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## Proposed Strategy for Epilepsy Care in Ontario

Epilepsy agencies in Ontario applaud Health Quality Ontario, the Ontario Health Technology Advisory Committee (OHTAC) and the Epilepsy Expert Panel for their study and proposed recommendations to improve care for people with drug-refractory epilepsy in Ontario.

Epilepsy agencies emphatically support the vision that ***Ontarians of all ages who suffer from epilepsy should have universal access to quality, evidence-based, comprehensive health care at the right time and in the right place.***

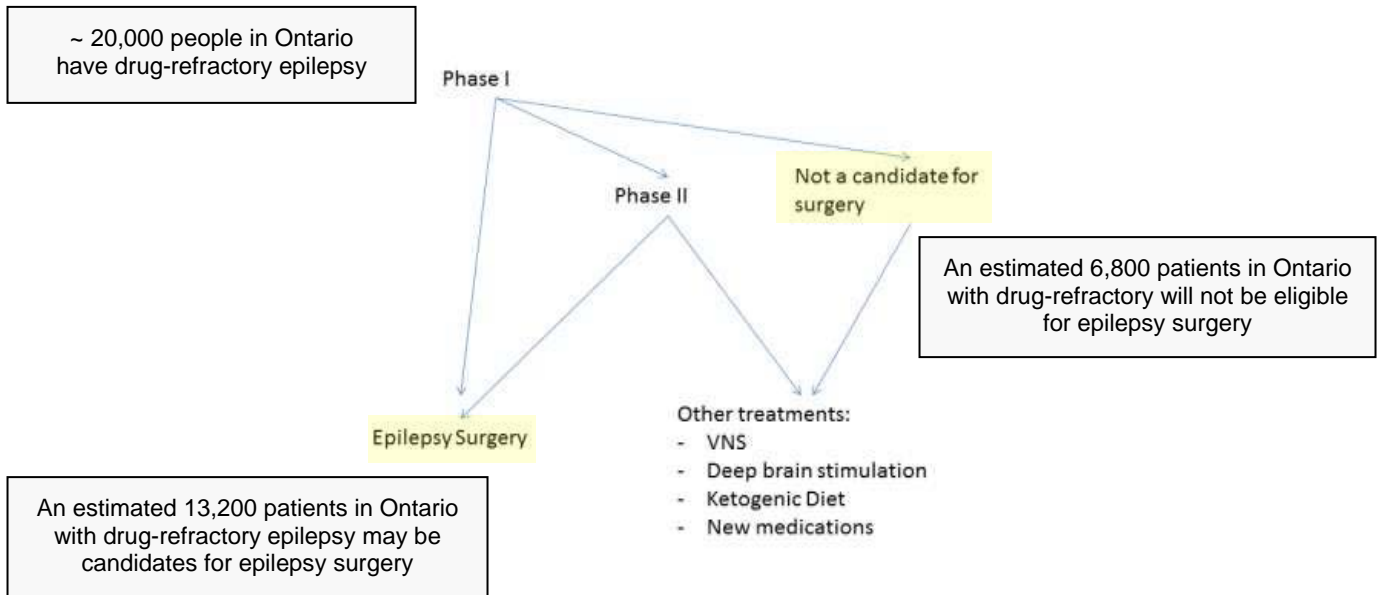
According to the draft OHTAC report<sup>1</sup>, an estimated 65,000 individuals (10,000 children and 55,000 adults) Ontarians have epilepsy (not including aboriginal individuals with epilepsy). Of this group, approximately 30% or 20,000 Ontarians continue to experience seizures despite drug therapy, this is known as drug-refractory epilepsy. An additional 6,500 Ontarians will develop epilepsy each year and nearly 2,000 people with new onset epilepsy will not obtain seizure control with medication. Epilepsy agencies agree with Health Quality Ontario and OHTAC that epilepsy is a major public health issue in this province.

***epilepsy is a major public health issue in Ontario which, to date, has been inadequately addressed. Epilepsy care in Ontario varies from being nonexistent to fragmented, and access to whatever care exists is uneven and unpredictable.***<sup>2</sup>

The proposed strategy for epilepsy care aims to address the disparities that currently exist in Ontario. The OHTAC recommendations are a very important step towards optimizing patient outcomes for people with drug-refractory epilepsy. A provincial plan to standardize epilepsy care in Ontario and ensure people can access effective treatment no matter where they live is crucial. The epilepsy strategy has the potential to improve treatment outcomes for the estimated 13,200 people in Ontario who may be candidates for epilepsy surgery.

**Figure: Pathway to Epilepsy Surgery**

Source: OHTAC Recommendation: Care for Drug-Refractory Epilepsy in Ontario (DRAFT). June 2012, Figure 1 page 11. Modified from the original.



Drug-refractory epilepsy is associated with a significant burden of illness and severely impacts independence, productivity and overall quality of life. Epilepsy agencies in Ontario can attest that the current situation in the province for many people with drug-refractory epilepsy is grim. There is a huge need to address disparities in epilepsy care for Ontarians living with epilepsy. The proposed strategy for patients with drug-refractory epilepsy has the potential to make an enormous difference in the lives of thousands of people in Ontario.

*Given these grim realities of living with epilepsy, the prevalence and incidence of epilepsy in Ontario and the status of care being provided to those with epilepsy in the province, are quite sobering for anyone interested in the health and well-being of the people of Ontario, regardless of socio-economic or cultural barriers.<sup>3</sup>*

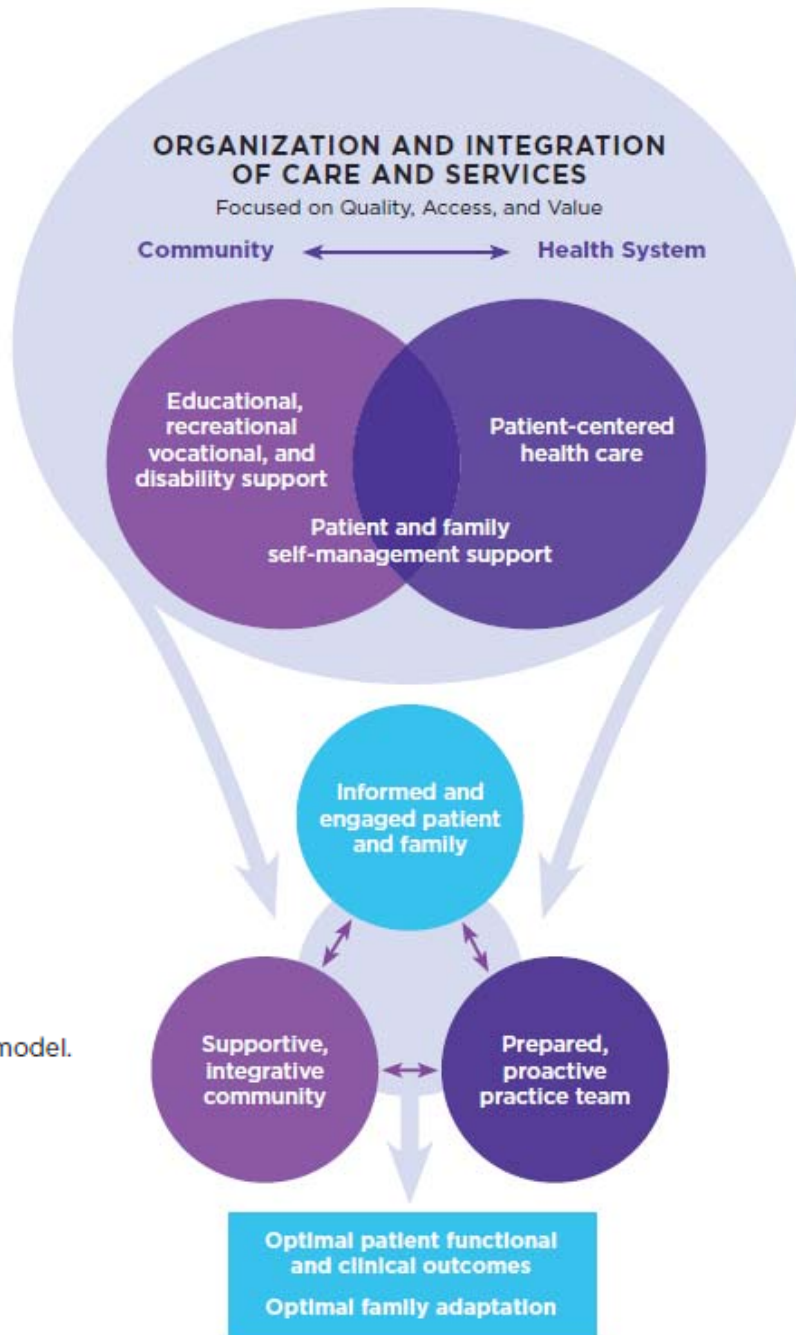
The OHTAC recommendations have the potential to prevent premature death and to also significantly improve quality of life for many people and their families. Epilepsy agencies in Ontario fully support this proposal to standardize epilepsy care in the province and improve access to effective treatments for people with drug-refractory epilepsy.

The OHTAC and Health Quality Ontario study of epilepsy care is also supported by studies in other jurisdictions. In March 2012, a prepublication report was released by the Institute of Medicine (IOM) in the United States: ***Epilepsy Across the Spectrum: Promoting Health and Understanding***<sup>4</sup>. The detailed IOM report identifies serious gaps in epilepsy care and support.

There are many parallels between the OHTAC study and the findings of the IOM's Committee on the Public Health Dimensions of the Epilepsies, including several similarities in the recommendations. The IOM report emphasizes five key messages<sup>5</sup>:

- 1. Epilepsy is a common and a complex neurological disorder that affects health and quality of life. In the provision of coordinated health and human services, a whole-patient perspective is needed.*
- 2. Effective treatments are available for many types of epilepsy, but timely referrals and access to those treatments fall short. Better data from surveillance and research could improve epilepsy care and prevention.*
- 3. Many health professionals need to be better informed about epilepsy.*
- 4. Education efforts for people with epilepsy and their families need to be thorough and sensitive to health literacy and cultural considerations.*
- 5. The stigma of epilepsy has to be eliminated.*

The IOM Committee on the Public Health Dimensions of the Epilepsies proposed a model for epilepsy care in their report. The suggested model is “*an integrated and collaborative approach to health care and community services*”. The primary focus of the IOM epilepsy care model is on the individual with epilepsy and their family (light blue circle in the model below: “Informed and engaged patient and family”). The goal of the model is **high quality health outcomes**: optimal functional and clinical outcomes for the patient and optimal family adaptation.



**FIGURE 4-5**  
Epilepsy care model.

Source: IOM (Institute of Medicine) *Epilepsy across the spectrum: Promoting health and Understanding*. March 2012, Figure 4-5 page 149.

Epilepsy agencies in Ontario recognize the need for a whole-patient perspective in the delivery of epilepsy care. Epilepsy agencies suggest that an integrated model for epilepsy care that involves coordination between medical services and community-based services would provide optimal care for people with drug-refractory epilepsy in Ontario.

## **Optimizing Patient Outcomes for People with Epilepsy in Ontario**

Epilepsy agencies are interested in partnering with health care providers, clinical epilepsy centres, other community agencies, government and most importantly people with epilepsy and their families to optimize patient outcomes for people living with epilepsy in Ontario.

### **Provincial epilepsy expert advisory panel**

The OHTAC report has recommended the creation of a permanent provincial epilepsy expert advisory panel to establish outcome measurements and benchmarks and to evaluate the Ontario Epilepsy Program. The proposed recommendation is for local epilepsy agencies as well as Neurological Health Charities of Ontario have a role on this panel. Epilepsy agencies support this recommendation and also highlight the importance of hearing directly from people with epilepsy and their families to ensure the Ontario Epilepsy Program is truly meeting the needs of people living epilepsy. Epilepsy agencies are closely linked to people living with epilepsy in Ontario communities and can gather their input and feedback. Epilepsy agencies also recommend representation from a person living with epilepsy and a family member of a person with epilepsy on the expert advisory panel.

### **Epilepsy care strategy for non-surgical candidates**

The proposed epilepsy care strategy will improve access to epilepsy surgery for people with drug-refractory epilepsy. Of the estimated 20,000 people with drug-refractory epilepsy in Ontario, an estimated 13,200 people are potentially candidates for surgery.

There are an estimated 6,800 people in Ontario who will not be candidates for epilepsy surgery. Some of these people may benefit from other treatments, such as deep brain stimulation, vagal nerve stimulation, ketogenic diet or new medications. Even with the best medical care and access to other treatments, there will still be a significant number of people in this province who will continue to experience uncontrolled seizures.

An epilepsy care strategy **must** include a plan for all patients with drug-refractory epilepsy, both surgical and non-surgical candidates. People who are not candidates for epilepsy surgery will require ongoing support to help them and their families achieve the best possible quality of life.

## **Conclusion**

Epilepsy is a major public health issue in Ontario. Fortunately, there are effective treatments for many people with drug-refractory epilepsy and Ontario has some of the best epilepsy specialists and clinical epilepsy programs not only in Canada but world-wide. Despite the existence of specialty programs in this province, there is not an

effective system to ensure that Ontarians living with uncontrolled seizures can gain access to these medical services.

Setting standards for epilepsy care and providing access to the right care at the right time and in the right place is an expectation that Ontarians have of our health care system. Many people in this province would be shocked to learn of the disparities that currently exist for people living with epilepsy. The detailed study by Health Quality Ontario has determined that the proposed strategy for epilepsy care in Ontario is evidence-based and is cost effective. It is also in keeping with the societal and ethical values on Ontarians to establish a system that ensures universal access to quality, evidence-based health care.

The proposed epilepsy strategy is the most exciting development many people in the Ontario epilepsy community have witnessed in their lifetime, with the greatest potential to positively impact many people's lives short of a cure for epilepsy. Epilepsy agencies fully support this proposal and suggest that implementation of the epilepsy care strategy should be an integrated approach to health care and community services. The epilepsy strategy has the potential to improve the quality of life of thousands of Ontarians living with epilepsy and their families. Epilepsy agencies strongly urge the provincial government and the Ministry of Health and Long-Term Care to adopt the proposed strategy for epilepsy care in Ontario.

## Footnotes

1. HQO (Health Quality Ontario) *OHTAC Recommendation: Care for Drug-Refractory Epilepsy in Ontario (DRAFT)* Ontario Health Technology Advisory Committee, draft report June 2012.
2. HQO, *OHTAC Recommendation*, pg 10.
3. HQO, *OHTAC Recommendation*, pg 8.
4. IOM (Institute of Medicine) *Epilepsy across the spectrum: Promoting health and understanding*, prepublication report March 2012.
5. IOM, *Epilepsy across the spectrum*, pg x.