PROVINCIAL GUIDELINES FOR REGIONAL EPILEPSY SURGERY CENTRES

Epilepsy Implementation Task Force
Critical Care Services Ontario | May 2016

These Guidelines are a Product of Critical Care Services Ontario (CCSO)

The *Provincial Guidelines for Regional Epilepsy Surgery Centres* is the result of a collaborative effort between CCSO, the Epilepsy Implementation Task Force (EITF), and Provincial Neurosurgery Ontario (PNO). The EITF was established in June 2013 to develop and implement a provincial framework to maximize value from the system of epilepsy care in Ontario. CCSO supports the work of the EITF, a subgroup of PNO, as part of its mandate to support equitable and timely access to neurosurgical care, including epilepsy surgery, and to help maintain the province's neurosurgical capacity.

How to Use This Document

The Guidelines included in this document have been developed by a subgroup of the Epilepsy Implementation Task Force for reference by Regional Epilepsy Surgical Centres. The guidelines are based on current processes and represent expectations for the highest standards in epilepsy care

This document provides recommendations only.

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Disclaimer: The contents of these guidelines may change over time. Clinicians and hospital administrators should use sound judgment for individual patient encounters. Critical Care Services Ontario, the Epilepsy Implementation Task Force, and Provincial Neurosurgery Ontario strongly recommend evidence-based practices.

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Please see Appendix 2 for a list of the EITF members.

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About this Document

The EITF has developed this document in an effort to provide guidelines for evidence-based practice for all health care providers in Ontario who are the primary point of care for patients with epilepsy. This document presents guidelines that set out accountabilities for hospitals and their collaborative interdisciplinary teams that provide care for patients at Regional Epilepsy Surgical Centres. This document is also intended for all specialists involved in the care of patients with new onset and/or established epilepsy.

Target Audience

The intended target audience of this document includes, but is not limited to, clinicians and administrators from District Epilepsy Centres (DECs) and Regional Epilepsy Centres (RESCs).

The EITF Guidelines Series

The EITF is developing a series of guidelines intended to support primary care providers, community neurologists, and district and regional epilepsy centres. These guidelines aim to increase the awareness of, and referrals to, appropriate diagnostic assessment and surgical care of patients in Ontario.

For Primary Care Providers

- 1. Provincial Guidelines for the Management of Epilepsy in Adults and Children (January 2015) To support the flow of patients towards appropriate treatment for epilepsy, this document contains a set of guidelines to help with the diagnosis, treatment, and referral practices from the moment of a patient's first seizure.
- 2. Provincial Guidelines for Epilepsy Surgery Referrals in Ontario (February 2016) This document provides an approach to referral of medically-refractory epilepsy patients by defining evidence-based indications to epilepsy surgery in all age groups, with careful consideration given to age-specific issues ranging from infants to the elderly.
- 3. Provincial Guidelines for the Management of Medically-Refractory Epilepsy in Adults and Children who are not Candidates for Epilepsy Surgery (March 2016) This guideline will provide an approach to the management of the patient with medically intractable epilepsy in whom surgical treatment is not an option. It will include the use of antiepileptic medications and non-antiepileptic therapy such as dietary management and neurostimulation.
- 4. Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult (to be released soon) To ensure uninterrupted quality medical care for adolescent patients with chronic disorders, this document provides guidelines for paediatric and adult practitioners to assist in the seamless transition of epilepsy care for adolescents who are departing the paediatric system and entering the adult health care network.

For Providers and Administrators in District and Regional Epilepsy Centres:

- 5. Provincial Epilepsy Monitoring Unit (EMU) Guidelines for Ontario (January 2014) This document outlines protocols and provides guidelines for EMUs for diagnostic evaluation for epilepsy. It can be used as a guide for neurosurgical centres with EMU beds.
- 6. Provincial Guidelines for Regional Epilepsy Surgical Centres This document presents guidelines that set out accountabilities for hospitals and their collaborative interdisciplinary teams that provide care for patients at Regional Epilepsy Surgical Centres.
- 7. Regional Epilepsy Surgery Centres Program Model and Technical Guide This document presents best practices as a recommended, but not mandatory, clinical protocols and program model for hospitals and their collaborative interdisciplinary teams that provide care for patients at Regional Epilepsy Surgical Centres.

I. Introduction

Epilepsy affects around 95,000 Ontarians, of whom approximately 80,000 are adults and over 15,000 are children under the age of 18 (Ng et al., 2015). While most individuals with epilepsy can be treated effectively by a primary care physician or general neurologist, an estimated 30% have medically-refractory epilepsy, experiencing seizures that do not respond to treatment with two or more appropriate antiepileptic drugs (Bowen et al., 2012). These numbers are not static. It is estimated that 6,500 Ontarians will develop epilepsy each year, and 1,950 of them will have medically-refractory epilepsy (Tellez-Zenteno et al., 2004; Wiebe et al., 1999).

Surgical intervention could be successful in eliminating seizures; there is approximately an 80% chance that an individual will be seizure-free after surgery, resulting in improved outcomes with respect to seizure freedom, improved quality of life, and reduction of psychosocial comorbidities that accompany medicallyrefractory epilepsy than continued medical treatment (Bowen et al., 2012). However, not all individuals with epilepsy are candidates for surgery – approximately one third of those suffering from medically-refractory epilepsy will not be considered candidates. Despite its effectiveness, surgical treatment is underutilized in Ontario, with only a fraction of the population who may be eligible for surgery assessed every year. A 2012 report by the Expert Panel on a Provincial Strategy for Epilepsy Care (HQO, 2012) identified that long wait lists at the province's Epilepsy Monitoring Units (EMUs) and low referral rates contributed to the underutilization of surgical treatment. The panel also noted that awareness of surgical treatment options was low and patients were not diagnosed, treated and referred appropriately. A 2011 estimate determined that less than 2% of potential surgical candidates accessed surgical treatment (HQO, 2012).

The panel recommended action to improve epilepsy care infrastructure and surgical referral in the province (HQO, 2012). As a result, the Ministry of Health and Long-Term Care (the Ministry) made an investment of 21 new EMU beds in Ontario, bringing the total number of EMU beds to 39 (26 adult and 13 paediatric). The Ministry also resourced additional epilepsy surgery and vagal nerve stimulator capacity through CCSO's Provincial Neurosurgery Strategy and established the Epilepsy Implementation Task Force to oversee epilepsy system improvements.

Epilepsy Implementation Task Force

The Epilepsy Implementation Task Force (EITF) was formed in June 2013 to develop and implement a provincial approach to an integrated system for epilepsy care in Ontario. Supported by CCSO, this committee is co-chaired by Dr. Carter Snead, Paediatric Neurologist at the Hospital for Sick Children, and Brenda Flaherty, Executive VP and Chief Operating Officer at Hamilton Health Sciences.

The EITF brings together senior clinical and administrative leaders from the epilepsy community to:

- Improve access along the full continuum of care by coordinating resources and wait lists
- Establish standardized diagnostic and surgical protocols across hospitals with comprehensive epilepsy programs
- Develop supports for primary care providers

CCSO supports the work of the EITF, a subgroup of Provincial Neurosurgery Ontario, as part of its mandate to support equitable and timely access to neurosurgical care, including epilepsy surgery, and to help maintain the province's neurosurgical capacity. CCSO is supported by the Ministry of Health and Long-Term Care. For a list of EITF membership, please see Appendix 2.

The creation of the EITF stemmed from a report by the Expert Panel on a Provincial Strategy for Epilepsy Care in Ontario, assessing the challenges to access in epilepsy care in Ontario (HQO, 2012). The report notes that the community of health care providers treating epilepsy needs support with a standardized approach to diagnosis and treatment (such as antiepileptic drugs (AED), electroencephalography (EEG), or neuroimaging), and process for referral to a neurologist or for surgery (if the seizures are determined to be medically refractory). This document is the outcome of the recommendation to provide provincewide guidelines for first-contact health care providers (such as primary care and emergency department physicians) to standardize the diagnosis, treatment and referrals of patients with epilepsy in the province.

Epilepsy Care in Ontario

In order to maximize value and ensure that patients are receiving timely, high quality care, it is crucial to clarify system capacity and referral paths. This will help set clear expectations for planning, coordination and performance for all hospitals with specialty epilepsy care programs.

The EITF has developed a definition of a Comprehensive Epilepsy Program (CEP) and established a planning and integration framework for epilepsy care in Ontario:

A CEP is an integrated care model for the management of individuals with epilepsy within a multidisciplinary team. A CEP covers various aspects of care including medical, psychosocial, and nutritional management, appropriate neuro-diagnostic investigations, a mandatory EMU, capability for pre-surgical diagnostic evaluation, and established links to Community Epilepsy Agencies.

Hospitals with CEPs are divided into two categories based on the level of services they provide:

1. A District Epilepsy Centre (DEC) houses a comprehensive epilepsy program that provides all appropriate epilepsy related clinical services except epilepsy surgery. A DEC should provide basic investigations necessary to determine candidacy for epilepsy surgery including assessment by an epileptologist, and full EMU service including neuropsychological evaluations.

The following hospitals are classified as District Epilepsy Centres:

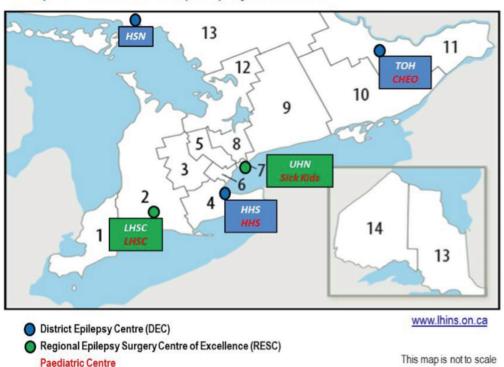
| Hospital | Adult EMU Beds | Paediatric EMU Beds |
|--|----------------|---------------------|
| Health Sciences North (operational 2015) | 1 | - |
| Hamilton Health Sciences | 3 | 2 |
| The Ottawa Hospital | 2 | - |
| Children's Hospital of Eastern Ontario | - | 2 |

2. A Regional Epilepsy Surgery Centre (RESC) is a facility with a comprehensive epilepsy program that provides all the services available in a DEC, and in addition, epilepsy surgery including facility for intracranial monitoring. An RESC is also a DEC for its catchment area.

The following hospitals are classified as Regional Epilepsy Surgery Centres:

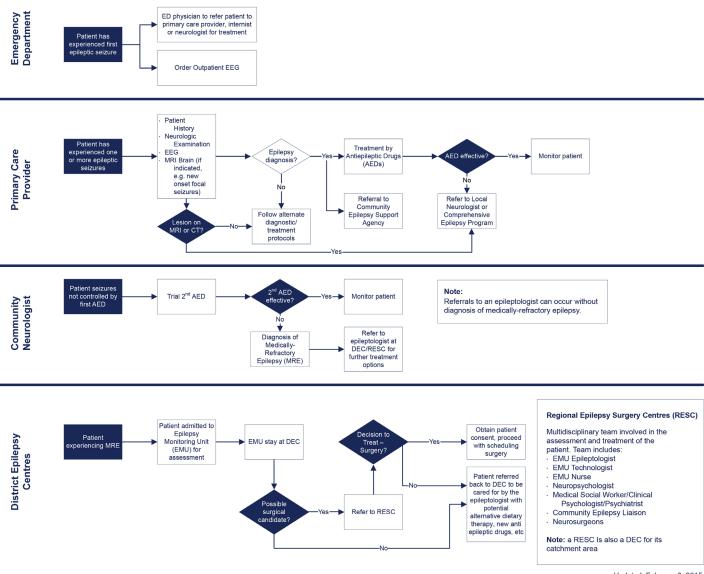
| Hospital | Adult EMU Beds | Paediatric EMU Beds |
|---|----------------|---------------------|
| London Health Sciences Centre | 10 | 2 |
| Hospital for Sick Children (SickKids) | - | 7 |
| University Health Network (Toronto Western Hospital) | 10 | - |

Map of Ontario's Epilepsy Centres



The following flow chart is a high-level depiction of the process each provider should follow in order to appropriately diagnose and manage a patient with epilepsy:

Epilepsy Patient Flow by Provider



Updated: February 3, 2015

II. The Surgical Treatment of Epilepsy

Overview

Most patients with epilepsy can be effectively treated by a primary care physician or general neurologist. However, about 30% of people with epilepsy have medically-refractory epilepsy, i.e., seizures that do not respond to treatment with two or more appropriate antiepileptic drugs (Kwan & Brodie, 2000). It is estimated that 27,000 Ontarians suffer from frequent disabling seizures, many on a daily basis, despite being on multiple antiepileptic medications. It is important to realize that patients who continue to have seizures despite appropriate trials of two antiepileptic drugs are unlikely to ever achieve sustained freedom from seizures with medical therapy alone and are therefore destined to a life of disabling seizures with all of the comorbidities that this entails. Of the 27,000 patients with medically-refractory epilepsy, approximately 12,150 could be further assessed for suitability for surgery and other non-conventional treatment. These numbers are not static. It is estimated that 6,500 Ontarians will develop epilepsy each year, and 1,950 of them will have medically-refractory epilepsy. Up to one half of these patients with drug-resistant epilepsy may benefit from surgical treatment of their epilepsy (Tellez-Zenteno et al., 2004; Wiebe et al., 1999; Jette et al., 2014; Lim et al., 2013).

Epilepsy surgery is the standard of care for appropriately selected adults and children with medicallyrefractory epilepsy (Wiebe and Jette, 2012). Both the American Academy of Neurology (Engel et al., 2003) and the European Federation of Neurological Societies (2000) have published practice guidelines with recommendations to this effect. Few interventions in medicine are as effective as epilepsy surgery for medically-refractory epilepsy. Surgical treatment for epilepsy is highly effective, has durable benefits, and can result in far better outcomes with respect to seizure freedom, improved quality of life, and reduction of the psychosocial comorbidities that accompany medically-refractory epilepsy (Engel, 2013; Wiebe and Jette, 2012; Jette et al., 2014). As well, surgical treatment of epilepsy is cost effective (Bowen et al., 2012) and yet still remains arguably the most underutilized of all accepted medical interventions (Engel, 2013).

Despite the mounting evidence supporting the effectiveness of surgery for patients with medically-refractory epilepsy (Wiebe and Jette, 2012; Jette et al., 2014), there remain barriers in access to this potentially curative treatment modality in both adults and children. Studies continue to show long seizure duration (5 to 7 years and greater) preceding epilepsy surgery in children (Harvey et al., 2008) and between 19 and 22 years before referral for evaluation of surgical candidacy in adults (Choi et al., 2009; Gilliam et al., 1999; Wiebe et al., 2001; Jette et al., 2014; Jehi & Mathern, 2015; Roberts et al., 2015). Unfortunately, there are a number of misconceptions about indications, contraindications, and complications of epilepsy surgery which have led to its gross underutilization (Table A). To take an adage from the stroke literature: Time is brain in chronic severe epilepsy. Chronic ongoing seizures are devastating to both children and adults who suffer from medically-refractory epilepsy. The comorbidities are cumulative and the longer the seizures last, the worse the quality of life for these patients and their families and the greater the risk of seizureinduced brain injury. Therefore, epilepsy surgery should never be considered as a last resort (Jette et al. 2014; Ibrahim et al. 2014). It is imperative that any patient in Ontario who meets the criteria for medicallyrefractory epilepsy, regardless of age, be referred to a District Epilepsy Centre (DEC) in order to be assessed for surgical candidacy.

TABLE A: Common Misconceptions about Epilepsy Surgery

| Misconception | Fact |
|---|--|
| All drugs need to be tried. | Seizure freedom is unlikely after two drugs have failed. |
| Bilateral EEG spikes are a contraindication to surgery. | Patients with unilateral onset seizures often have bilateral spikes. |
| Normal MRI is a contraindication to surgery. | Other techniques often detect a single epileptogenic zone in patients with normal MRIs. |
| Multiple or diffuse lesions are a contraindication to surgery. | The epileptogenic zone may involve only a part of the lesion on MRI. |
| Surgery is not possible if primary cortex is involved. | Essential functions can be localized and protected. |
| Surgery will make memory worse if there is an existing memory deficit. | Poor memory will not usually get worse and could get better. |
| Chronic psychosis is a contraindication to surgery. | Patients will still benefit if seizures are eliminated. |
| IQ less than 70 is a contraindication to surgery. | Outcome depends on the type of epilepsy and the type of surgery. |
| Patients with focal epilepsy and a focal lesion can have the lesion removed without detailed pre-surgical evaluation. | Focal lesions can be incidental findings unrelated to the epilepsy. Epileptogenicity of a lesion always needs to be confirmed. |

From Engel, 2013 [with permission]

Referral for the Evaluation of Epilepsy Surgery

The following [please see Provincial Guidelines for Epilepsy Surgery Referral in Ontario and Jette et al., 2014] are indications for referral to a District Epilepsy Centre (DEC) for preliminary evaluation of epilepsy surgery candidacy and potential referral to a Regional Epilepsy Surgery Centre (RESC) for definitive determination of whether the patient needs epilepsy surgery and what type of surgery.

- · Any child or adult (no matter how young or old) who meets the definition of medically-refractory epilepsy and has disabling seizures
- Children or adults with complex syndromes or requiring complex surgeries
- Children or adults with epilepsy that cannot be clearly assigned to a known electroclinical syndrome, but with stereotyped or lateralized seizures or focal findings
- Children with an MRI lesion amenable to surgical removal regardless of seizure status

Candidacy for Epilepsy Surgery

A successful outcome from epilepsy surgery may be defined as a seizure-free state with no imposition of neurologic deficit (Snead, 2001; Chakraborty & Rutka, 2010). The key to this goal is to identify precisely the epileptogenic zone, which is defined as the area necessary and sufficient for generation of habitual seizures, and the smallest amount of tissue that can be removed to achieve a seizure-free outcome (Obeid et al., 2009; Engel, 2013).

In order to achieve seizure-freedom without an imposition of a neurologic deficit, three fundamental questions need to be answered:

- 1. Can the epileptogenic zone be lateralized to one side of the brain?
- 2. Can the precise localization of the epileptogenic zone be determined in the involved hemisphere?
- 3. What brain function (i.e., motor, sensory, language, and memory) might be damaged if the epileptogenic zone is surgically removed?

These questions are complex and require an integrated, multidisciplinary series of pre-surgical diagnostic measures to select those adults and children who have the best chance of achieving a successful outcome from epilepsy surgery. Please see Figure 1.0 below.

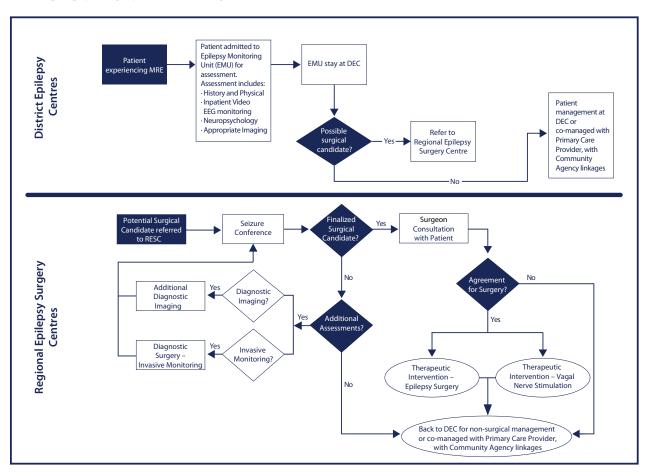


Figure 1.0: Medically-refractory epilepsy surgical patient referral pathway

However, it should be stated that there is no single test upon which one can rely to consign a patient with medically-refractory epilepsy to surgery. Rather, one has to obtain agreement, or concordance, between multiple studies in order to make a judgment about candidacy for epilepsy surgery.

There is general agreement about the diagnostic evaluation for epilepsy surgery in adults and children (Obeid et al., 2009; Engel, 2013; Jayakar et al., 2014; Lim et al., 2013). In Ontario, the initial evaluation for epilepsy surgery takes place in a District Epilepsy Centre (DEC) or a Regional Epilepsy Surgery Centre (RESC). This consists of a logical progression of diagnostic procedures, including an initial careful history of the seizure pattern (i.e. semiology) and physical examination by the epileptologist. Additional testing proceeds from the least to the most invasive. If no EEG has been done, a standard EEG should be performed using the 10-20 system, according to standards suggested by the Canadian Society of Clinical Neurophysiologists. A video-EEG in an EMU is always indicated as part of the initial evaluation for epilepsy surgery [please see Provincial Epilepsy Monitoring Unit (EMU) Guidelines for Ontariol as is neuroimaging with an MRI. Because patients with medically-refractory epilepsy almost always suffer from a number of psychosocial comorbidities, social work evaluations, a neuropsychological assessment, and liaison with Community Epilepsy Agencies for support and advocacy are also required at the DEC. If, after reviewing the EMU, MRI and neuropsychology data, the patient is deemed a candidate for epilepsy surgery by the epilepsy team at the DEC, the patient is referred to the Regional Epilepsy Surgery Centre (RESC). The multidisciplinary epilepsy surgery team then meets formally as a group to review the data in order to confirm that the patient is indeed a candidate for epilepsy surgery and to design further diagnostic evaluation. This will entail more detailed neuroradiological evaluation which could include (where available) a 3T MRI, diffusion tensor imaging (DTI), and a number of functional neuroimaging modalities, depending on the type of surgery under consideration:

- Ictal/interictal Single Photon Emission Computed Tomography (SPECT): tool to assess blood flow/ perfusion. To be used for the purpose of seizure localization, particularly when suspecting extratemporal epileptogenic foci.
- Interictal Positron Emission Tomography (PET): tool to assess for hypometabolic areas which may represent epileptogenic regions. Particularly useful in temporal lobe epilepsy and focal epilepsy due to tuberous sclerosis.
- Functional MRI (fMRI): for language and memory assessment. It can also be used for mapping of somatosensory, motor and visual cortices.
- Interictal Magnetoencephalography/Magnetic Source Imaging (MEG/MSI): for localization of the epileptogenic focus. Can also be used for mapping of vital cortices.

As well, additional neuropsychological testing may be necessary depending upon the data from the DEC. Psychiatric assessment of the patient and family is also undertaken at the RESC. Intracarotid amytal/etomidate testing (Wada testing) may be indicated for language lateralization. Once all appropriate pre-surgical diagnostic data are available, the multidisciplinary epilepsy surgery team will meet and determine the best course of action to recommend to the patient and his/her family. If the team arrives at the conclusion that the patient is a candidate for epilepsy surgery, the next step is to decide whether the data support proceeding directly to surgery or whether additional data are required from invasive monitoring to more accurately localize the epileptogenic zone and eloquent cortex, which refers to that part of brain which sub-serves vital functions such as speech, language, memory, movement, sensation, and vision. Invasive monitoring consists of surgical placement of electrodes in or on the brain itself with subsequent monitoring of the interictal and ictal EEG directly from the brain. The electrodes also can be stimulated to localize eloquent function. Invasive monitoring is the gold standard for accurate localization of the epileptogenic zone and eloquent cortex. If the patient is not a candidate for resective surgery, considerations should be made for a palliative epilepsy surgery (hemispherotomy or functional hemispherectomy, corpus callosotomy, multiple subpial transections), neurostimulation (vagus nerve stimulation, thalamic stimulation, hippocampal

stimulation, or responsive cortical stimulation), or no surgery. If the decision is not to proceed with surgery, other treatments may be considered. These would include the ketogenic diet or trials of newer antiepileptic drugs [please see Provincial Guidelines for Patients with Medically-Refractory Epilepsy who are not Candidates for Epilepsy Surgery]. The possibility of re-assessment for surgical candidacy should be left open.

A detailed description of the procedures, personnel, equipment, and infrastructure, required for each of these pre-surgical tests is provided in the section below.

Surgical Procedures

The key to determining successful resective surgical treatment is delineation of the epileptogenic zone, which, as mentioned above, is defined as the area necessary and sufficient for generation of habitual seizures, and the smallest amount of tissue that can be removed to achieve a seizure-free outcome (Obeid et al., 2009; Engel, 2013).

Follow up Care after Epilepsy Surgery

If seizure freedom is achieved, the district epilepsy program where the initial investigation was performed should follow the patient for at least two years. If patient remains seizure free after two years, the patient should be referred back to the referring physician. If seizure freedom is not achieved, re-assessment is recommended in a timely fashion. As for discontinuation of AEDs after surgery, there is no evidence on how to proceed once the individual is rendered seizure free with epilepsy surgery.

III. Regional Centre for Epilepsy Surgery – Requirements

Overview

The care of the epilepsy patient with medically-refractory epilepsy before, during, and after epilepsy surgery at the Regional Epilepsy Surgery Centre is provided by a collaborative multidisciplinary team that is directed by a neurologist and/or neurosurgeon with special expertise in epilepsy. This team has the capability to conduct and interpret all studies and procedures shown in Figure 1.0 and outlined above in Candidacy for Epilepsy Surgery. At a minimum, this team includes neurologists, neurosurgeons, neuropsychologists, nurse specialists, EEG technologists, psychiatrists, social workers, neuroradiologists, and other personnel with special training and experience in the treatment of epilepsy (National Association of Epilepsy Centers, 2010). In brief, the mandatory requirements for a Regional Epilepsy Surgery Centre in Ontario are as follows:

- Administrative oversight
- Clinical neurophysiology
- EMU (please see <u>Provincial Guidelines for Epilepsy Monitoring Units in Ontario</u>)
- Capability for continuous EEG monitoring from intracranial electrodes
- Capability for functional mapping of eloquent cortex from intracranial electrodes
- · Capability for EEG support of intracarotid amytal/etomidate testing may be indicated for language lateralization
- Neurology (epileptologist)
- Neurosurgery (epilepsy surgeon)
- Nursing (advanced practice nursing in epilepsy)
- Neuroimaging: functional magnetic resonance imaging for language dominance
- Cerebral angiography
- Computerized axial tomography
- Access to one or more of the following:
 - o magnetoencephalography
 - o SPECT
 - o PET
 - o 3T MRI with DTI
- Neuropsychology
- · Psychosocial services
- · Community epilepsy agency liaison
- · Access to rehabilitation

Administration

This section outlines the overall commitment to excellence in the care of patients with epilepsy through the administration of a Regional Epilepsy Surgery Centre. The following outlines the centre requirements and key accountabilities of the centre's oversight structure.

The Regional Epilepsy Surgery Centre will:

- · Implement an administrative and leadership structure to provide oversight and management of the complexity and interdisciplinary nature of the centre. The centre will have identified medical and administrative leadership
- Demonstrate evidence of strong partnership and collaboration within the leadership structure by ensuring representation from administration, clinical care, research and education
- Ensure accountability and transparent processes for resource allocation and overall centre operations taking into account relevant stakeholder input and ongoing evaluation of outcomes
- Develop a consistent, comprehensive service model for epilepsy that is fiscally responsible, aligned with case costing methodology and is coordinated with Health System Funding Reform efforts across centres
- Ensure a culture of accountability for safety and continuous quality improvement by contributing to the development of system wide epilepsy performance metrics and implementing processes for ongoing data collection, measurement, monitoring and management of those metrics
- Adhere to the established reporting schedule of activity and performance metrics as determined by the Ministry of Health and Long-Term Care and participate in regular joint strategic planning to improve system wide performance and health outcomes for patients and their families
- Establish and maintain relationships with other centres to monitor and respond to emerging trends and technologies in epilepsy care provincially, nationally and internationally
- Collaborate with provincial and community partners in the development and dissemination of evidencebased best practice guidelines and protocols associated with clinical care, research and education
- Participate in health human resources planning specific to epilepsy care
- Commit to having representation on EITF and PNO to ensure expert leadership and stakeholder input for epilepsy policy development

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V. Appendix 1: Commonly Used Abbreviations and **Definitions in Epilepsy Guidleine Series**

Abbreviations

ABNM American Board of Neurophysiologic Monitoring **ABPN** American Board of Psychiatry and Neurology **ADHD** Attention Deficit Hyperactivity Disorder

Antiepileptic Drug (also known as Antiseizure or Anticonvulsant Drug) **AED**

AEF Auditory Evoked Fields

AFNI Analysis of Functional NeuroImages APA American Psychological Association

American Society of Electroneurodiagnostic Technologists **ASET**

ASNFR American Society of Functional Neuroradiology

BOLD Blood-Oxygen-Level Dependent (context: fMRI findings)

BScN Bachelor of Science in Nursing

Canadian Board of Registration of Electroencephalograph Technologists **CBRET**

CEP Comprehensive Epilepsy Program **CMAP** Compound Muscle Action Potentials

CNIM Certification in Neurophysiologic Intraoperative

College of Nurses of Ontario **CNO**

CPA Canadian Psychological Association **CPO** College of Psychologists of Ontario

CPR/BCLS Cardio Pulmonary Resuscitation/Basic Cardiac Life Support

CPSO College of Physicians and Surgeons of Ontario

CSF Cerebral Spinal Fluid CT Computerized Tomography

CUSA Cavitron Ultrasonic Surgical Aspirator

Diplomat of American Board of Neurophysiologic Monitoring D.ABNM

DBS Deep Brain Stimulation DCS Direct Cortical Stimulation **DEC** District Epilepsy Centre

DICOM Digital Imaging and Communications in Medicine

DSM Digital Switch Matrix DTI Diffusion Tensor Imaging DWI Diffusion Weighted Imaging

ECG Electrocardiography **ECoG** Electrocorticography ED **Emergency Department EEG** Electroencephalography

EITF Epilepsy Implementation Task Force

Electrocardiogram **EKG EMG** Electromyogram

EMU Epilepsy Monitoring Unit

Epilepsy Monitoring Unit Invasive Monitoring Technologist EMU-IM tech

EOG Electro-Oculogram **EP Evoked Potential EPI** Echo Planar Image

eTNS External Trigeminal Nerve Stimulation

FDA Food and Drug Administration Fluoro-2-deoxy-D-glucose **FDG FHP** First Health Care Provider

fMRI Functional Magnetic Resonance Imaging

Functional Magnetic Resonance Imaging of the Brain **FMRIB**

FP Family Physician

FRCPC Fellow of the Royal College of Physicians and Surgeons of Canada

FSL FMRIB Software Library

Full Width Half Maximum (context: image processing) **FWHM**

Gamma Amino Butyric Acid **GABA**

GP General Practitioner

HF-TOF High Frequency Train-of-Five (technique for direct cortical stimulation)

Health Quality Ontario HQO

IAP Intracarotid Anesthetic Procedure

ICES Institute for Clinical and Evaluative Sciences

ICU Intensive Care Unit

iEEG Intracranial Electroencephalography International League Against Epilepsy **ILAE** IOM Intraoperative Neuromonitoring

KD Ketogenic Diet

Low Glycemic Index Therapy **LGIT**

LP Lumbar Puncture MAD Modified Atkins Diet Doctor of Medicine MD

MDD Major Depressive Disorder **MEF** Motor Evoked Fields **MEG** Magnetoencephalography **MRE** Medically-Refractory Epilepsy Magnetic Resonance Imaging MRI MSI Magnetic Source Imaging **MScN** Master of Science in Nursing

Magnetic Source Imaging MSI **MSW** Master of Social Work NAS Network Attached Storage

National Institute of Neurological Disorders and Stroke **NINDS**

NP Nurse Practitioner OBI Ontario Brain Institute

Provincial Guidelines for Regional Epilepsy Surgery Centres

OCOral Contraception

OCSWSSW Ontario College of Social Workers and Social Service Workers

OHTAC Ontario Health Technology Advisory Committee

OR Operating Room

Ordered Subset Expectation-Maximization (context: image processing) **OSEM**

OT Occupational Therapist

PACS Picture Archiving and Communication System

Positron Emission Tomography PET **PNES** Psychogenic Nonepileptic Seizures PNO Provincial Neurosurgery Ontario

PT Physiotherapist PTZ Pan-tilt-zoom RD Registered Dietitian

R.EEG T Registered Electroencephalography Technologist

RET Registered Engineering Technologist **REPT** Registered Evoked Potential Technologist Registered Nurse in the Extended Class RN(EC) **RESC** Regional Epilepsy Surgery Centre

SAN Storage Area Network

SEF Somatosensory Evoked Field **SEP** Somatosensory Evoked Potentials

Single Photon Emission Computed Tomography **SPECT**

SPM Statistical Parametric Mapping **SuMEDS** Single-use Medical Devices **SWI** Susceptibility Weighted Imaging Trans-cranial Motor Evoked Potentials tceMEP

TDM Therapeutic Drug Monitoring TIVA Total-intravenous Anaesthesia **TMS** Transcranial Magnetic Stimulation Repetition Time (context: MRI) TR UPS Uninterruptible Power Supply **VEEG** Video Electroencephalography

VEF Visual Evoked Fields VNS Vagus Nerve Stimulation

VP Vice President

VPN Virtual Private Network **WWE** Women With Epilepsy

Definitions

| Adolescent | A person 13 to 17 years of age. | |
|---|---|--|
| Adolescent Medicine Specialist | Paediatrician practicing adolescent medicine. | |
| Child | A person less than 18 years of age. | |
| Community Epilepsy Agencies | Community Epilepsy Agencies provide a range of support services to persons with epilepsy and their families. These services include epilepsy information, seizure first aid training, support groups, social opportunities, employment counseling and school advocacy. | |
| Co-morbidity | Co-morbidity refers to the co-occurrence of two conditions with a greater frequency than found in the general population. This does not infer a causal relationship. Co-morbid conditions are common in people with epilepsy. They are found across the lifespan and have important implications for treatment and quality of life. | |
| Comprehensive Epilepsy Program (CEP) | Denotes an integrated care model for the management of individuals with epilepsy within a multidisciplinary team. A CEP covers various aspects of care including medical, psychosocial, and nutritional management, appropriate neurodiagnostic investigations, a mandatory epilepsy monitoring unit [please see Provincial Epilepsy Monitoring Unit (EMU) Guidelines for Ontario], capability for pre-surgical diagnostic evaluation, and established links to Community Epilepsy Agencies. All epilepsy centres, whether designated as District Epilepsy Centre or Regional Epilepsy Surgical Centre, should have a CEP to deliver the clinical mandate. | |
| District Epilepsy Centre (DEC) | A comprehensive epilepsy program that provides all appropriate epilepsy- related clinical services except epilepsy surgery. DEC should provide basic investigations necessary to determine candidacy for epilepsy surgery including assessment by an epileptologist, and full EMU service including neuropsychological evaluations. | |
| Epilepsy | Disorder of the brain characterized by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological, and social consequences of this condition. The definition of epilepsy requires the occurrence of at least one epileptic seizure (Fisher et al, 2005). In most situations, occurrence of two epileptic seizures is evidence of enduring predisposition to generate epileptic seizures. | |
| Epileptic Seizure | An epileptic seizure is a transient occurrence of signs and or symptoms due to abnormal excessive and or synchronous neuronal activity in the brain (Fisher et al., 2005) | |
| Epileptologist | Qualifications and Training: Clinical fellowship training in epilepsy and video-EEG for at least 12 months in a specialized centre in Canada, US or abroad; Recognized as a neurologist by the College of Physicians and Surgeons of Ontario (CPSO); and certification for EEG reporting (EEG examination by the Canadian Society of Clinical Neurophysiologists or American Board of Psychiatry and Neurology (ABPN) exam in epilepsy) is mandatory. Neurologists who have/had been reporting Video EEG recordings without supervision in any jurisdiction in Canada or the United States of America anytime in or before 2013 are exempt from EEG/Epilepsy examination. | |

| Family Physician | A physician recognized by the CPSO as a family physician | |
|--|--|--|
| General Practitioner | A physician licensed by the CPSO for general practice | |
| Internist | A physician recognized by the CPSO as a specialist in internal medicine | |
| Medically-Refractory Epilepsy | Failure of adequate trials of two tolerated, appropriately chosen and used antiepileptic drugs (whether as monotherapy or in combination) to achieve sustained seizure-freedom (Kwan, 2010, from International League Against Epilepsy). | |
| Neurologist | A physician recognized by the CPSO as a specialist in neurology. | |
| Neuropsychologist | A psychologist registered with the College of Psychologists of Ontario (CPO) | |
| Nurse Practitioner | A nurse registered in the Extended Class through the College of Nurses of Ontario with experience in epilepsy care. | |
| Paediatrician | A physician recognized by the CPSO as a specialist in paediatrics | |
| Psychiatrist | A physician recognized by the CPSO as a specialist in psychiatry. | |
| Psychologist | A health care provider registered with the College of Psychologists of Ontario (CPO) for the practice of clinical psychology | |
| Regional Epilepsy Surgery Centre (RESC) | A comprehensive epilepsy program that provides all the services available in a DEC and, in addition, epilepsy surgery including facility for intracranial monitoring | |
| Registered Dietitian (RD) | Registered as a dietician with the College of Dietitians of Ontario. RDs without previous experience in diet therapies for epilepsy should receive training from a registered dietitian who practices diet therapies for epilepsy. | |
| Senior | A person 65 years of age or older | |
| Social Worker | Registered as a Social Worker with the Ontario College of Social Workers and Social Service Workers (OCSWSSW) | |
| Specialists | Internists, paediatricians, and neurologists | |

VI. Appendix 2: Epilepsy Implementation Task Force Membership

| Name | Title/Role | Organization |
|-----------------------------|---|---|
| Dr. Carter Snead (Co-Chair) | Paediatric Neurologist | The Hospital for Sick Children |
| Brenda Flaherty (Co-Chair) | Executive Vice President & Chief Operating Officer | Hamilton Health Sciences |
| Dr. Jorge Burneo | Adult Neurologist | London Health Sciences Centre |
| Liz Ferguson | Director, Centre for Brain and Behavior | The Hospital for Sick Children |
| Laurie Gould | EVP Patient-Centered Care | London Health Sciences Centre |
| Dr. Salil Gupta | Epileptologist | Health Sciences North |
| Dr. Ayman Hassan | Neurologist | Thunder Bay Regional Health Sciences Centre |
| Dr. Athen MacDonald | Paediatric Neurologist | Kingston General Hospital |
| Kathryn LeBlanc | Director, Neurosciences | Hamilton Health Sciences |
| Louise MacRae | Director, Regional Stroke Program | Hamilton Health Sciences |
| David McNeil | Vice President Clinical Programs/CNO | Health Sciences North |
| Janet Newton | Clinical Director | University Health Network |
| Kirk Nylen | Manager, Knowledge Translation/Ops | Ontario Brain Institute |
| Dr. Rajesh RamachandranNair | Paediatric Neurologist | McMaster Children's Hospital / HHS |
| Dr. De Ribaupierre | Paediatric Neurosurgeon | London Health Sciences Centre |
| Mary Secco | Director of Strategic Initiatives | Epilepsy Support Centre |
| Dr. Laurene Sellers | Family Practice Physician | Grand River Hospital Corporation |
| Dr. Michelle Shapiro | Adult Epileptologist | Hamilton Health Sciences |
| Rosalee (Rosie) Smith | Director of Adult Services | Epilepsy Toronto |
| Mike Tierney | VP Clinical Programs | The Ottawa Hospital |
| Dr. Taufik Valiante | Adult Neurosurgeon | University Health Network |
| Dr. Sharon Whiting | Paediatric Neurologist | Children's Hospital of Eastern Ontario |
| Megan Wright | Chief Nurse Executive | Children's Hospital of Eastern Ontario |

