Social Programs

Referral Made By: __________
Phone: __________ Fax: __________
Consent to Contact (client / guardian signature): __________

One

Health care provider obtains patient permission to refer them to the Clinic To Community© Program.

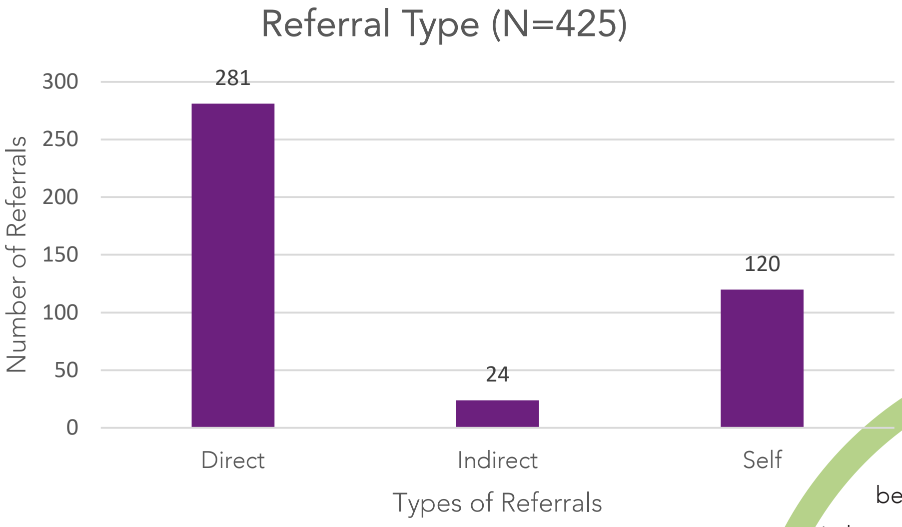
Two

Health care provider sends a referral form to Epilepsy Southwestern Ontario.

Three

A Clinic To Community© educator from Epilepsy Southwestern Ontario contacts the person with epilepsy (patient) within one week of receiving the referral to set up an education session in their preferred location: either the 'clinic or the community'.

Health Care Providers



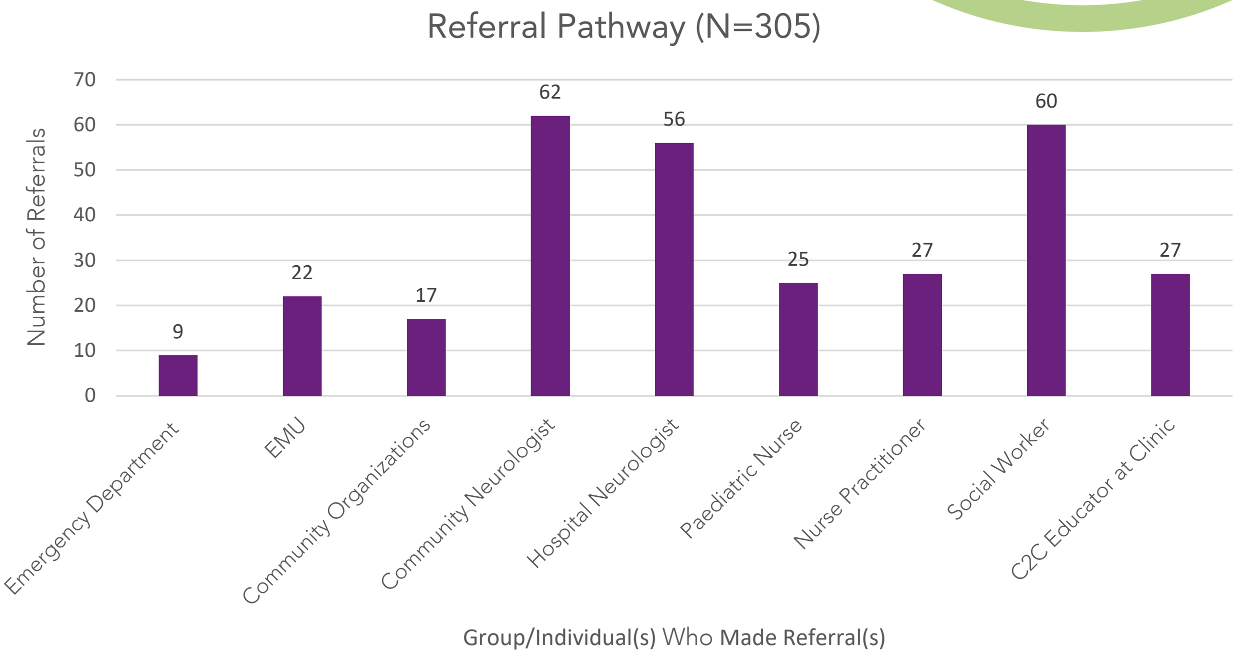
Direct Referral - health care provider sends a referral form directly to ESWO

In-direct Referral - health care provider recommends that their patient call ESWO but does not send a faxed referral

Self - person with epilepsy finds ESWO on their own (website, word of mouth, poster, brochure, friend, teacher or colleague)

72% of new clients were referred through this health care linkage program

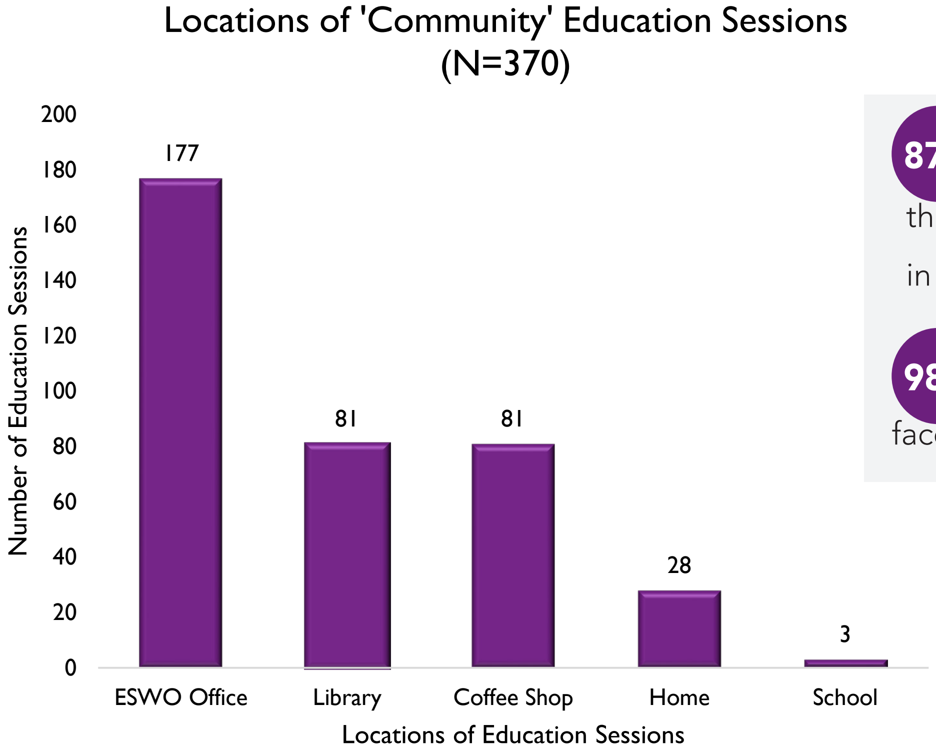
> "It is a pleasure to pledge tremendous support behind the Clinic To Community© Program in hopes of seeing it burgeon and grow in all areas of Ontario. The need for this program is extraordinary. Epilepsy is a chronic condition where patients face many hardships: apart from seizure control, they often have to deal with driving restrictions, strained relationships, reduced employment opportunities and income, as well as psychiatric comorbidities including major depression and anxiety. This is the first and only program to provide community education, counselling during periods of crisis, access to mental health resources and above all, care coordination."
>
> - Adult Neurologist



EMU: Epilepsy Monitoring Unit at London Health Sciences Centre

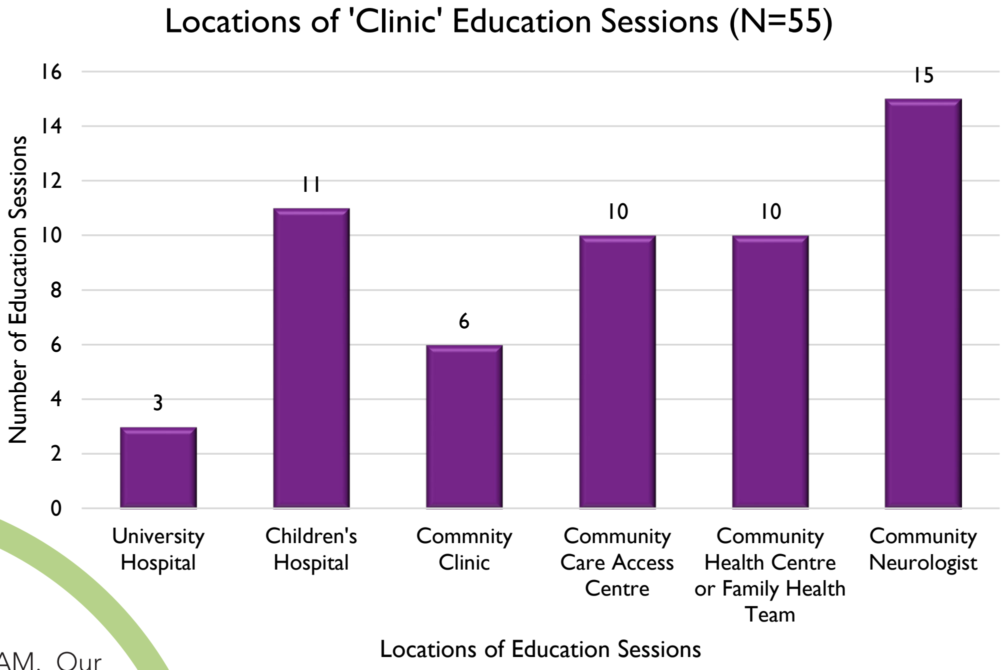
Community Organizations: Schools, Family Health Teams, Community Care Access Centre, Health Unit

Health Care Providers



87% (370/425) requested the presentation take place in their community.

98% requested a face to face education session.



"We left Windsor this morning at 7 AM. Our son had a sleep deprived EEG [Children's Hospital in London] when we arrived. Our appointment to see the neurologist was at 1 pm. We are all exhausted. We are very interested in the education session but we are too tired to process the information today. Our son has been crying for the past hour and he just wants to go home."

- Parent

Health Care Providers

We learned what works for persons living with epilepsy. They acknowledged that their time in the clinic with their health care provider is limited and feel that this time should be dedicated to diagnosis and treatment. They prefer meeting after their appointment to discuss self management strategies to cope and to live well with their diagnosis.

Space limitations, hospital wait times and parking fees at hospitals were barriers to providing education in the clinic.

Offering the education sessions in the community allowed persons with epilepsy to invite their spouse, children and extended family to attend. The meeting in the community gave the persons with epilepsy and their family time to schedule the session based on their availability.

"I think in those appointments with the doctor you feel a little bit rushed and you're trying to take in a lot of information so it was helpful after those initial appointments to talk to somebody else who could provide some more answers to some of the questions we had."

- Parent

"One of the unique strengths of the program is that it is individualized to meet the psychosocial and emotional needs of each patient. As you may recognize, many parents feel very anxious and afraid when they see their child have a seizure. The programming helps to educate and relieve some of the anxiety parents and their families have. In many cases upon giving a diagnosis, patients are not able to fully process and comprehend the information given during their initial appointment. The Clinic To Community© in-service allows patients to go home, review the information and ask questions in a more causual environment outside of the physician-patient setting."

- Community Neurologist

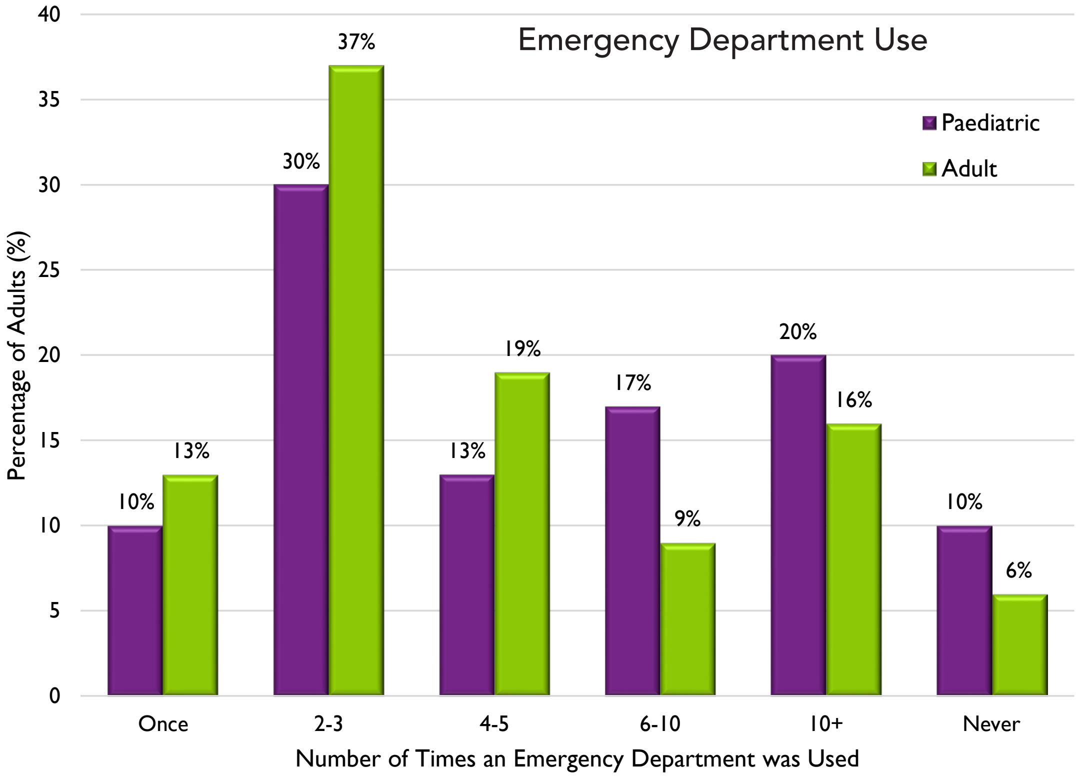
"Epilepsy is a complex disorder, impacting not only health but also learning, safety, and quality of life. Newly diagnosed patients and their families are often overwhelmed and afraid of what their future holds. For many, the diagnosis of epilepsy is associated with stigma and social isolation. There is a need to engage this vulnerable population in their communities. We are fortunate to have strong community partners that are willing to work with health care practitioners to ensure that families receive the needed education regarding epilepsy and the services available to them."

- Health Care Provider

Emergency Departments

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). 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).

We asked parents of children with epilepsy and adults living with epilepsy to tell us how many times they had used an emergency department for seizures or epilepsy.



- The most frequent response was 2 – 3 times (30% of parents and 37% of adults)

- 20% of parents and 16% of adults reported that they had used an emergency department more than 10 times

"We have had a horrendous time getting the diagnosis. We have visited an ER 7 times and I have taken a year off work to get control of his health."
- Parent

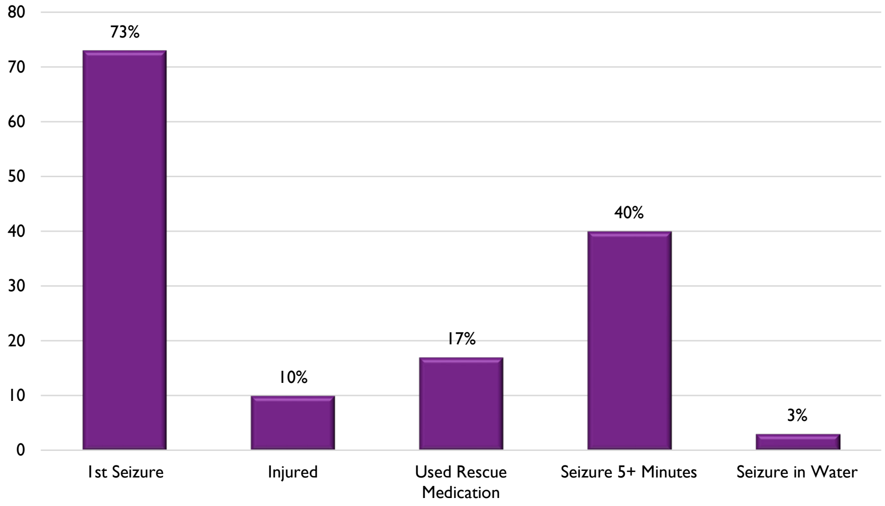
"Had we known about Epilepsy Southwestern Ontario from day one…our hospital visits and constant EMS calls could have been avoided. We went 5 times in 6 months while we waited to see a paediatric neurologist."
- Parent

"My next appointment was in 5 months but I was having a lot of issues. The ER doc actually kept calling my neurologist's office until they got the secretary and got my appointment changed. We were pretty impressed by that."
- Adult

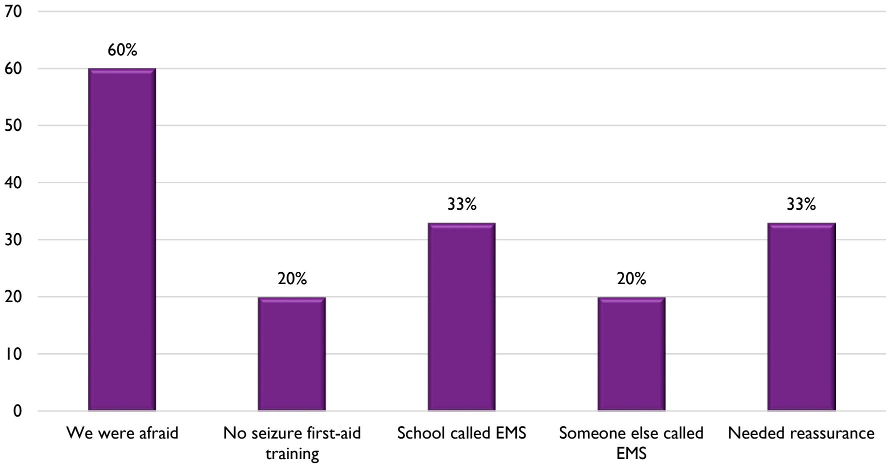
Emergency Departments

We tried to gain a better understanding of 'why' they chose to go to an emergency department and whether the seizure event should be classified as a medical emergency (non-avertable) or potentially avertable.

Non-Avertable Use of Emergency Departments



Potentially-Avertable Use of Emergency Departments



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

Emergency Departments

Guidelines for referring patients from the emergency department state that "Patients with an established diagnosis of epilepsy should be advised to follow up with their GP/FP or specialist." Referring a person with epilepsy to see their GP/FP or specialist is essential but it does not alleviate the fear nor does it provide them with the necessary information to know when a seizure is a medical emergency and when it is not.

We held two adult focus groups to better understand the first person experience of individuals who have used an emergency department more than 5 times for their seizures.

We heard: The Emergency Department Is Not The Right Place to Learn More About My Epilepsy

"After a seizure I can't get my stuff together. I can't even make words. Let alone understand it. "

"You are too stressed out, you are exhausted and this is not the right time to talk about your epilepsy."

"I'm too upset when I wake up in an ER and I can't think straight."

We heard: Discharge Should Include a Direct Referral to a Community Epilepsy Agency

"When you are scared you want to sit down and talk to a real person. I have been to an emergency department multiple times. The nurse or the doctor should have referred me to Epilepsy Southestern Ontario."

"How the family reacts is contagious. If one person freaks out everybody goes crazy. The whole family needs to be taught how to react."

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?

Emergency Departments

Recommendations

☐ Outpatient education is a valuable tool to reduce emergency department use, which may, in turn, cut down on health-care cost.

☐ In two focus groups, persons with epilepsy and their families recommended that they be referred to their local Community Epilepsy Agency to receive education, system navigation and support services after a second seizure.

☐ Training in self-care has been found to be associated with reduced health care service utilization in conditions like asthma and diabetes but there is no equivalent investment in providing self management support for persons living with epilepsy.

Children Living with Epilepsy

Our Community Epilepsy Agency was able to document the significant stress, worry and isolation that parents feel when their child has unpredictable seizures and a diagnosis of epilepsy.

Our research indicates that the Clinic To Community© program helped these parents feel less anxious about their child's epilepsy diagnosis and helped them to manage their child's seizures.

Our parents recommended that the Clinic To Community© program be a mandatory referral at diagnosis for all children with epilepsy in Ontario.

Parents of Children Living with Epilepsy

236 children and youth were enrolled in the demonstration program

Three age groups:

23	**144**	**69**
birth to 3 year olds	4 – 12 years	13 – 18

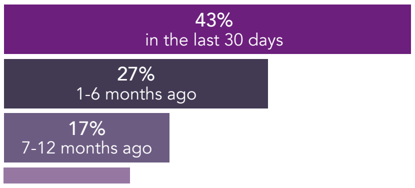
A mixed methods design with field notes, clinic journals, parent surveys, in-depth interviews, website analytics, and tracking sheets was used to identify the information and program requests of each family.

Parents provided information related to their child's age of seizure onset, seizure types, seizure frequency, number of medications tried and comorbidities (both diagnosed and undiagnosed).

Throughout the 30 month demonstration program we surveyed parents to see if the program needed to be amended or changed. Based on parent feedback, we added several strategy sheets: epilepsy and memory in children, anxiety in children, seizure dogs, surgery and epilepsy syndromes.

Seizure Frequency

Paediatric



87% have active epilepsy

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

The top 3 Identified Needs of Parents:

- #1 School Support
- #2 Emotional Support
- #3 Information

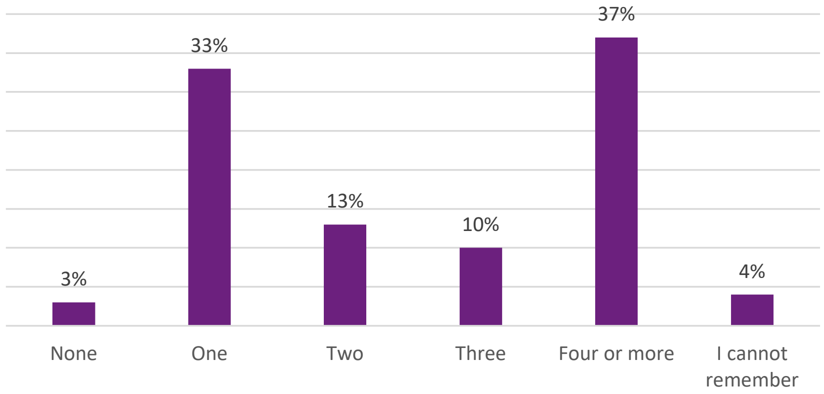
> "We waited for 8 months to see a specialist. There should have been a fast track clinic after our son had his seizure. This would have reduced our anxiety and started us on the right track. We did not know what was happening and our family doctor did not know anything about seizures."
>
> \- Parent

Profile of Children

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

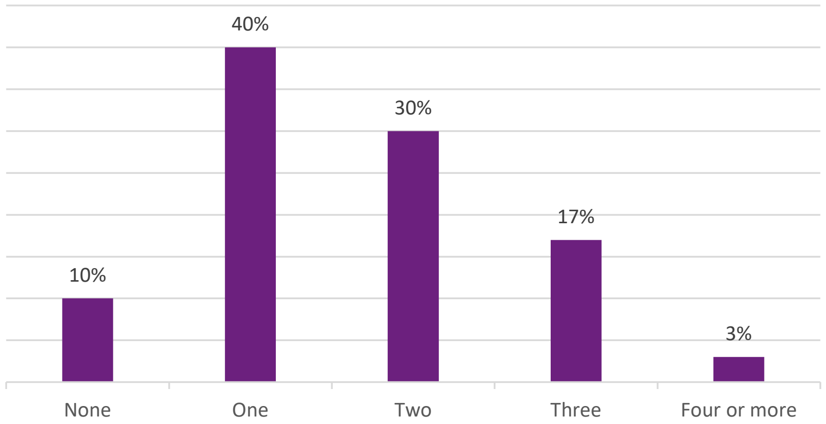
Total # of Anti-Seizure Medications Tried by Children Living with Epilepsy

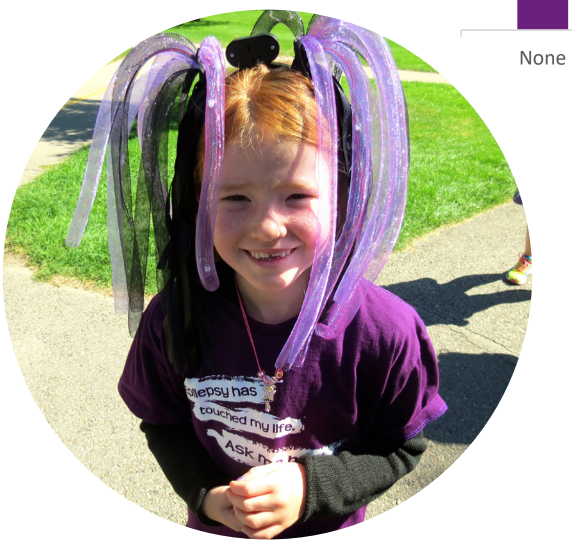


“This program needs to be mandatory. Every person should meet with an educator the day they are diagnosed.”
- Parent

"Hearing our daughter had epilepsy was far more emotional than being told our son had type 1 diabetes."
- Parent

Current # of Daily Medications (Children)





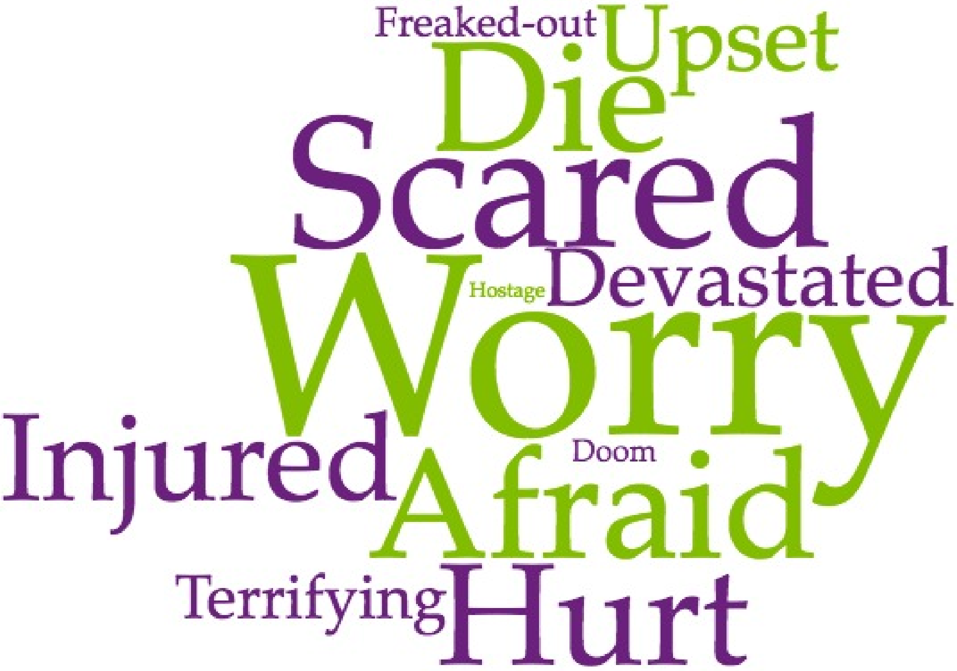
“We had pamphlets but they did not help us to cope.”
- Parent

Parents of Children Living with Epilepsy

Through interviews we heard parents wanted an individualized session where they could ask their personal questions and share their child's seizure story. Having the meeting in person allowed parents to establish a relationship with the educator and to talk about their fear. Parents shared that they worried that their child with epilepsy would have a seizure and be embarrassed, teased or bullied. They lived in constant fear that their child would be injured or die during a seizure. They were afraid that their child's teacher would not know what to do if a seizure happened at school. They were worried that the medications would cause brain damage or cognitive impairment in their child. Many parents spoke about sleeping in their child's room to watch for night time seizures. Many parents asked for advice on how and when to disclose the diagnosis to others.

> "We worry about everything. We worry about his future. We worry about how he's gonna adjust and adapt and we worry about school."
>
> \- Parents

Words Parents Used to Describe Their Child's Epilepsy Diagnosis



Parents of Children Living with Epilepsy

The goal of the Clinic To Community© Program is to provide parents with the information they need to understand their child's epilepsy diagnosis, treatment options and care pathways and to advocate for their child in the clinic, at school and in the community. There is no 'one size fits all' script or booklet as each parent is at a different place in their epilepsy journey. Some of the children in our demonstration project have severe medical conditions and are medically fragile while others have a good prognosis and will likely outgrow their seizures. The challenge for parents is knowing what the future holds for their child.

All 236 families had a meeting with our Clinic To Community© educators. The time for these presentations ranged from 45 to 90 minutes.

75% (177/236) families used additional programs offered by ESWO.

"I'm scared of
a head injury."
- Parent

"I worry about him being hurt.
I just went to a parent group and
they were saying how their kids had
chipped teeth and I'm just like I don't
want that for him. Like it just seems
unfair."
- Parent

"I'm freaked out cause she's
going to probably go for
surgery cause she's allergic
to all of the other meds."
- Parent

"Just worrying about
him having another
one. Suffocating in
bed. Like I don't want
to lose him."
- Parent

Parents of Children Living with Epilepsy

Our data shows that parents feel less anxious and more knowledgeable about taking care of their child's seizures as a result of the Clinic To Community© Program. Our next steps are to find out if that translates to safer and better care, with less hospital and emergency room visits and better long term outcomes.

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?

"I get a feeling of impending doom. It's because of the diagnosis. It can be nothing. Like she could never have another seizure again, or it could be devastating so it's holding me a bit hostage."
- Parent

"I'm just scared that she'll have a seizure overnight and then I'll be sleeping. That's my worry. And then she passes away on me. That's what they think happened to another girl here in town. She had a seizure – a non-stop seizure in the middle of the night when everybody was sleeping."
- Parent

"My most common comment after the presentation is: 'I feel so much better now'."
- Community Educator

Parents of Children Living with Epilepsy

Recommendations

☐ Information needs to be offered outside of the clinic in a supportive environment.

☐ Parents view the topic as very emotional and devastating and need more than written materials to cope.

☐ Information needs to be shared more than once. We documented our conversations with parents and tracked the strategy sheets that parents downloaded from the website and/or requested from our educators. Despite receiving verbal and/or written information, parents posed the same questions repeatedly.

☐ When asked 'how to improve the program' parents recommend that the Clinic To Community© educator telephone or email them one month after the initial education session to do a check in and to see if there are any additional questions or needs.

☐ In interviews and surveys, parents in the demonstration program felt that the Clinic To Community© program should be a mandatory referral.

☐ The program should be covered by Ministry of Health.

☐ Parents requested a paediatric new onset seizure clinic at Children's Hospital of Western Ontario.

☐ The psychosocial support that is available to surgical candidates through the District Epilepsy Centres and the Regional Epilepsy Surgical Centres should be offered to non-surgical candidates. This includes psychological and neuropsychological testing.

School Support Program for Children with Epilepsy

Parents were anxious and afraid to send their child with epilepsy to school citing a general lack of understanding from teachers and school administrators about how to recognize and manage seizures.

Social opportunities were limited by parents and teachers citing safety concerns and lack of available school staff for supervision. The result was that many children with epilepsy were restricted at recess, lunch and gym class. Parents agreed to attend field trips to provide 1:1 support for their child with epilepsy.

Parents were also concerned that their child living with epilepsy needed psychological and neuropsychological testing that was not offered by the school or the hospital.

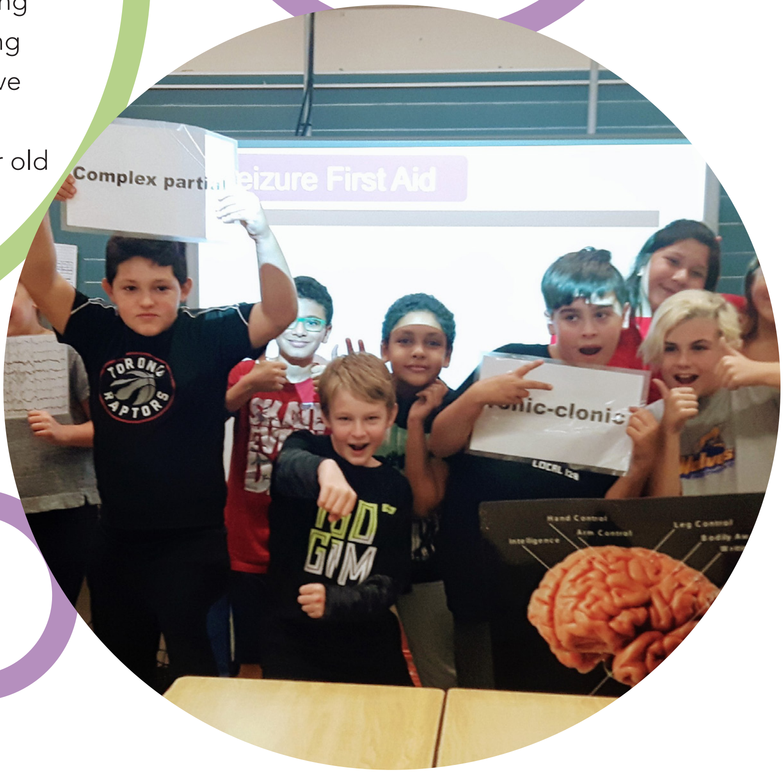
School support was identified by **73%** (105/144) parents as their top priority.

All along I've been saying there's something not right and she's not remembering what she learned one day and the teachers have said that too. It took 5 years to get the psychological testing done because the school told us that the hospital should do it and the hospital told us to follow up at the school. The test results showed she had a significant learning disability which is something we've been saying all along and now she is in grade 6 and we have wasted so much valuable time."

- Mother of a 12 year old

"She refuses to go to school. She has told me on many occasions that she doesn't feel like they (teachers) understand or hear her."

- Mother of a 5 year old



School Support Program for Children with Epilepsy

Teacher Training

61 of 105 (58%) parents requested that ESWO facilitate a teacher training at their child's school. The teacher training includes a scripted presentation with seizure identification videos.

In total:

1112 School staff (teacher, administration and educational assistants)

received a 45 minute epilepsy presentation. During the presentations, school staff learned about seizure identification and first aid, risk management and how epilepsy can impact a student's cognition, mood, behaviour, school attendance, social skills and peer relationships.

Individualized Advocacy

40 of 105 (38%) of the parents requested individualized support for their child with epilepsy. Our educators worked 1:1 with these parents to support their identified needs. They developed seizure safety plans and emergency protocols. They also helped to identify strategies to reduce absenteeism and find solutions to challenges related to student cognition, memory, learning, social isolation, teasing, bullying and classroom behaviour.

Classroom Presentations

67 of 105 (64%) of the parents requested a classroom presentation. Adapted for each grade, ESWO teaches seizure first aid, uses interactive material and videos to explain how epilepsy is diagnosed and treated and how to help a classmate during a seizure. The program helps to make the classroom a safer and more welcoming environment for the student living with epilepsy.

"I wrote a note to say that my son was very emotional. He had a seizure the night before. I get a phone call from his Principal saying: "He is crying. He's out of control. He created more work for my staff today. I can't have him in class like this, you have to come and get him". All I could think is that if he is creating more work post seizure how is she gonna handle him if he ever had a seizure at school because THAT creates work."

- Parent of a 12 year old

"I am not working because I need to be home to get my child when the school calls. We have an agreement that I will pick her up if the EA [educational assistant] is away or if she is being disruptive."

- Mother of an 8 year old

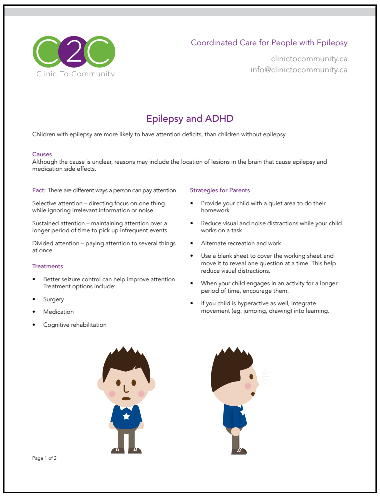
School Support Program for Children with Epilepsy

Parents were aware that their child with epilepsy was lagging behind their peers academically but struggled to get the school or hospital to provide psychological assessments. They compared their child with epilepsy to his/her siblings and identified that the child with epilepsy had more difficulty making friends, participating in programs and following routines.

Parents identified that the child with epilepsy was absent from school frequently because of medical appointments, nocturnal and post seizures symptoms, fatigue, "impending" seizures, medication changes, inadequate school accommodations, anxiety and/or parent withdrawal.

Using website analytics we identified the three most common parent downloads:

Most Common Parent Download



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Epilepsy and ADHD

Children with epilepsy are more likely to have attention deficits, than children without epilepsy.

Causes
Although the cause is unclear, reasons may include the location of lesions in the brain that cause epilepsy and medication side effects.

Fact: There are different ways a person can pay attention.

Selective attention – directing focus on one thing while ignoring irrelevant information or noise.

Sustained attention – maintaining attention over a longer period of time to pick up infrequent events.

Divided attention – paying attention to several things at once.

Treatments

- Better seizure control can help improve attention. Treatment options include:
- Surgery
- Medication
- Cognitive rehabilitation

Strategies for Parents

- Provide your child with a quiet area to do their homework
- Reduce visual and noise distractions while your child works on a task.
- Alternate recreation and work
- Use a blank sheet to cover the working sheet and move it to reveal one question at a time. This help reduce visual distractions.
- When your child engages in an activity for a longer period of time, encourage them.
- If you child is hyperactive as well, integrate movement (eg. jumping, drawing) into learning.

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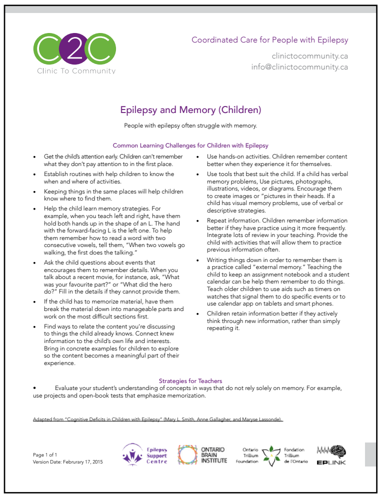
ADHD
54%



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Epilepsy and Memory (Children)

People with epilepsy often struggle with memory.

Common Learning Challenges for Children with Epilepsy

- Get the child's attention early. Children can't remember what they don't pay attention to in the first place.
- Establish routines with help children to know the when and where of activities.
- Keeping things in the same places will help children know where to find them.
- Help the child learn memory strategies. For example, when you teach left and right, have them hold both hands up in the shape of an L. The hand with the forward-facing L is the left one. To help them remember how to read a word with two consecutive vowels, tell them, "When two vowels go walking, the first does the talking."
- Ask the child questions about events that encourages them to remember details. When you talk about a recent movie, for instance, ask, "What was your favourite part?" or "What did the hero do?" Fill in the details if they cannot provide them.
- If the child has to memorize material, have them break the material down into manageable parts and work on the most difficult sections first.
- Find ways to relate the content you're discussing to things the child already knows. Connect knew information to the child's own life and interests. Bring in concrete examples for children to explore so the content becomes a meaningful part of their experience.
- Use hands-on activities. Children remember content better when they experience it for themselves.
- Use tools that best suit the child. If a child has verbal memory problems, Use pictures, photographs, illustrations, videos, or diagrams. Encourage them to create images or "pictures in their heads. If a child has visual memory problems, use of verbal or descriptive strategies.
- Repeat information. Children remember information better if they have practice using it more frequently. Integrate lots of review in your teaching. Provide the child with activities that will allow them to practice previous information often.
- Writing things down in order to remember them is a practice called "external memory." Teaching the child to keep an assignment notebook and a student calendar can be help them remember to do things. Teach older children to use aids such as timers on watches that signal them to do specific events or to use calendar app on tablets and smart phones.
- Children retain information better if they actively think through new information, rather than simply repeating it.

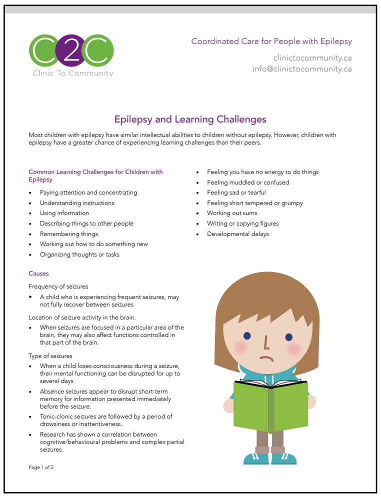
Strategies for Teachers

- Evaluate your student's understanding of concepts in ways that do not rely solely on memory. For example, use projects and open-book tests that emphasize memorization.

Adapted from "Cognitive Deficits in Children with Epilepsy" (Mary L. Smith, Anne Gallagher, and Maryse Lassonde).

Page 1 of 1
Version Date: Februrary 17, 2015

MEMORY
52%



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Epilepsy and Learning Challenges

Most children with epilepsy have similar intellectual abilities to children without epilepsy. However, children with epilepsy have a greater chance of experiencing learning challenges than their peers.

Common Learning Challenges for Children with Epilepsy

- Paying attention and concentrating
- Understanding instructions
- Using information
- Describing things to other people
- Remembering things
- Working out how to do something new
- Organizing thoughts or tasks
- Feeling you have no energy to do things
- Feeling muddled or confused
- Feeling sad or tearful
- Feeling short tempered or grumpy
- Working out sums
- Writing or copying figures
- Developmental delays

Causes

Frequency of seizures

- A child who is experiencing frequent seizures, may not fully recover between seizures

Location of seizure activity in the brain.

- When seizures are focused in a particular area of the brain, they may also affect functions controlled in that part of the brain.

Type of seizures

- When a child loses consciousness during a seizure, their mental functioning can be disrupted for up to several days
- Absence seizures appear to disrupt short-term memory for information presented immediately before the seizure.
- Tonic-clonic seizures are followed by a period of drowsiness or inattentiveness.
- Research has shown a correlation between cognitive/behavioural problems and complex partial seizures.

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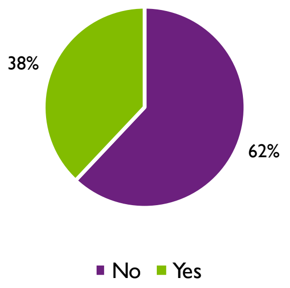
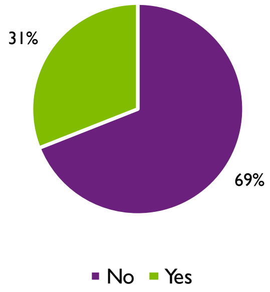
LEARNING CHALLENGES
52%

We asked parents:

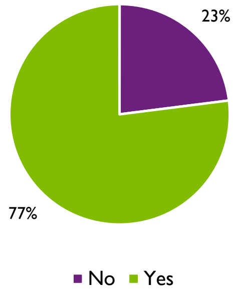
Do you feel your child with epilepsy is doing well academically?



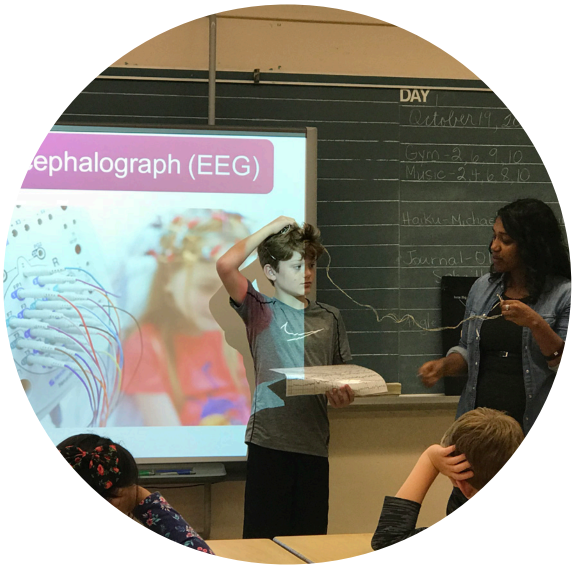
Do you feel your child with epilepsy is doing well socially?



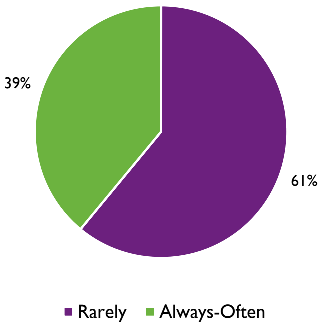
Do you have concerns about your child with epilepsy's behaviour?



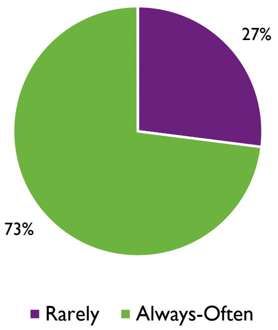
School Support Program for Children with Epilepsy



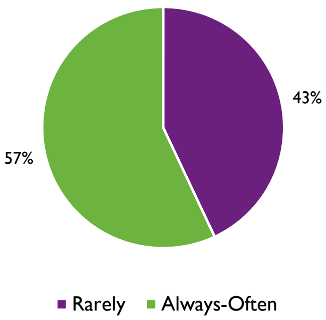
I allow my child with epilepsy to be alone.



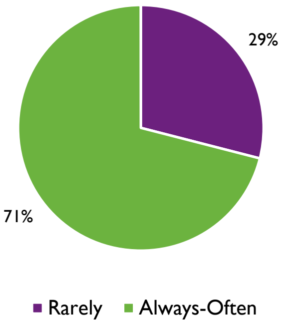
I am concerned about my child with epilepsy's school performace.



I worry my child with epilepsy will be teased or bullied.



I worry my child with epilepsy will be injured during a seizure.



School Support Program for Children with Epilepsy

"About 20% of my work is school related, mostly giving reassurance to parents and teachers and filling out seizure forms for schools."
- Paediatric Neurology Nurse Clinic Manager

"Perhaps the biggest value in the program is that ESWO is able to support my families in the community and in their schools. The program addresses school emergency plans, school staff education, and school advocacy. Many of my patients have utilized these services and have expressed that they feel more confident sending their child to school knowing that their child's teachers are capable of recognizing and responding to seizures."
- Paediatric Neurologist

"Not only did we receive information, but we had peace of mind that we were equipped with the information needed to keep these kids safe."
- Teacher

Recommendations

☐ Although seizure control in childhood is important, parents identified that improving their child's school experience through education and support is also a top priority. Providing school based support to children living with epilepsy has the potential to reduce the burden of epilepsy on the child, parent, family, teacher, health care team and economy.

☐ Core funding is needed to deliver school support for every child living with epilepsy attending school.

☐ Research is needed to determine whether school based intervention programs can improve the long term academic and social outcomes in children with epilepsy.

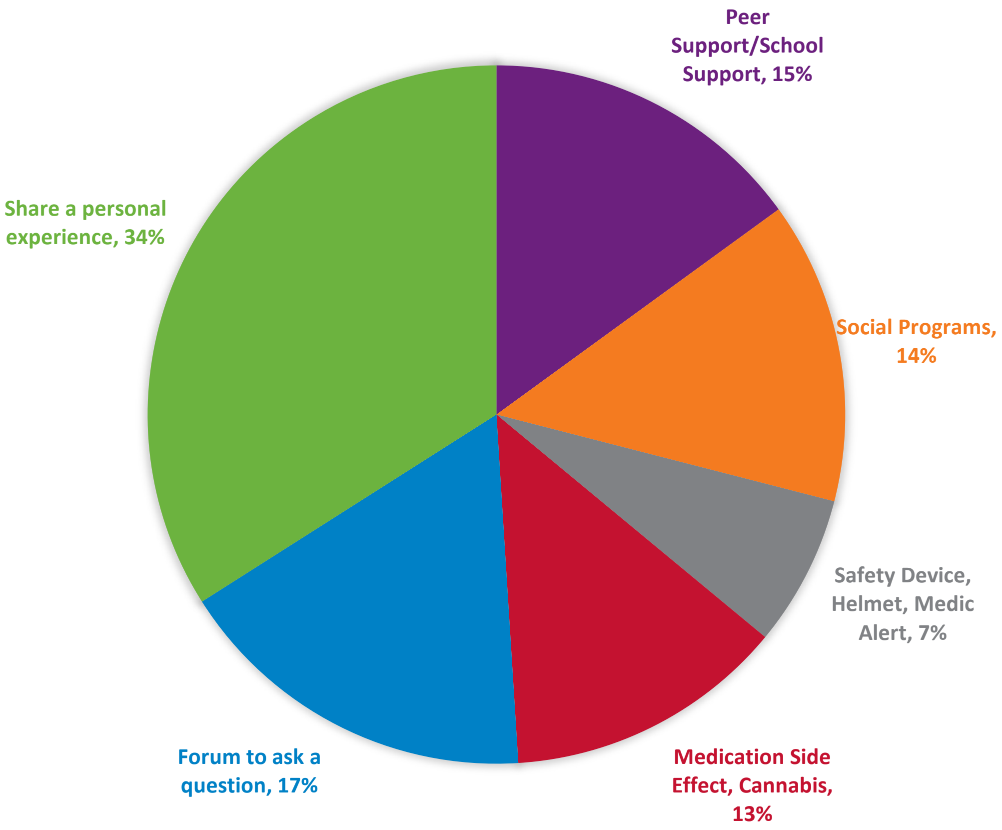
Connecting Parents to Reduce Social Isolation

Parents frequently asked us to link them with another parent for ongoing social and emotional support. We were overwhelmed by the number of parents who requested to be matched with a peer mentor, and we could not meet the demand for peer mentors. Recognizing that this peer interaction was extremely important to our parents, our solution in April 2016 was to develop a private Facebook group. We invited any parent who had received the Clinic To Community© education session to join the group.

There are currently **77** active members in the group. Of these members **20** have reached beyond the group and have become mutual friends.

Between April 13, 2016 and July 1, 2017 there were **71** conversation threads with **2577** views.

Facebook Conversation Threads



During the same period, our staff posted **136** times with **4384** total views. Staff used the group to inform parents about agency programs and to post evidence based articles or other authoritative resources related to parent conversation threads.

Connecting Parents to Reduce Social Isolation

We interviewed parents who use the group to better understand the value of this peer network:

"You can just post exactly how you feel to parents who get it. Like I can go and tell my friends what's going on and how much of a struggle things are but they don't get it. So at least when I can go to this group they all get it. You know, they understand the processes and what you're feeling and what you're going through so it's kind of like a group of friends that you can actually talk to and be able to relate to."
- Parent

"I mean some parents are on there to vent about situations that are difficult and I totally understand that you want to do that in a group that other people understand. It makes sense. But sometimes I'm like we're not there yet. We haven't had to go through that and it's daunting to think we might be there in a year. "
- Parent

"It's just nice to hear what other people are going through. It's nice to hear and to know you're not alone with struggling with some of those things with doctors or whatever for the day-to-day needs of a kid with special needs. So yeah, it's helpful."
- Parent

"I think there are some of us that are a little bit more reluctant in social situations so something like an online group appeals to people like me who are a little bit shy I guess. You can be – not anonymous but it's just easier to interact I think sometimes in that way. And usually there's somebody, so if you post something, somebody will be able to relate in some way, which is good. Yeah. So typically you get some kind of response or answer fairly quickly."
- Parent

Connecting Parents to Information

1500 users logged onto the site in the demonstration period and

44% of these users looked at multiple pages.

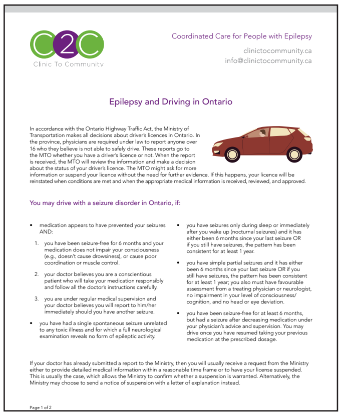
32% were returning visitors, **35%** were between the ages of 25 - 34

and **41%** accessed the site directly through a bookmark/URL.

www.clinictocommunity.ca

Highest Page Views

Epilepsy and Driving in Ontario



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Epilepsy and Driving in Ontario

In accordance with the Ontario Highway Traffic Act, the Ministry of Transportation makes all decisions about driver's licences in Ontario. In the province, physicians are required under law to report anyone over 16 who they believe is not able to safely drive. These reports go to the MTO whether you have a driver's licence or not. When the report is received, the MTO will review the information and make a decision about the status of your driver's licence. The MTO might ask for more information or suspend your licence without the need for further evidence. If this happens, your licence will be reinstated when conditions are met and when the appropriate medical information is received, reviewed, and approved.

You may drive with a seizure disorder in Ontario, if:

- medication appears to have prevented your seizures AND:
  1. you have been seizure-free for 6 months and your medication does not impair your consciousness (e.g., doesn't cause drowsiness), or cause poor coordination or muscle control.
  2. your doctor believes you are a conscientious patient who will take your medication responsibly and follow all the doctor's instructions carefully.
  3. you are under regular medical supervision and your doctor believes you will report to him/her immediately should you have another seizure.
- you have had a single spontaneous seizure unrelated to any toxic illness and for which a full neurological examination reveals no form of epileptic activity.
- you have seizures only during sleep or immediately after you wake up (nocturnal seizures) and it has either been 6 months since your last seizure OR if you still have seizures, the pattern has been consistent for at least 1 year.
- you have simple partial seizures and it has either been 6 months since your last seizure OR if you still have seizures, the pattern has been consistent for at least 1 year; you also must have favourable assessment from a treating physician or neurologist, no impairment in your level of consciousness/ cognition, and no head or eye deviation.
- you have been seizure-free for at least 6 months, but had a seizure after decreasing medication under your physician's advice and supervision. You may drive once you have resumed taking your previous medication at the prescribed dosage.

If your doctor has already submitted a report to the Ministry, then you will usually receive a request from the Ministry either to provide detailed medical information within a reasonable time frame or to have your license suspended. This is usually the case, which allows the Ministry to confirm whether a suspension is warranted. Alternatively, the Ministry may choose to send a notice of suspension with a letter of explanation instead.

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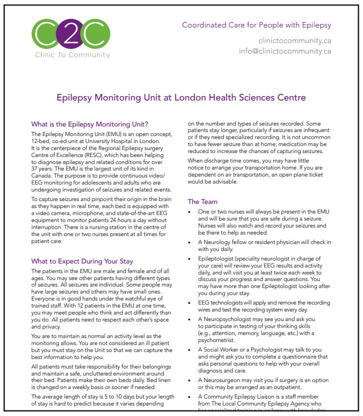
Epilepsy Monitoring Unit at London Health Sciences Centre



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Epilepsy Monitoring Unit at London Health Sciences Centre

What is the Epilepsy Monitoring Unit?

The Epilepsy Monitoring Unit (EMU) is an open concept, 12-bed, co-ed unit at University Hospital in London. It is the centerpiece of the Regional Epilepsy surgery Centre of Excellence (RESC), which has been helping to diagnose epilepsy and related conditions for over 37 years. The EMU is the largest unit of its kind in Canada. The purpose is to provide continuous video/ EEG monitoring for adolescents and adults who are undergoing investigation of seizures and related events.

To capture seizures and pinpoint their origin in the brain as they happen in real time, each bed is equipped with a video camera, microphone, and state-of-the-art EEG equipment to monitor patients 24 hours a day without interruption. There is a nursing station in the centre of the unit with one or two nurses present at all times for patient care.

What to Expect During Your Stay

The patients in the EMU are male and female and of all ages. You may see other patients having different types of seizures. All seizures are individual. Some people may have large seizures and others may have small ones. Everyone is in good hands under the watchful eye of trained staff. With 12 patients in the EMU at one time, you may meet people who think and act differently than you do. All patients need to respect each other's space and privacy.

You are to maintain as normal an activity level as the monitoring allows. You are not considered an ill patient but you must stay on the Unit so that we can capture the best information to help you.

All patients must take responsibility for their belongings and maintain a safe, uncluttered environment around their bed. Patients make their own beds daily. Bed linen is changed on a weekly basis or sooner if needed.

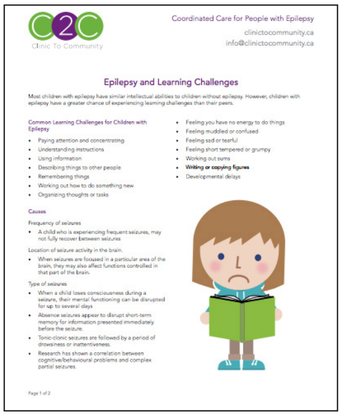
The average length of stay is 5 to 10 days but your length of stay is hard to predict because it varies depending on the number and types of seizures recorded. Some patients stay longer, particularly if seizures are infrequent or if they need specialized recording. It is not uncommon to have fewer seizure than at home; medication may be reduced to increase the chances of capturing seizures.

When discharge time comes, you may have little notice to arrange your transportation home. If you are dependent on air transportation, an open plane ticket would be advisable.

The Team

- One or two nurses will always be present in the EMU and will be sure that you are safe during a seizure. Nurses will also watch and record your seizures and be there to help as needed.
- A Neurology fellow or resident physician will check in with you daily.
- Epileptologist (speciality neurologist in charge of your care) will review your EEG results and activity daily, and will visit you at least twice each week to discuss your progress and answer questions. You may have more than one Epileptologist looking after you during your stay.
- EEG technologists will apply and remove the recording wires and test the recording system every day.
- A Neuropsychologist may see you and ask you to participate in testing of your thinking skills (e.g., attention, memory, language, etc.) with a psychometrist.
- A Social Worker or a Psychologist may talk to you and might ask you to complete a questionnaire that asks personal questions to help with your overall diagnosis and care.
- A Neurosurgeon may visit you if surgery is an option or this may be arranged as an outpatient.
- A Community Epilepsy Liaison is a staff member from The Local Community Epilepsy Agency who

Learning Challenges



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Epilepsy and Learning Challenges

Most children with epilepsy have similar intellectual abilities to children without epilepsy. However, children with epilepsy have a greater chance of experiencing learning challenges than their peers.

Common Learning Challenges for Children with Epilepsy

- Paying attention and concentrating
- Understanding instructions
- Using information
- Describing things to other people
- Remembering things
- Working out how to do something new
- Organizing thoughts or tasks
- Feeling you have no energy to do things
- Feeling muddled or confused
- Feeling sad or tearful
- Feeling short tempered or grumpy
- Working out sums
- **Writing or copying figures**
- Developmental delays

Causes

Frequency of seizures

- A child who is experiencing frequent seizures, may not fully recover between seizures

Location of seizure activity in the brain.

- When seizures are focused in a particular area of the brain, they may also affect functions controlled in that part of the brain.

Type of seizures

- When a child loses consciousness during a seizure, their mental functioning can be disrupted for up to several days
- Absence seizures appear to disrupt short-term memory for information presented immediately before the seizure.
- Tonic-clonic seizures are followed by a period of drowsiness or inattentiveness.
- Research has shown a correlation between cognitive/behavioural problems and complex partial seizures.

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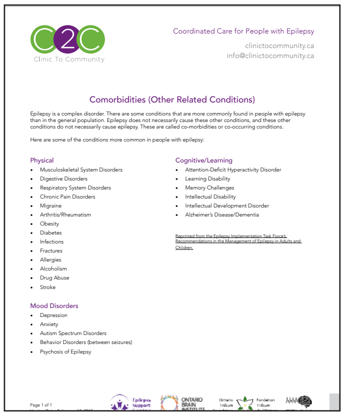
Epilepsy and Comorbidities



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Comorbidities (Other Related Conditions)

Epilepsy is a complex disorder. There are some conditions that are more commonly found in people with epilepsy than in the general population. Epilepsy does not necessarily cause these other conditions, and these other conditions do not necessarily cause epilepsy. These are called co-morbidities or co-occurring conditions.

Here are some of the conditions more common in people with epilepsy:

Physical

- Musculoskeletal System Disorders
- Digestive Disorders
- Respiratory System Disorders
- Chronic Pain Disorders
- Migraine
- Arthritis/Rheumatism
- Obesity
- Diabetes
- Infections
- Fractures
- Allergies
- Alcoholism
- Drug Abuse
- Stroke

Mood Disorders

- Depression
- Anxiety
- Autism Spectrum Disorders
- Behavior Disorders (between seizures)
- Psychosis of Epilepsy

Cognitive/Learning

- Attention-Deficit Hyperactivity Disorder
- Learning Disability
- Memory Challenges
- Intellectual Disability
- Intellectual Development Disorder
- Alzheimer's Disease/Dementia

Reprinted from the Epilepsy Implementation Task Force's Recommendations in the Management of Epilepsy in Adults and Children.

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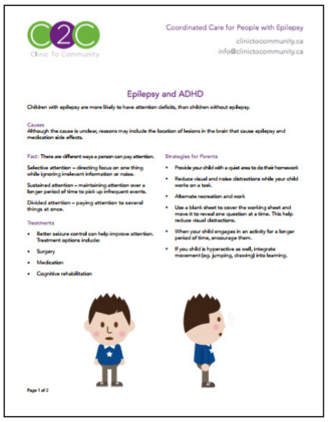
“You think that you understand what's going on and then something will change and then you'll have to go and look again at other information. If I have a question about something or even just need to be reminded about understanding something I call The Centre or go to the website.”
-Parent

Epilepsy and ADHD



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Epilepsy and ADHD

Children with epilepsy are more likely to have attention deficits, than children without epilepsy.

Causes

Although the cause is unclear, reasons may include the location of lesions in the brain that cause epilepsy and medication side effects.

Fact: There are different ways a person can pay attention.

Selective attention – directing focus on one thing while ignoring irrelevant information or noise.

Sustained attention – maintaining attention over a longer period of time to pick up infrequent events.

Divided attention – paying attention to several things at once.

Treatments

- Better seizure control can help improve attention. Treatment options include:
- Surgery
- Medication
- Cognitive rehabilitation

Strategies for Parents

- Provide your child with a quiet area to do their homework
- Reduce visual and noise distractions while your child works on a task.
- Alternate recreation and work
- Use a blank sheet to cover the working sheet and move it to reveal one question at a time. This help reduce visual distractions.
- When your child engages in an activity for a longer period of time, encourage them.
- If you child is hyperactive as well, integrate movement (eg. jumping, drawing) into learning.

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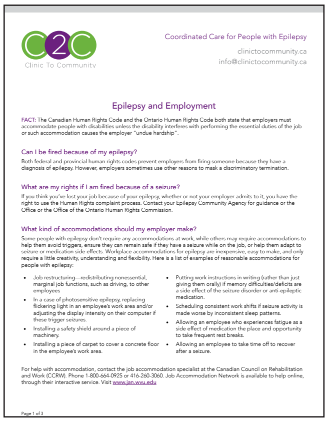
Epilepsy and Employment



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Epilepsy and Employment

FACT: The Canadian Human Rights Code and the Ontario Human Rights Code both state that employers must accommodate people with disabilities unless the disability interferes with performing the essential duties of the job or such accommodation causes the employer “undue hardship”.

Can I be fired because of my epilepsy?

Both federal and provincial human rights codes prevent employers from firing someone because they have a diagnosis of epilepsy. However, employers sometimes use other reasons to mask a discriminatory termination.

What are my rights if I am fired because of a seizure?

If you think you've lost your job because of your epilepsy, whether or not your employer admits to it, you have the right to use the Human Rights complaint process. Contact your Epilepsy Community Agency for guidance or the Office or the Office of the Ontario Human Rights Commission.

What kind of accommodations should my employer make?

Some people with epilepsy don't require any accommodations at work, while others may require accommodations to help them avoid triggers, ensure they can remain safe if they have a seizure while on the job, or help them adapt to seizure or medication side effects. Workplace accommodations for epilepsy are inexpensive, easy to make, and only require a little creativity, understanding and flexibility. Here is a list of examples of reasonable accommodations for people with epilepsy:

- Job restructuring—redistributing nonessential, marginal job functions, such as driving, to other employees
- In a case of photosensitive epilepsy, replacing flickering light in an employee's work area and/or adjusting the display intensity on their computer if these trigger seizures.
- Installing a safety shield around a piece of machinery.
- Installing a piece of carpet to cover a concrete floor in the employee's work area.
- Putting work instructions in writing (rather than just giving them orally) if memory difficulties/deficits are a side effect of the seizure disorder or anti-epileptic medication.
- Scheduling consistent work shifts if seizure activity is made worse by inconsistent sleep patterns.
- Allowing an employee who experiences fatigue as a side effect of medication the place and opportunity to take frequent rest breaks.
- Allowing an employee to take time off to recover after a seizure.

For help with accommodation, contact the job accommodation specialist at the Canadian Council on Rehabilitation and Work (CCRW). Phone 1-800-664-0925 or 416-260-3060. Job Accommodation Network is available to help online, through their interactive service. Visit www.jan.wvu.edu

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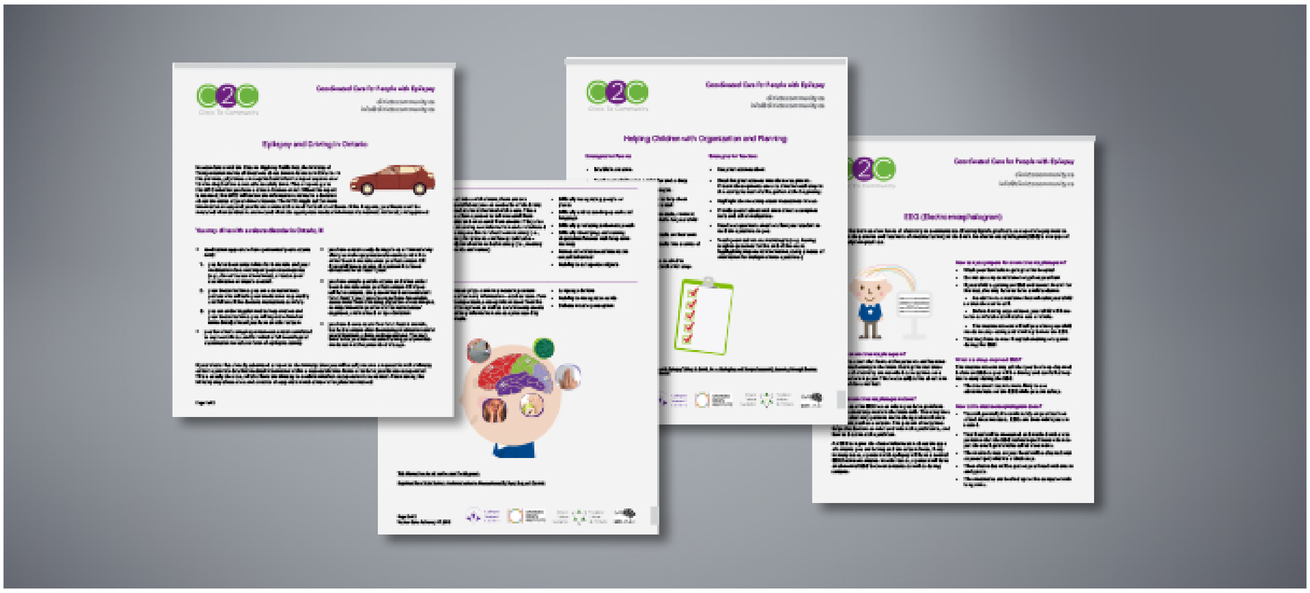

List of Strategy Sheets

How to help my family cope with the unpredictability of the next seizure

- ☐ Seizure Log
- ☐ Planning for your Health Care Appointment
- ☐ SUDEP
- ☐ Types of Seizures

How to help my child succeed in school

- ☐ Student Support Program
- ☐ Epilepsy and ADHD
- ☐ Learning Challenges
- ☐ Helping Children with Organization and Planning
- ☐ Epilepsy and Memory (Children)

Diagnosing and Treating Epilepsy

- ☐ Comorbidities
- ☐ EEG and VEEG
- ☐ Psychogenic Non-Epileptic Seizures
- ☐ Scalp EEG Leads in the Epilepsy Monitoring Unit
- ☐ Intracranial Electrode Implantation
- ☐ Epilepsy Monitoring Unit at London Health Sciences Centre
- ☐ Medications
- ☐ Surgery
- ☐ Ketogenic Diet Therapy for Epilepsy
- ☐ Complementary Therapies
- ☐ Lobes of the Brain/Functions

Living Well with Epilepsy

- ☐ Physical Activity and Epilepsy
- ☐ Life Insurance and Epilepsy
- ☐ Epilepsy and Driving in Ontario
- ☐ Epilepsy and Anxiety
- ☐ Epilepsy and Memory (Adults)
- ☐ Epilepsy and Depression
- ☐ Seizure Response Dogs

How to Talk to Others about my Epilepsy

- ☐ Talking About Your Epilepsy
- ☐ Epilepsy and Employment
- ☐ Employment Disclosure Chart

Women's Health

- ☐ Birth Control, Pregnancy, Breast Feeding, Menopause

Government Supports

- ☐ Financial Support (EI Sickness Benefits, Ontario Works, ODSP, CPP Disability Benefits, RDSPs, Tax Credits)
- ☐ Drug Benefit Programs (Trillium, ODSP)

Version Date:October, 2017

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SUDEP

Sudden Unexpected Death in Epilepsy (SUDEP)

Sudden Unexpected Death in Epilepsy (SUDEP) is a controversial topic and the most tragic outcome in epilepsy. Families that are bereaved by SUDEP feel it is very important that all health care providers discuss SUDEP and provide a risk management assessment to their epilepsy patients. In practice, 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 epilepsy patients.

Community Epilepsy Agencies believe that sharing accurate information about SUDEP can optimize epilepsy self-management, reduce anxiety and distress and engage the person with epilepsy and their families in their own care.

In the demonstration program we provided every parent and adult with epilepsy with a brochure from SUDEP Aware. We spent time with the individual and their family going through the brochure and answering their questions. We encouraged them to contact their health care provider to talk about their personal situation if they felt that they were at risk.

We surveyed 90 parents to better understand whether they felt the information about SUDEP should be included in the Clinic To Community© Program and **89%** said YES.

"I am burdened by the fact that I learned more about epilepsy since Sarah's SUDEP death than during the 7 years that Sarah had seizures. Sarah needed to be taught how to cope and manage her epilepsy on her own. We all should have been told about SUDEP."

- Sarah's Mom

"A frightening but necessary conversation"
-Parent

"..my husband has epilepsy and he's…somewhat loosey-goosey with medication. Our son also has epilepsy, and we're very careful with our son's medication. Neither of us had a clue that SUDEP was a thing. Which is strange - since my husband has lived with epilepsy for, 20 some odd years – that we didn't know that. I will say to him you need to be careful about taking your medication."
- Parent and spouse

Adults Living with Epilepsy

The following pages relate to adults with epilepsy who were referred to our Community Epilepsy Agency between December 2015 and July 2017.

The data clearly highlights the impact of epilepsy as adult life was seen as unsatisfactory with high rates of unemployment, poverty and poor mental health.

The average length of time from diagnosis to receiving the Clinic To Community© education session was 9.7 years for the adults in our research study.

In our opinion these adults needed to be linked with a system navigator and community support at the time of their epilepsy diagnosis and not a decade later when they had given up hope.

Adults Living With Epilepsy

189 adults were enrolled in the demonstration program

Age groups:

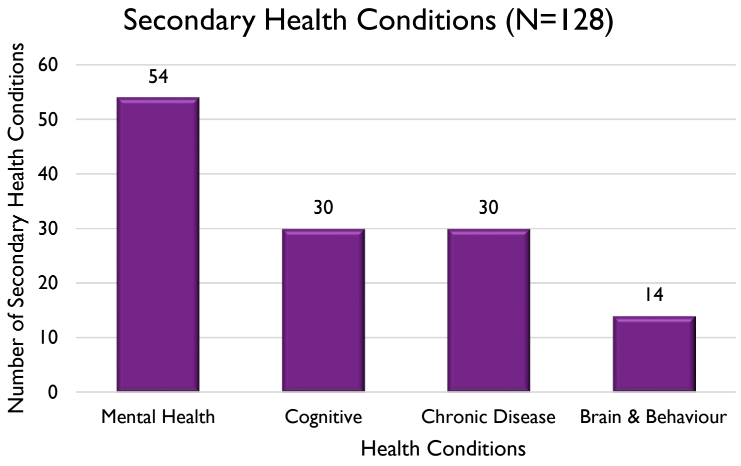
144
19-50 years

26
51-64 years

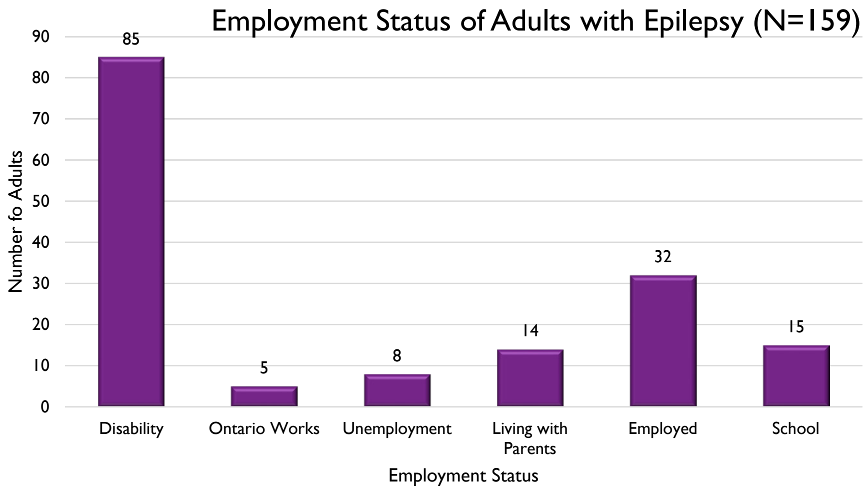
6
65+

13
Unknown

We asked adults to identify whether they had any other medical conditions or impairment beyond their epilepsy diagnosis.



42% (54/128) reported that they had epilepsy and depression and/or epilepsy and anxiety.

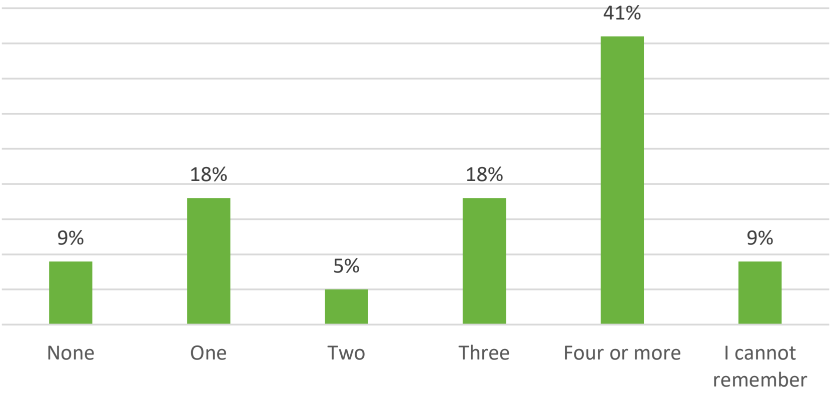


20% identified that they were currently employed

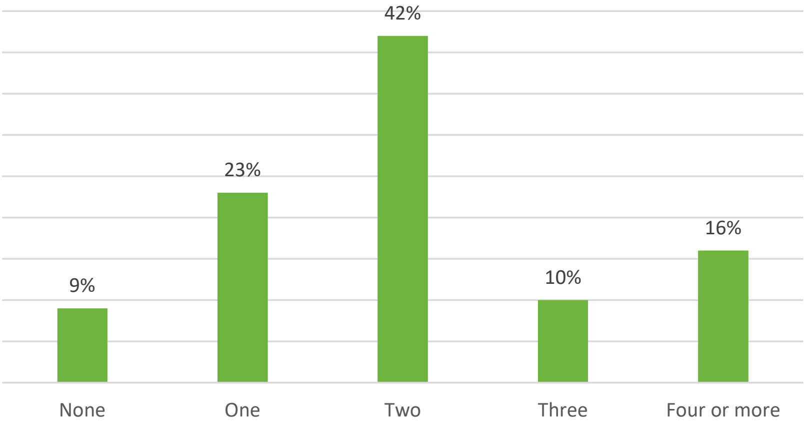
53% identified that they were living on disability support programs (LTD, ODSP or CPP)

Profile of Adults

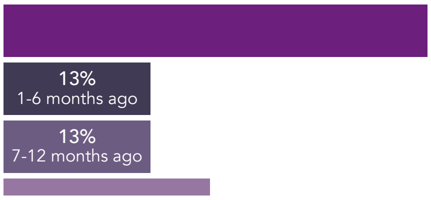
Total # of Anti-Seizure Medications Tried by Adults Living with Epilepsy



Current # of Daily Medications (Adults)



Adult



68% have active epilepsy

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

Adults Living With Epilepsy

Top 3 Priorities of Adults 19 - 50 years

Advocacy #1 request (used by 42% of adults)

- 38% employment support - help finding or keeping a job
- 35% mental health support - help with depression and anxiety
- 27% disability - help finding income support

> "My neurologist told me I'm not eligible for surgery and that I should come to the Centre to see what you guys could do for me"
> - Adult

Social Support #2 request (used by 37% of adults)

- 59% peer support or support groups
- 41% social events

Advocacy #3 request (used by 21% of adults)

- 64% seeking individualized support - lifestyle, surgery, cannabis
- 36% seeking standardized health information

> "My doctor told me to come to get help filling out my disability forms"
> - Adult

All **189** adults received a 60 minute education session.

- **64%** (121/189) adults used at least 2 other programs or services.
- In total, adults requested **222** programs during the demonstration period.
- **Average length of time from diagnosis to receiving the Clinic To Community© education session was 9.7 years**

Top Priority of Adults Aged 51+ was 'Financial and Drug Benefits'

Adult Life with Epilepsy

Adult life with epilepsy is unsatisfactory with high rates of unemployment, poverty, social isolation and mental health.

- Nationally, 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, Statistics Canada)

- Persons living 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)

- 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)

Recommendations

☐ Health care providers should recognize that the burden of epilepsy is significant and that the seizure itself is only one part of this burden. Early referrals for community based support may change long term outcomes in epilepsy and improve employment rates in persons with epilepsy.

☐ Epilepsy needs to be identified as a public health priority with funding across Ministries in Ontario to improve the outcomes of this marginalized group.

☐ Policy makers should look at indirect economic costs due to working-age disability. These costs are the greatest in traumatic brain injury followed by epilepsy (from $2.5 billion in 2011 to $2.8 billion projected in 2031). Providing early patient education and self management skills may reduce costs. It will also restore dignity in this marginalized group.

☐ Designated mental health funding should be available for persons with epilepsy and depression and anxiety.

☐ The psychosocial support that is available to surgical candidates through the District Epilepsy Centres and the Regional Epilepsy Surgical Centres should be offered to non-surgical candidates. This includes psychological and neuropsychological testing.

☐ Funding needs to be available so that every newly diagnosed person with epilepsy is provided with epilepsy education to improve their knowledge and self management skills. We have existing models that can be replicated for epilepsy (for example First Link for Alzheimer's, Diabetes Care Strategy).

C2C
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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 (797 York St. Unit 3 London, ON N5W 6A8).

Referral Date: ____________________

Name: ____________________ Date of Birth: ____________________

Address: ____________________

City: __________ Postal Code: __________ E-mail: __________

Phone: __________ Seizure Type(s): ____________________

Reason For Referral (check all that apply):

- ☐ New Diagnosis / Coping Strategies
- ☐ Seizure Education / First Aid Training
- ☐ Parent and Family Support
- ☐ Other ____________________
- ☐ School/ Workplace Support
- ☐ Volunteering / Social Programs

Referral Made By: ____________________

Phone: ____________________ Fax: ____________________

Consent to Contact (client / guardian signature): ____________________

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