



Epilepsy Action Day at Queen's Park

March 6th 2012



Who we are

Dedicated to promoting independence and optimal quality of life for children and adults living with seizure disorders, by promoting information, awareness, support services, advocacy, education and research



EPILEPSY YORK REGION



EPILEPSY PETERBOROUGH & AREA



Epilepsy Durham Region
Building Healthy Communities



The Epilepsy Support Centre
Providing support for those living with epilepsy and seizure disorders.



EPILEPSY
KINGSTON



**SUDEP
aware**
www.sudepaware.org

Epilepsy
Huron-Perth-Bruce-Grey



EPILEPSY WATERLOO-WELLINGTON



UNIVERSITY OF TORONTO EPILEPSY RESEARCH PROGRAM



Epilepsy Niagara

SEIZURE & BRAIN INJURY CENTRE



EPILEPSY
Toronto



**Epilepsy
Halton Peel**

Who we are



- Approximately 10,100 people are served by epilepsy agencies in Ontario through a variety of supports and services including (but not limited to):
 - Support and information via phone, online and walk-ins
 - Brochures in doctor offices
 - School advocacy/education
 - Referrals to other community supports (community connectors)
 - Public education displays / newsletters/ social media
 - Employer advocacy
 - Seizure First Aid training
 - Support groups/peer support/counselling/social (psychosocial)
- Contributions of nearly 2,000 volunteers
- Our collective budgets are shoestring at \$2,963,000 - average budget is about \$100,000 (excluding Epilepsy Toronto at \$1,300,000)





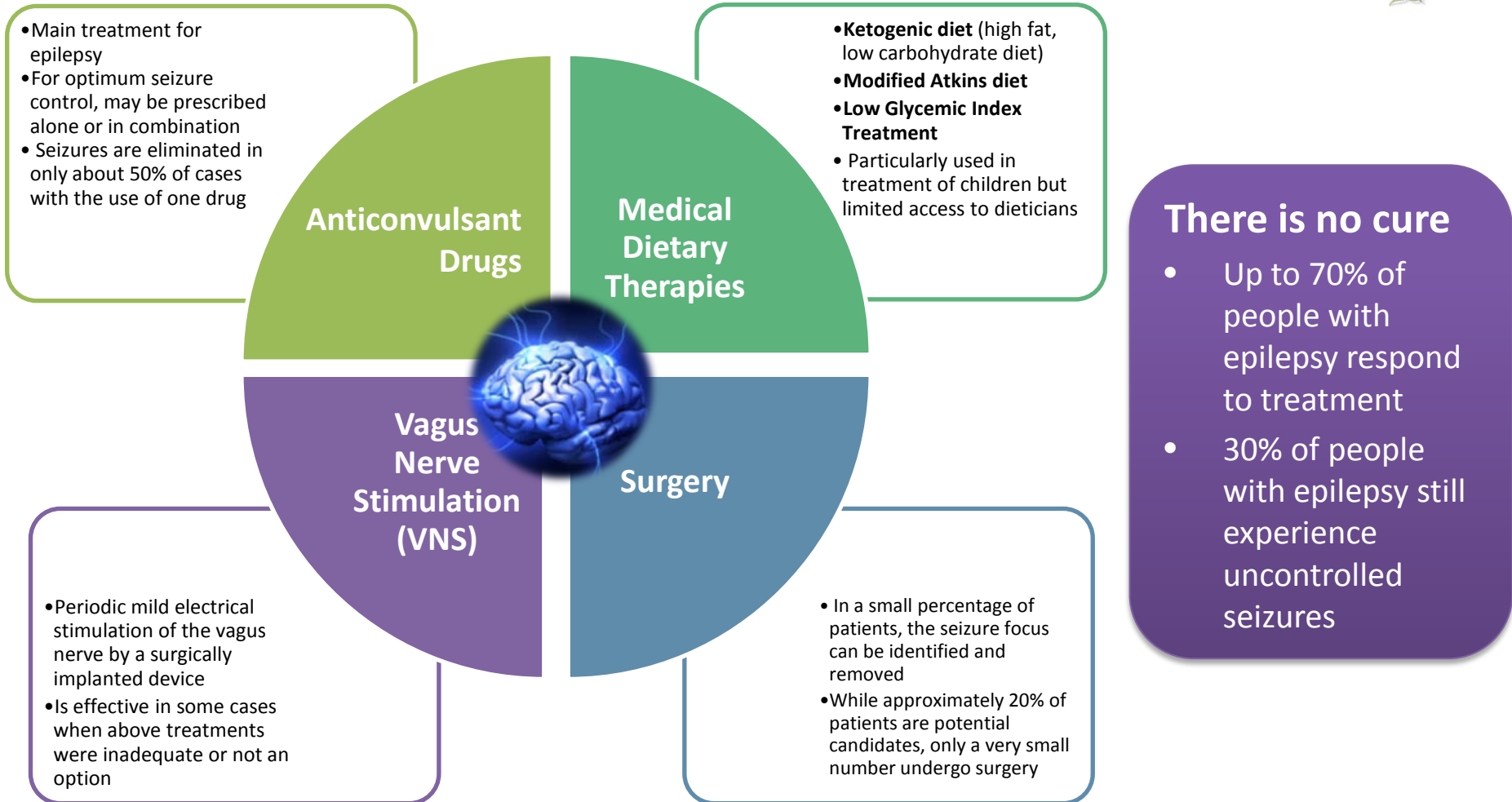
What is Epilepsy?

A group of disorders of the central nervous system (brain), characterized by recurrent unprovoked seizures

What is a Seizure?

- Occurs when normal electrical balance in the brain is lost – nerve cells misfire, firing at abnormally higher frequencies
- Convulsions are the physical effects of these sudden, brief, uncontrolled bursts of abnormal electrical activity
- Type of seizure depends on which area of the brain is involved
- May experience an alteration in behaviour, consciousness, movement, perception and/or sensation

Treatment





The Impact of Epilepsy...

- Epilepsy is the second most common neurological condition (after headache)
- Significant mortality: 2-3 times higher than in the general population
- Physical hazards are a particular concern due to the unpredictability of the seizures
- Can occur at any age but is especially prevalent in childhood, adolescence and old age
- Comorbidities include:
 - Depression
 - Cognitive impairment
 - Sleep disorders
 - Migraine
- Affecting 300,000 people in Canada and approximately 65,000 in Ontario (10,000 children and 55,000 adults)



The Impact
of Epilepsy on
Canadians

- *The Impact of Epilepsy on Canadians* survey was conducted on-line and on paper between August 9 and October 14, 2011 by Leger Marketing to explore how Canadian adults living with epilepsy are impacted in respect to quality of life, health and access to care and treatment.
- The survey reveals that Canadian adults struggling to control the common seizure disorder face serious health obstacles, including access to specialized care and treatment options, as well as numerous social impacts. Stigma, lack of independence, and social and work barriers are identified by respondents among the top challenges that need to be addressed.
- In addition to the challenges identified on a national level, the survey also highlights key regional disparities defining the differences in quality of life, health and access to care and treatment.

... in Ontario



Key Survey Findings for Ontario:

- More Ontarians believe their seizures could be better controlled (38% versus 25% among those in the West and 27% among those in Quebec).
- Ontarians and Westerners (both at 54%) agree that they are affected by the stigma surrounding epilepsy versus those living in Quebec (36%).
- At 80%, respondents in Ontario, the West (80%) and Atlantic Canada (83%) are in agreement that epilepsy should be classified as a disability (versus Quebec 70%).
- People in Ontario living with epilepsy have been prescribed a higher number of drugs in the past (4.3 versus 3.6 for those in the West and Quebec).
- Relative to Quebec (30%), Ontarians are much more likely to agree that they can't get a job if they disclose they have epilepsy (46%).
- People in Ontario (61%) are more likely to mention the biggest challenge they face is lack of independence (versus 48% in the West and 51% in Quebec).
- Ontarians (53%) are more likely to agree their family is overprotective when compared to Quebecers (37%) or Western residents (35%).
- More than three-in-10 (37%) Ontarians are unaware that government disability benefit programs even exist, which is almost in line with the response on a national level (32%).
- Ontarians and Westerners (both at 23%) with epilepsy are more likely to pay out-of-pocket for their medication versus Quebec (8%).
- Residents in Ontario (41%) are considerably more unsure as to whether or not social services are available to them versus Quebec (18%).

Key Issue: Standards of Care

Current situation

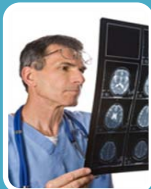
- There is no organized system of care in Ontario for people with epilepsy
- There is no support system for people with epilepsy and their families
- There are no evidence based clinical guidelines in place regarding medical treatment

Key Survey Findings

- Wait 4 years for diagnosis and 1 year to see epilepsy specialist
- 60% of respondents who were candidates for surgery waited up to 5 years to access the procedure
- 40% see GP/family doctor – only 30% have ever seen an epileptologist

OHTAC recommendations

- The Ontario Health Technology Advisory Committee (OHTAC) has made recommendations on **Care for Drug-Refractory Epilepsy in Ontario** which were released November 2011



Did you know that...

- ... on average, it takes nearly 4 years to be diagnosed with epilepsy?
- ... and 1 year to be seen for the first time by an epilepsy specialist?

Ontario Epilepsy Strategy Needed

RECOMMENDATIONS:

We strongly support and urge the adoption of the Ontario Epilepsy Strategy proposed by OHTAC

- Ontarians who suffer from epilepsy should have universal access to quality, evidence based, comprehensive healthcare through the development and execution of the proposed Ontario Epilepsy Strategy
- The role of the community organizations – currently operating with no government funding – must not be overlooked. Their valuable role should be incorporated into Ontario's Epilepsy Strategy



A brief of summary OHTAC's recommendations

- * Short-Term: maximize system's capacity for surgery:
 - Undertake surgery gap analysis
 - Provide increased resources for surgery
 - Standardize protocols for pre-surgical evaluations
 - Deal with LHIN challenges
- * Long-Term: develop new integrated system for epilepsy care in Ontario
 - Establish new distinct and regional epilepsy centres
 - Standardizations of care and development of guidelines
 - Establish permanent expert epilepsy advisory panel to establish and evaluate benchmarks
 - Medical training programs
 - Epilepsy-specific wait-time strategy
 - Establish epilepsy database



Key Issue: Access to Treatment

Current situation

- Many Ontarians living with epilepsy depend on the Ontario Public Drug Program (OPDP) for access to medications
- The last 3 epilepsy drugs approved for reimbursement by the OPDP are only available through the Exceptional Access Program (EAP) – a process which is very lengthy leading to significant delays for Ontarians to access the medications they desperately need to control their seizures

Important to know...

- **30% of people do not respond to currently available treatments and still experience uncontrolled seizures**
- Lack of seizure control severely impacts independence, productivity and overall quality of life for Ontarians living with epilepsy
- 1 in 1000 people with epilepsy die of SUDEP (sudden unexpected death in epilepsy) per year. Having as few seizures as possible is the only way to reduce the risk of SUDEP. Quality of care and prompt access to medications is vital to prevent SUDEP

Recent drug shortages



- Over the past 2 years there have been shortages of several AEDs
- Sudden discontinuation of an AED is potentially life-threatening for someone with epilepsy
- Life-threatening seizures are the most serious concern
- In addition to the immediate concerns when an AED is not available (breakthrough seizures and possibly status epilepticus which can be fatal) there is also the risk that people whose seizures are well-controlled may not achieve seizure control with a different medication (if a substitution is made) or when they resume their regular AED (if it becomes available again)

Ensure Access to Treatment



Did you know that...

... since 2003 only 2 new drugs have been approved in Canada for treatment of epilepsy?

... 82% depend on medications to manage seizures and have been prescribed an average of 4 since diagnosis?

RECOMMENDATIONS:

As new treatments for epilepsy become available Ontario must ensure access to these treatment options so people with epilepsy have the chance to better control their seizures and improve their quality of life

- Side effects of drug shortages negatively impact the healthcare system
 - Increased usage of health system, often emergency room trips
 - Negative impacts on employment
- Recent drug shortages mean there is an even greater and more urgent need for people to have access to new medications in Ontario

Key Issue: Access to Disability & Employment Supports



Current situation

- Those with **uncontrolled** seizures experience significant difficulties in all aspects of life
- Many are denied employment due to their disability
- Ontario's employment support programs do not recognize the unique needs of people with epilepsy in the work force
- **Despite uncontrolled seizures, many are denied ODSP support because epilepsy is not considered a "substantial impairment"**


Key Findings...

- Those in the workforce often face: negative and uninformed attitudes, outright (and illegal) discrimination, unnecessary driving requirements, fear of repercussions after disclosure, under-utilization of their skills
- 50% say their job choices are limited
- 40% say they can't get a job if they disclose that they have epilepsy
- 77% believe uncontrolled epilepsy should be classified as a disability

Improve Accessibility



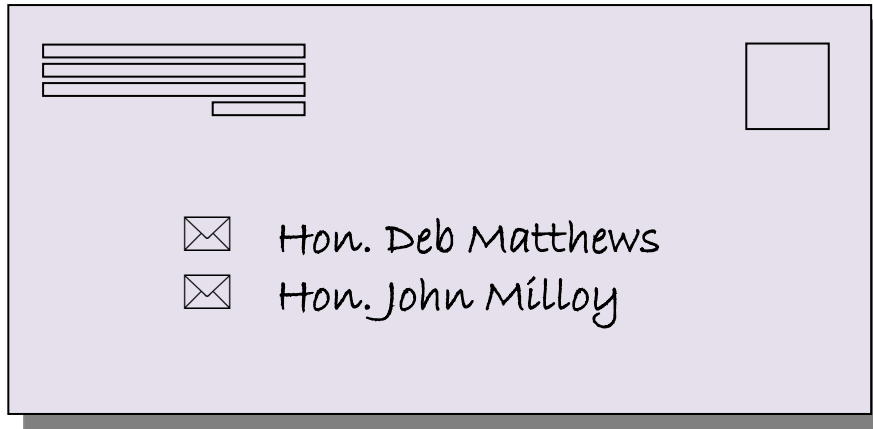
RECOMMENDATIONS:

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- ODSP recognize that uncontrolled seizures constitutes a “**substantial impairment**” therefore making those individuals eligible for income support
 - **Employment services are made available** to persons with epilepsy in a manner that recognizes and incorporates their unique need for assessment, counselling, advocacy and accommodation
 - **Employers are educated** how to facilitate individual’s best contributions



What Can You Do?

We need your help!



✓ **Help raise awareness by wearing purple on March 26**



Please advocate for **consistent standards of patient care and access to epilepsy medication and the adoption of the Ontario Epilepsy Strategy OHTAC recommendations including community involvement** with:

- ☑ Hon. Deb Matthews, Minister of Health and Long-Term Care

Please advocate for **access to disability and employment supports** with:

- ☑ Hon. John Milloy, Minister of Community and Social Services

Thank you!



For more information, please contact:

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