FOR COMMUNITY EPILEPSY AGENCIES: GUIDELINES SUMMARY

BACKGROUND

There are approximately 90,000 Ontarians with epilepsy. Around 6,500 Ontarians will develop epilepsy every year. In 2014, the Epilepsy Implementation Task Force, supported by Critical Care Services Ontario, began releasing a series of guidelines for epilepsy care. These guidelines aim to improve treatment and access to care for people with epilepsy. This document highlights some of the key recommendations, which are based on current evidence. This information can be used to help counsel your clients and caregivers to make informed decisions about their treatment. For full details, please refer to the relevant sections in the original documents, which can be found at OntarioEpilepsyGuidelines.ca.

KEY POINTS

- Most people living with epilepsy have seizures that can be controlled by **anti-seizure drugs**
- Any child or adult who is not seizure-free after trying two different anti-seizure drugs may have **drug-resistant epilepsy**
- Anyone with drug-resistant epilepsy should be referred to a **specialized epilepsy centre** to explore treatment options
- Treatment options include **surgery, diet therapy**, **immune therapy**, **drug therapy** or **brain/nerve stimulation**
- People with epilepsy can work with health care providers to develop a management plan for **co-exisiting conditions**
- **Women with epilepsy** may need to modify their treatment during pre-conception, pregnancy and menopause
- Families of children who are **moving to the adult health care system** can begin preparing well in advance to ensure a smooth transition

A. Management of Epilepsy

DIAGNOSIS[1]

There is no single feature that is used to diagnose epilepsy. Doctors will use a detailed medical history, a description of the seizure and any related symptoms in order to make a diagnosis. Testing should include a careful examination of heart and brain function, including a mental health assessment.

Brain imaging techniques such as magnetic resonance imaging (MRI) can provide detailed images that can help to confirm a diagnosis. An important part of the evaluation for epilepsy is observing brain wave activity using electroencephalography (EEG). These tests cannot be used alone to make a diagnosis, but can offer additional information to support a diagnosis or a treatment plan.

ANTI-SEIZURE DRUG TREATMENT[2]

Anti-seizure drugs (ASDs) (also known as anti-epileptic drugs) are the most common treatment for epilepsy. There are many different drugs available that work to treat different types of seizures. The choice of drug will depend on the type of seizures and the potential side effects of the drug. It is ideal to take only one anti-seizure drug when possible. Sometimes two or more drugs may be prescribed to improve seizure control. The risks and benefits of any changes in drug therapy (such as adding/removing a drug, or stopping drug therapy) should be discussed with a health care provider.

It is recommended that people with epilepsy who are starting drug treatment discuss the following topics with their health care providers:

- Risk of further seizures
- Type of seizures and negative effects of seizures
- Different anti-seizure drug options and their possible side effects
- Cost and duration of treatment
- Goals of treatment

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MONITORING[3]

It is recommended that people with epilepsy book regular follow-up appointments with their doctors. During these appointments, doctors can check how well anti-seizure drugs are working and monitor any side effects. The suggested follow-up times are:

- Infants (under 1 year): every 3 months
- Children (1-12 years): every 3-6 months
- Teenagers (13-17 years): every 6-12 months
- Adults (over 17 years): every 3-6 months

CO-EXISTING CONDITIONS[4]

People with epilepsy are at risk of having other health conditions that can have a negative impact on quality of life. These co-existing conditions (also known as co-morbidities) can affect both physical and mental health. For instance, many people with epilepsy have difficulties with memory, learning disabilities, or attention deficit hyperactivity disorder. Physical conditions such as migraines, digestive problems, bone fractures and chronic pain can also occur. Managing these conditions should be a part of a patient's overall treatment plan.

Anxiety and depression are commonly reported among people with epilepsy. Depression screening tools can help identify those who may require treatment. Treatment may include antidepressant drugs or cognitive behavioural therapy. It is recommended that people with epilepsy be screened for depression shortly after they are first diagnosed, and then once per year afterwards.

WOMEN WITH EPILEPSY[5]

It is recommended that women who are pregnant or thinking of becoming pregnant, or who are sexually active or taking birth control pills, talk to their doctors to develop a management plan. Important information for females of childbearing age with epilepsy include:

- Certain ASDs, such as phenytoin, carbamazepine and phenobarbital, topiramate and oxcarbazepine can make birth control pills and other forms of contraception less effective.
- During pregnancy, only one ASD at the lowest dose should be taken (if possible).
- Some ASDs can pose risks to an unborn child during pregnancy. In particular, valproic acid increases the risks of spina bifida, autism spectrum disorders and lower verbal IQ.
- Some ASDs can cross the placenta and may pose risks to unborn children. However, uncontrolled seizures can also pose a risk to a developing baby. Expectant mothers can work with health care providers to develop a treatment plan that is best for both the mother and baby.
- Folic acid supplements are suggested before and during pregnancy to promote healthy development of the brain and nervous system.
- Menopausal women who are taking ASDs may be at greater risk of bone fractures. Daily vitamin D and calcium supplements are suggested.

For women who are thinking of becoming pregnant, the guidelines recommend that treatment should aim for seizure freedom prior to pregnancy.

PATIENT EDUCATION AND COUNSELING[6]

Health care providers should offer guidance on how to deal with the effects of epilepsy, such as:

- Managing seizures at school or work
- Laws about driving
- Effects of drugs and alcohol on anti-seizure drugs
- Sexual and reproductive health
- Impact on relationships and families

People with epilepsy often experience stigma, both felt and enacted. This can prevent them from seeking out information. Doctors should provide referrals to a social worker or community epilepsy agency that can provide counselling, education, first aid training, and social support.

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B. Drug-Resistant Epilepsy[7]

- Most people with epilepsy can achieve seizure control with drug treatment. However, 1 in 3 people with epilepsy will continue to have seizures while taking anti-seizure drugs. This is known as drug-resistant epilepsy (also called *refractory* or *intractable* epilepsy). Anyone with epilepsy who is not seizure-free after trying two different anti-seizure drugs (taken alone or together) is said to have drug-resistant epilepsy.
- The diagnosis of drug-resistant epilepsy is made by a doctor. In order to meet the criteria, the drugs must have been appropriate for the type of seizures and taken at the proper dose.
- If a drug was stopped due to the side effects (whether or not good seizure control was established), these drugs would not count towards the criteria of having drug-resistant epilepsy.
- Seizure freedom means having no seizures for at least the past 12 months (or longer for those with infrequent seizures). Anyone with epilepsy who is not seizure-free after trying two different anti-seizure drugs should be referred to an epileptologist (a neurologist who specializes in epilepsy) at a District Epilepsy Centre or a Regional Epilepsy Surgery Centre.

DISTRICT EPILEPSY CENTRES (DECs) /REGIONAL EPILEPSY SURGERY CENTRES (RESCs)

A DEC or RESC offers a number of tests and assessments to evaluate if a person is a candidate for surgery. If surgery is not possible, a DEC or RESC can also suggest other treatment options. The DECs in Ontario are located at:

Hamilton Health Sciences
Adult: 905-527-4322 x 46755
Pediatric: 905-521-2100 x 78517

The Ottawa Hospital
Adult: 613-761-5353 x 0

Children's Hospital of Eastern Ontario
Pediatric: 613-738-4879

Kingston Health Sciences Centre
Adult: (613) 548-7835

A RESC provides the same services as a DEC and also offers epilepsy surgery. The RESCs in Ontario are located at:

London Health Sciences Centre (formerly Children's Hospital of Western Ontario)
Adult (fax:) 519-663-3753
Pediatric: 519-685-8332

Hospital for Sick Children
Pediatric: 416-813-7998

University Health Network - Toronto Western Hospital
Adult: 416-603-5232

EPILEPSY MONITORING UNIT

An EMU consists of dedicated hospital beds in a DEC or RESC for monitoring people with epilepsy. In the EMU, patients are weaned off their anti-seizure drugs and brain activity is monitored and recorded for a period of time. A stay in an EMU can last from a few days to a few weeks, depending on how many seizures need to be recorded. Each EMU has a comprehensive team including doctors, nurses, technicians, and social workers/mental health professionals. A stay in the EMU can serve several purposes: it can help to confirm or clarify a diagnosis of epilepsy; assist with classifying the seizure type or syndrome; assess for the possibility of surgery; and provide a safe environment to modify drug therapy or start immune therapy.

Anyone with epilepsy who is not seizure-free after trying two anti-seizure drugs should be referred to an epileptologist at a DEC or RESC.

C. Treatment Options for Drug-Resistant Epilepsy[8]

SURGERY

- Any person with drug-resistant epilepsy should be viewed as a potential candidate for resective surgery. This involves removing the part of the brain where seizures are thought to start. It is recommended that anyone with drug-resistant epilepsy be referred to a DEC or RESC to be assessed for the possibility of surgery.
- Many people do not consider surgery as an option. It is estimated that only 2-4% of eligible candidates undergo surgery. Patients often overestimate the risks of surgery, and some neurologists may view surgery as a last resort. Helping clients to become familiar with the guidelines can help them to have a conversation with their health care provider(s) around surgery.
- The assessment for surgery will include an extended stay in an epilepsy monitoring unit.
- There is a 60-80% chance that a person who is a suitable candidate will be seizure-free after surgery. The rate of success depends on several factors, including which area of the brain is removed.
- Any person considering surgery should consult with an epileptologist at a DEC/RESC in order to find out if they are a candidate for resective epilepsy surgery, as well as the expected risks and benefits of surgery for them.

IMMUNE THERAPY

- In some people, the activity of the immune system may cause seizures. This type of epilepsy is known as autoimmune epilepsy.
- To determine if seizures may have an immune basis, brain imaging and/or a lumbar puncture may be needed.
- For autoimmune epilepsy, steroids and anti-inflammatory drugs can adjust the activity of the immune system to help control seizures.

DIET THERAPY

- In people who have drug-resistant epilepsy or certain epilepsy syndromes, doctors may recommend diet therapy.
- The classic ketogenic diet is a high-fat, low-carbohydrate, adequate protein diet that can prevent seizures. Although this diet is commonly prescribed for children, it can be an effective treatment for adults as well.
- On this diet, the brain begins to use fats as fuel, rather than sugars. When fats are broken down, they produce ketone bodies, which have been shown to decrease the number of seizures.
- Some people may find this diet to be unpleasant tasting or hard to maintain. Other, less restrictive diet options are also available.
- A medical team, including doctors and dietitians, will guide and monitor any diet treatments.

BRAIN AND NERVE STIMULATION

- Some people with drug-resistant epilepsy may benefit from stimulation of specific nerves or brain areas to reduce the risk of seizures.
- Since brain stimulation is generally less effective than resective surgery, this treatment should only be considered after surgery has been explored as an option.
- Stimulation can be delivered by devices can be placed in the brain or under the skin or through electrodes (sensors) on the forehead. Surgery may be required to implant the device.
- Common types of stimulation include vagus nerve stimulation and deep brain stimulation.
- A detailed assessment can help to determine if a patient is a candidate for brain or nerve stimulation. If this is the case, a qualified medical team will direct the treatment.

All treatments must be medically recommended and supervised.

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D. Transition from Pediatric to Adult Care

For a child turning 18, moving from the pediatric to the adult health care system can be a challenging process. In the adult system, there may be fewer support services available, and people with epilepsy are expected to make more decisions on their own. The guidelines suggest that families and pediatric health care providers start preparing for this process as early as age 12. Over time, it is recommended that responsibilities gradually shift from health care providers, to families, to children themselves.

To assist with the transition, families can research available services, plan for future needs and help children to develop the knowledge and skills needed to be more independent. A smooth transition will ensure that good quality medical care is not interrupted while switching health care providers, and that future social and financial support needs are planned for.

DURING THE TRANSITION[9]

- A child's seizures and how they respond to treatment can change throughout childhood as the brain develops. Children should be re-assessed at 16-17 years of age to plan for any treatment changes as an adult. Doctors may perform additional brain monitoring or brain imaging prior to the transition to look for any changes.
- If complete genetic testing was not available when a child was first diagnosed, it may be useful to do this testing before the transition to adult care. If there is a genetic basis for seizures, more effective treatments may become available.
- Mental health issues can often appear during adolescence. Mental health screening should be done at 12-14 years of age, and both before and after the transition to adult care.

Transition can be more challenging for children with intellectual or developmental delays. Proper screening and documentation can help families to access additional support services.

FUTURE PLANNING[10]

- Government social services and financial support for children with disabilities usually ends at age 18 or 21. Things to consider may include personal care (such as bathing and dressing) and lifts/transfers, as well as future assistance if seizures or overall health worsen. There may also be added stress on caregivers when social support ends.
- Children who are on the ketogenic diet may be weaned off as they move into the adult system. There is currently one adult epilepsy diet clinic in Toronto.
- It is advisable to discuss birth control and family planning with young females as soon as they can potentially become pregnant, and ideally earlier. It is important to be aware of the risks that certain anti-seizure drugs pose to unborn babies, and the possible interactions between anti-seizure drugs and certain forms of birth control.
- Patients and their families should receive a complete discharge package from pediatric health care providers. This includes a full medical history, copies of all referrals, treatment goals and records of any social or financial support needs.
- A list of services for youth with disabilities is available at OntarioEpilepsyGuidelines.ca/transition

[1]Refer to Section III: Initial Evaluation in *Provincial Guidelines for the Management of Epilepsy in Children and Adults*

[2]Refer to Section IV: Drug Treatment in *Provincial Guidelines for the Management of Epilepsy in Children and Adults*

[3]Refer to Section VIII: Guidelines on Follow-Up in *Provincial Guidelines for the Management of Epilepsy in Children and Adults*

[4]Refer to Section IX: Guidelines on Co-morbidities in *Provincial Guidelines for the Management of Epilepsy in Children and Adults*

[5]Refer to Section VI: Guidelines for Management of Women with Epilepsy in *Provincial Guidelines for the Management of Epilepsy in Children and Adults*

[6]Refer to Section V: Patient Education and Counselling in *Provincial Guidelines for the Management of Epilepsy in Children and Adults*

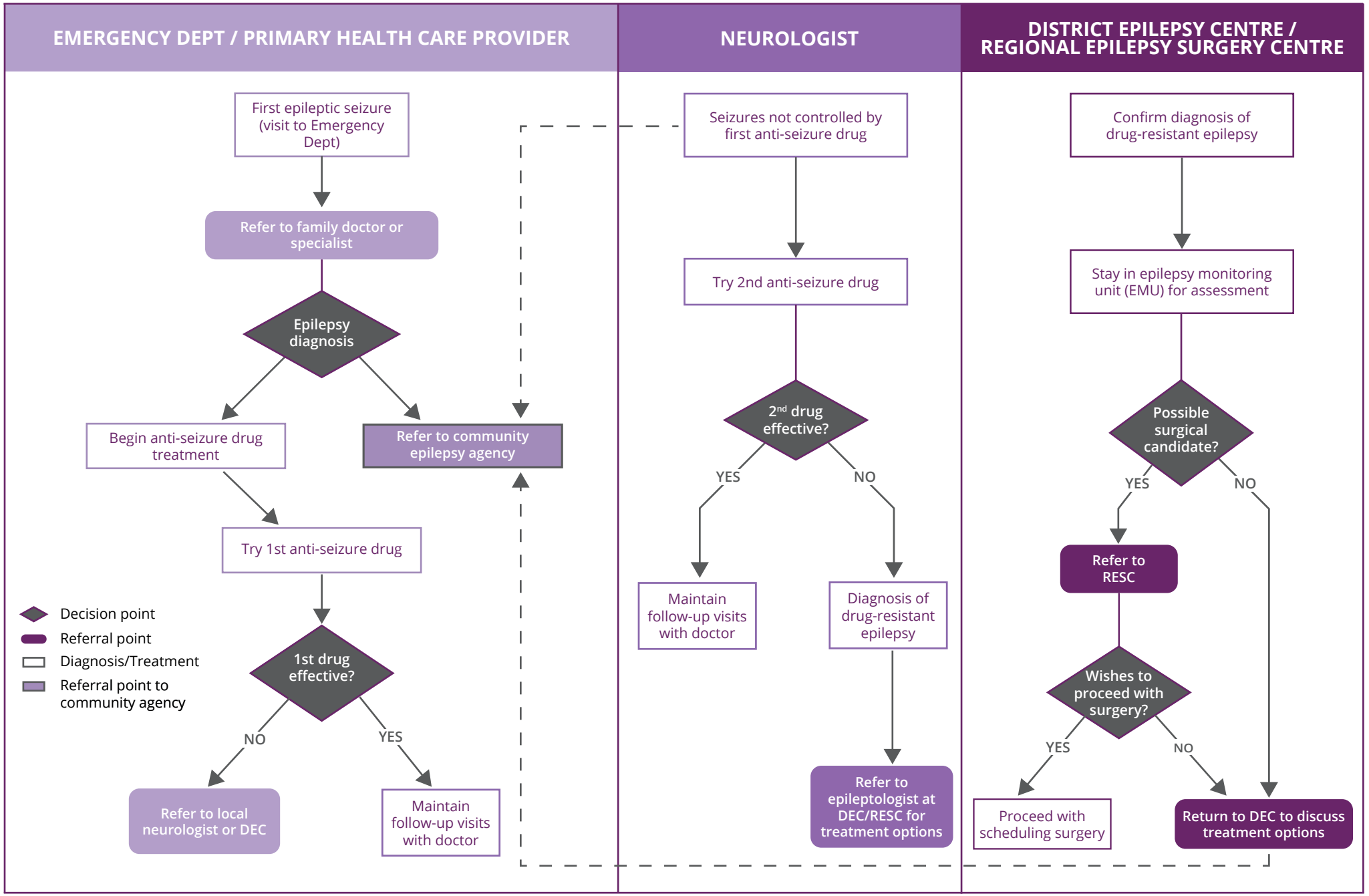
[7]Refer to Patients with Medically-Refractory Epilepsy as Candidates for Referral in *Provincial Guidelines for Epilepsy Surgery Referrals in Ontario*

[8]Refer to Section III. Management of Refractory Epilepsy in *Provincial Guidelines for the Management of Medically-Refractory Epilepsy in Adults and Children Who are not Candidates for Epilepsy Surgery*

[9]Refer to Step 3: Epilepsy Re-evaluation, Screening and Management during Transition in *Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult*

[10]Refer to Steps 3-6 in *Provincial Guidelines for Transitional Care of Paediatric Epilepsy Programs to Adult*

DIAGNOSIS AND TREATMENT PATHWAY



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