

Community Pathways

for people with seizures and epilepsy



Sarah died of Sudden Unexplained Death in Epilepsy (SUDEP) on August 27, 2012. She was 23 years old. Her mother Julie has asked that we share her epilepsy story as a legacy to her daughter so that others can learn from her family's devastating loss.

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30% of people with epilepsy have medically refractory seizures. If there is no improvement after two adequate trials of anti-seizure medications, the person with epilepsy should be referred to the District Epilepsy Centre.

“Projected indirect economic costs due to working-age death and disability in epilepsy are \$2.7 billion per year.”

Statistics Canada, Public Health Agency of Canada, 2015

“Persons with epilepsy have lower quality of life, family function and social support as compared to other chronically ill individuals”

Health Quality Ontario 2012

94,500 Ontarians have a diagnosis of epilepsy



‘Stroke is the number one cause of epilepsy in seniors’

‘A management plan for women with epilepsy should address pregnancy and contraception’



*‘A diagnosis of Epilepsy is given to a person who has **two unprovoked seizures** or one seizure with a strong possibility that they will have another.’*

Seizures are due to brief disturbances in the electrical functions of the brain

*the term **TONIC CLONIC** replaced the term Grand Mal in 1969*

All persons with medically refractory focal seizures should be referred to the District Epilepsy Centre for assessment of surgical candidacy.

Generalized Seizures

In generalized seizures, abnormal electrical activity occurs throughout the whole brain (both hemispheres)

Generalized seizures alter awareness.

They can be convulsive or non-convulsive: Tonic Clonic, Tonic, Clonic, Absence, Atonic, Myoclonic



Focal Seizures

Originate within networks limited to one hemisphere.

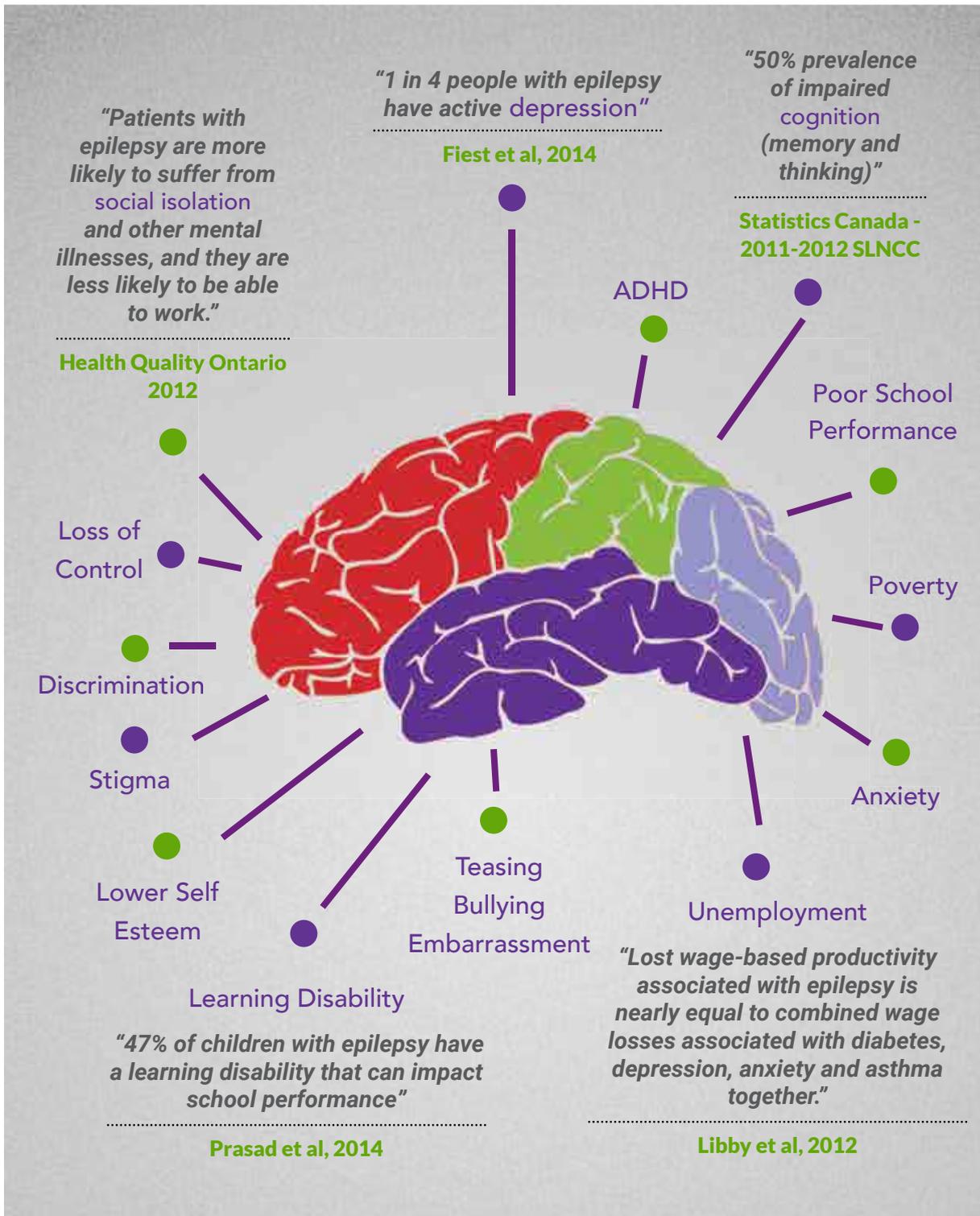
They are characterized according to one or more features: Aura, Motor, Autonomic

Focal seizures may or may not alter awareness.



Epilepsy has **life consequences** that extend well beyond the experience of having seizures. The impact can be on any aspect of cognitive, physical, social, sensory or emotional functioning.

The **unpredictability** of when a seizure occurs is one of the main causes of disability in epilepsy.



Clinic To Community[®] 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) 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.



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
- Epilepsy Program at Children's Hospital of Western Ontario
- Treatment Pathways
- 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
- Student Support Program
- 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)

Access to these strategy sheets online at clinictocommunity.ca

Sarah's Story *Continued from page 1.*

Dear Health Care Provider:

Sarah's first seizure was in July 2005. She was 16 years old and it happened at night. Sarah was very confused and I was terrified. I called an ambulance and we went to the Emergency Department. One month later, Sarah had her second seizure. We returned to the Emergency Department and this time Sarah was referred to a neurologist.

The neurologist diagnosed Sarah with 'epilepsy' and put her on a medication. I remember that at this initial meeting the tone was that 'epilepsy' was not a big deal. The neurologist covered seizure first aid and gave us instructions on how to take the medication. There was no discussion about so many topics that could have helped Sarah to live a long, healthy life with epilepsy. Sarah needed to be told about her risks and she needed to understand that depression was common in epilepsy. We needed to be told about SUDEP.

Sarah saw her neurologist once a year. At these appointments they talked about the number of seizures she had in the past year and he renewed her prescription.

At age 20 Sarah moved into her own apartment. After moving out she made the decision to discontinue her medication because she hated the side effects. She felt very tired, had headaches, eye sensitivity, and felt that she could not concentrate because of the medication. We have since learned that Sarah's age, discontinuation of her medication and nocturnal seizures put her at greater risk of SUDEP.

I feel enormous guilt and anger when I think about Sarah's death. I am burdened by the fact that I have learned more about epilepsy since Sarah's death than during the 7 years that Sarah had seizures. I now realize that Sarah had depression but it went undiagnosed and untreated.

Families need more than medication to manage their seizures. They need information about the diagnosis and guidance on who to talk to when they are struggling to cope. They need to be referred to the Epilepsy Support Centre where they can find answers to their questions. Sarah needed to be supported when she moved out of our home to live alone. She needed to be taught how to cope and to manage her epilepsy on her own. We all should have been told about SUDEP.

I am writing this letter because I believe that we need to have a better system of care when someone is diagnosed with epilepsy in Ontario. Doctors need to be trained to talk to families about every aspect of epilepsy. Families need to be provided with information about SUDEP and the other challenges that are associated with this misunderstood diagnosis.

Sincerely,
Julie & Jon Jackson



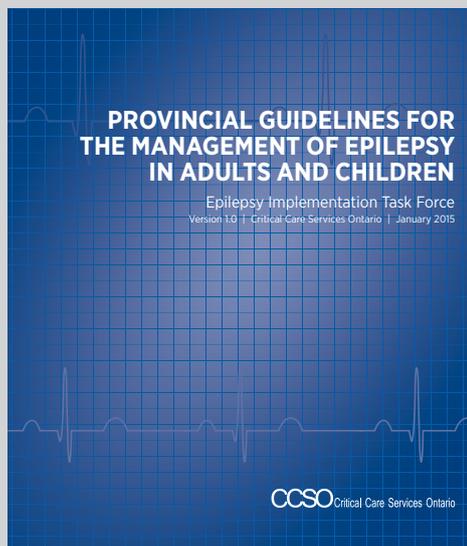
Downloads of these brochures are available at www.clinictocommunity.ca

In January 2015, Critical Care Services Ontario published Provincial Guidelines for the Management of Epilepsy in Adults and Children. The guidelines were developed by the Epilepsy Implementation Task Force in an effort to standardize and improve epilepsy care across the Province.

In the guidelines there is an **education checklist** and sections on diagnosis, treatment, patient and caregiver education, women with epilepsy, patient referrals, follow-up and co-morbidities.

The 'Clinic to Community' program was developed in response to these guidelines. It is a referral program for healthcare providers to link their patients to community based seizure and epilepsy education and a network of community supports. It is offered to your patients at no cost.

You will find referral information and the entire Guidelines document at www.clinictocommunity.ca in the 'Health Care Provider' Section.



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 your patient 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 your patients to cope with the unpredictability and stigma associated with this misunderstood disease.

The program will link your patient to a network of community support.

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 the Epilepsy Support Centre.
- 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 Support Centre
690 Hale St - London, ON N5W 1H4

Fax: 519.433.4079
Email: info@clnictocommunity.ca
Website: www.clnictocommunity.ca



Thames Valley - 519.433.4073	Sarnia - 519.330.0416
Huron Perth - 519.433.4073	Chatham - 519.365.5131
Grey Bruce - 519.433.4073	Windsor - 519.890.6614



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Trillium
Foundation



Fondation
Trillium
de l'Ontario





Coordinated Care for People with Epilepsy

clinictocommunity.ca
info@clinictocommunity.ca

Referral Form

Please fill out and return to Epilepsy Support Centre:

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

School/ Workplace Support

Seizure Education / First Aid Training

Volunteering / Social Programs

Parent and Family Support

Other _____

Referral Made By: _____

Phone: _____ Fax: _____

Consent to Contact (client / guardian signature): _____

