

CLINICAL GUIDELINES FOR THE MANAGEMENT OF EPILEPSY

Information for People with Seizures



THE EPILEPSY RESEARCH PROGRAM
OF THE ONTARIO BRAIN INSTITUTE



ONTARIO BRAIN INSTITUTE
INSTITUT ONTARIEN DU CERVEAU

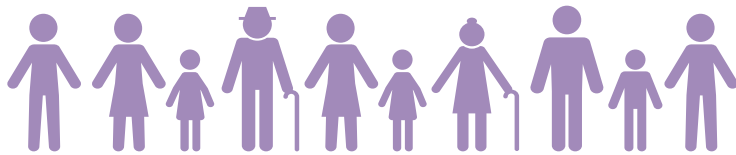


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ABOUT THIS BOOKLET

Beginning in 2014, a task force supported by Critical Care Services Ontario released a series of guidelines for epilepsy care. The goal of these guidelines is to improve treatment and access to care for people with epilepsy. This booklet highlights some of the key recommendations from the guidelines, which are based on current evidence. If you have epilepsy, the information in these guidelines can help you, your caregivers and your health care providers to make informed decisions about your treatment. To learn more about these documents, please visit www.OntarioEpilepsyGuidelines.ca.



WHAT IS EPILEPSY?

A seizure occurs when there is a sudden burst of brain activity. Seizures can appear differently, ranging from blank stares to uncontrolled body movements. Awareness may or may not be affected, and seizures can affect one or both sides of the body.

Epilepsy is a brain disease that causes unprovoked, repeated seizures. There are many different causes and there are different kinds of seizures. Epilepsy can affect people of all ages.

HOW IS IT DIAGNOSED?

There is no single test to diagnose epilepsy. Doctors may use some or all of the following tests:

- ◆ Taking your health and medical history, including a description of any seizures
- ◆ Recordings of brain activity (known as electroencephalography, or EEG)
- ◆ Brain imaging (such as magnetic resonance imaging, or MRI)

Having seizures does not always mean that you have epilepsy. If a health care provider cannot make a clear diagnosis, they may refer you to a specialist for further testing. Your health care provider should tell you what kind of seizures you have and whether or not the cause of your epilepsy is known.

HOW IS EPILEPSY TREATED?

The most common treatment for epilepsy is taking medication. Anti-seizure drugs (also known as anti-epileptic drugs) provide the best chance of preventing seizures with the lowest risk of treatment side effects.

Number
of People in Ontario
Living with Epilepsy

90,000

Number
of People in Ontario
Who Will Develop
Epilepsy Each Year

6,500



Your treatment goals may be different, so ask your healthcare provider about the different treatment options that might be right for you. If your seizures are triggered by things like a lack of sleep, stressful situations or alcohol consumption, avoiding these triggers can decrease the chances of having a seizure.

WHAT SHOULD I KNOW ABOUT ANTI-SEIZURE DRUGS?

There are many different anti-seizure drugs available. The choice of drug will depend on the type of seizures you have and the possible side effects of the drug. It is ideal to take only one anti-seizure drug when possible. Sometimes a doctor may prescribe two or more of these drugs to improve seizure control. If you do not become seizure free with the first drug that you try, it is recommended that you be referred to a **neurologist** (a doctor who specializes in treating the brain). Your doctor may recommend switching to a different drug or adding a second drug to the one you are already taking.

Each drug has different side effects, so ask your health care providers what side effects you should expect.

Before making any changes in drug treatment (such as adding/removing a drug or stopping drug therapy), it is important to discuss the risks and benefits with your doctor.

DRUG-RESISTANT EPILEPSY

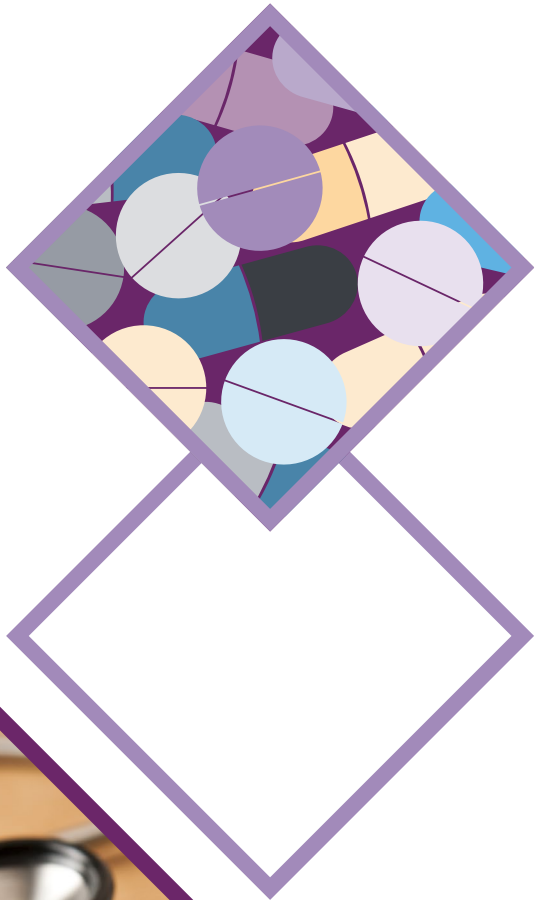
I'm taking anti-seizure drugs, but I'm still having seizures. What should I do?

Most people with epilepsy have seizures that can be controlled with anti-seizure drugs. However, 1 in 3 people with epilepsy continue to have seizures despite taking medication. This is known as **drug-resistant epilepsy**.

People who live with drug-resistant epilepsy find their seizures have a significant impact on social interactions, education and employment opportunities, and cognitive functions such as memory. Having frequent **generalized tonic-clonic seizures** is also associated with a higher risk of sudden unexpected death in epilepsy (SUDEP). Please visit OntarioEpilepsyGuidelines.ca/SUDEP-information for more information about SUDEP.

Anyone with epilepsy who is not seizure-free after trying two different anti-seizure drugs (taken alone or together) may have drug-resistant epilepsy.

The diagnosis of drug-resistant epilepsy is made by your health care provider. In order to meet the criteria, you must have taken the right drug for your type of seizures at the proper dose. If a drug was stopped early due to side effects, it may not count as a trial.



Being “seizure-free” means that you have had no seizures for at least the past 12 months (or longer if you have infrequent seizures).

If you are not seizure-free after trying two different anti-seizure drugs, you should be offered a referral to an **epileptologist** (a neurologist specializing in epilepsy) at a specialized epilepsy centre to talk about your treatment options.

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

- ◆ A DEC or RESC is a specialized epilepsy centre in Ontario. If you have drug-resistant epilepsy, these centres offer a number of different tests and assessments to see what treatment options might be right for you.
- ◆ DECs/RESCs have a comprehensive team, including an epileptologist, nurses and technologists, social workers, mental health professionals and neurosurgeons.
- ◆ These specialized centres are located at hospitals in Toronto, Hamilton, London, Ottawa and Kingston.

? If I have drug-resistant epilepsy, what are my treatment options?

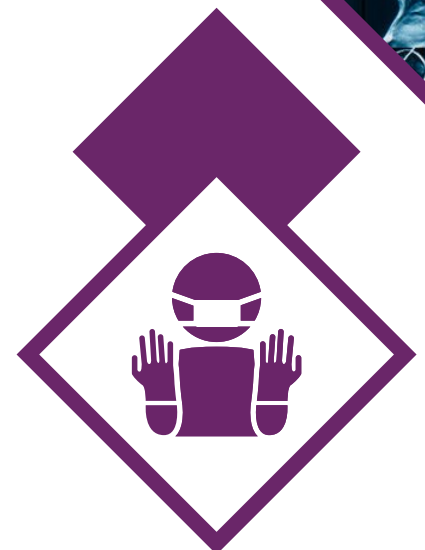
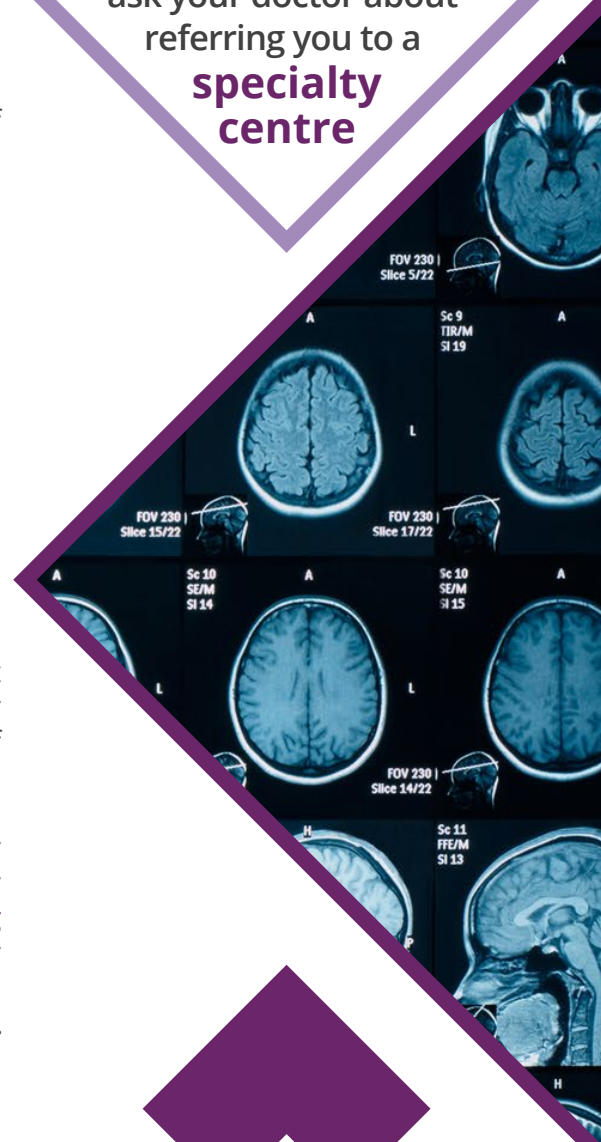
SURGERY

One of the options for treating drug-resistant epilepsy is **resective surgery**. In this procedure, a surgeon locates and removes the part of the brain where seizures start, while avoiding the areas of your brain that are important for movement, sensation, and language. If you have drug-resistant epilepsy, a DEC or RESC offers a full assessment to find out if you are a candidate for surgery. At a DEC or RESC, you can undergo tests that will provide more details about your brain’s structure and function. The assessment for surgery is very thorough and includes an extended stay in an **epilepsy monitoring unit (EMU)**, where a medical team can monitor your brain activity for long periods of time. You may be given tests that you have never had before so that the medical team can learn more about your epilepsy.

Resective surgery offers a greater chance of being seizure-free than anti-seizure drugs alone. If you are a candidate for surgery, there is a 60-80% chance that you will be seizure-free after surgery.

Although surgery can be an effective treatment, it is not right for everyone. If surgery is an option, your health care team will provide information about the risks and benefits as well as your chances of achieving seizure freedom. After your stay in the EMU, if you choose to have surgery, this will be scheduled for a later date. If surgery is not an option, or if you choose not to undergo surgery, your team at the DEC or RESC will discuss treatment options with you. These options include diet therapy, drug therapy, immune therapy, and brain or nerve stimulation.

If you are not seizure-free after trying 2 drugs, ask your doctor about referring you to a **specialty centre**





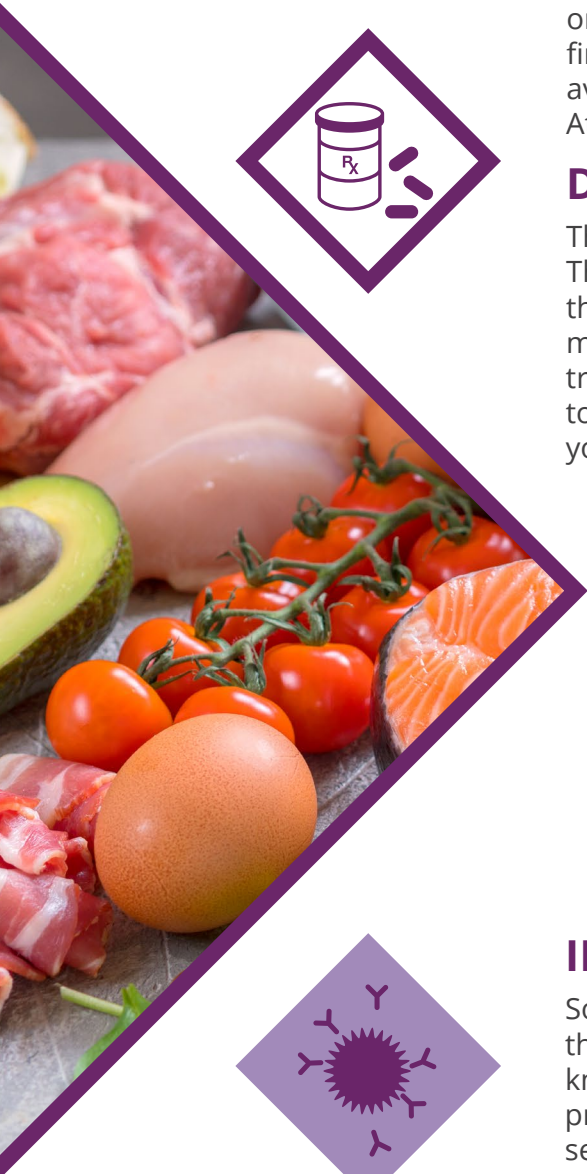
DIET THERAPY

The **ketogenic diet** is a high-fat, low-carbohydrate diet that can effectively treat seizures. It is commonly prescribed for children but can be effective in 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. Diet therapy can be an option for any child or adult with drug-resistant epilepsy who is not a candidate for surgery, or is awaiting an assessment for surgery. Since some people may find this diet hard to maintain, less restrictive diet options are also available, such as the medium chain triglycerides (MCT) or modified Atkin's diets.

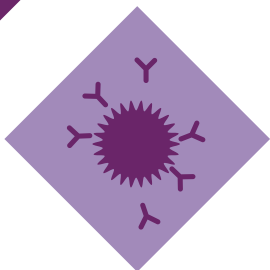


DRUG THERAPY

There are at least 21 different anti-seizure drugs available today. These drugs work in different ways, and some are more effective than others for treating certain types of seizures. An epileptologist may suggest trying a different kind of drug before exploring other treatment options. They may also prescribe two or more drugs together that target different proteins in the brain. This can improve your chances of seizure control.



All treatments must be medically supervised



IMMUNE THERAPY

Sometimes the activity of the immune system (the defense network that protects the body) can cause seizures. This type of epilepsy is known as autoimmune epilepsy. If this is the case, medication can be prescribed to adjust the activity of the immune system to help control seizures.



BRAIN AND NERVE STIMULATION

For some people, electrical stimulation of specific nerves or brain areas can reduce the risk of seizures. Stimulation may be delivered through devices implanted in the brain or under the skin, or through electrodes placed on the forehead. Examples include vagus nerve stimulation and deep brain stimulation. Since stimulation is less effective than resective surgery, this treatment should only be considered after surgery has been explored as an option.

MANAGEMENT OF EPILEPSY

CO-EXISTING CONDITIONS

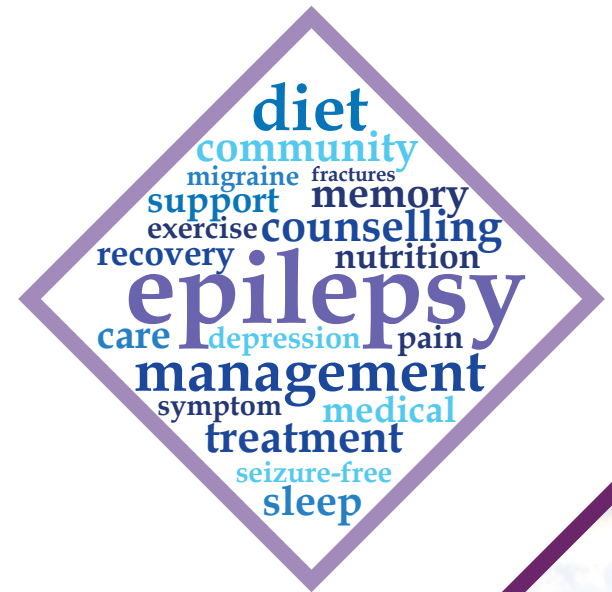
Epilepsy is not just a seizure disease. If you have epilepsy, you are at risk of having other health conditions that can affect your quality of life. These co-existing conditions can impact both your physical and mental health.

- ◆ Many people with epilepsy have **learning disabilities, attention deficit hyperactivity disorder**, or difficulties with **memory**.
- ◆ Physical conditions such as **migraines, digestive problems, bone fractures** and **chronic pain** can also occur.
- ◆ **Anxiety** and **depression** are also common. Depression screening tools can help identify people who may require treatment. You should be offered depression screening soon after diagnosis and once a year afterwards. If needed, treatment for depression may include antidepressant drugs or cognitive behavioural therapy.
- ◆ Managing these conditions should be included in the treatment plan that you and your health care providers develop. You may also choose to seek other sources of support, such as counselling or visiting a community epilepsy agency (call 1-866-EPILEPSY to find your local agency).

MONITORING

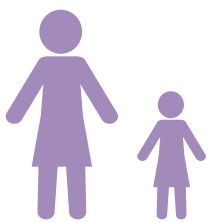
It is recommended that you schedule regular follow-up appointments with your doctor. At each visit, doctors can check how well your anti-seizure drugs are working and monitor any side effects since these can change or develop over time. The suggested follow-up times are:

- ◆ **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





Some anti-seizure drugs can pose risks to unborn babies or reduce the effectiveness of birth control



FEMALES WITH EPILEPSY

For girls and women with epilepsy, there may be times when your treatment needs to be adjusted. Talk to your health care providers to develop a management plan if you are pregnant or thinking of becoming pregnant, or if you are sexually active or taking birth control pills.

Some things to consider include:

- ◆ Some anti-seizure drugs can make birth control pills and other forms of contraception less effective.
- ◆ If you are thinking of becoming pregnant, your doctor will aim for seizure freedom prior to pregnancy.
- ◆ If you are pregnant, your doctor will aim to simplify your treatment to a single anti-seizure drug (if possible) at the lowest dose.
- ◆ Anti-seizure drug levels may decrease during pregnancy, so your doctor may want to monitor your blood levels.
- ◆ Folic acid supplements are suggested before and during pregnancy to help with the development of your baby's brain and spinal cord.
- ◆ Some anti-seizure drugs can cross the placenta and may pose risks to unborn children. However, uncontrolled seizures can also pose a risk to you and your developing baby. It is important to work with your health care providers to develop a treatment plan that is best for you and your baby.
- ◆ If you are menopausal and taking anti-seizure drugs, you may be at greater risk of bone fractures. Your doctor may recommend daily vitamin D and calcium supplements.



TRANSITIONING FROM PEDIATRIC TO ADULT CARE

For a child who is turning 18, moving from the pediatric to the adult health care system can be a complex process. If you have a child with epilepsy, you can start preparing for this process as early as age 12. This may include researching what services are available, planning for future needs and helping your child develop the knowledge and skills needed to be more independent. Planning ahead for the transition can help ensure that good quality medical care is maintained while switching health care providers, and that future social and financial support needs are met.

DURING THE TRANSITION

- ◆ Both seizures and the response to treatments 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. Additional testing, such as brain wave monitoring or brain imaging, may be done prior to the transition.
- ◆ If complete **genetic testing** was not available when your child was first diagnosed, ask your doctor if it would be useful to do this testing before the transition to adult care.
- ◆ 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.

FUTURE PLANNING

- ◆ **Government social services and financial support** for children with disabilities usually ends at age 18 or 21. Things to consider planning for may include personal care (e.g. bathing and dressing), lifts/transfers for your child, and future assistance if seizures or overall health worsen. There may also be added stress on caregivers when support services end.
- ◆ Children who are on the **ketogenic diet** may be weaned off as they become adults, unless there is a need to continue.
- ◆ It is important to discuss **birth control and family planning** with young women as soon as they can potentially become pregnant (ideally earlier). Some anti-seizure drugs can pose risks to unborn babies or reduce the effectiveness of birth control.
- ◆ You and your child should receive a complete **discharge package** from pediatric health care providers. This will include a full medical history, copies of referrals, records of any social or financial support needs, and your goals of care.
- ◆ You can find **readiness checklists** and information about **available resources** and **support programs** online at OntarioEpilepsyGuidelines.ca/transition

In the **adult system**, there may be fewer **support services** available





There are
14
 Community Epilepsy
 Agencies in
Ontario



EDUCATION AND COUNSELING

Your health care providers and local community epilepsy agency 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

You can use the **Epilepsy Education Checklist** on page 9 of this booklet to ensure that you have the information you need from your health care providers.

Upon diagnosis, your doctor should provide contact information or a referral to a social worker or community epilepsy agency that can provide additional support.

COMMUNITY EPILEPSY AGENCIES

A community epilepsy agency offers resources and support for all aspects of an epilepsy diagnosis. The services they offer may include:

- ◆ Teaching first response protocol to your family, friends and employers
- ◆ Offering epilepsy education services
- ◆ Providing counselling for depression, anxiety and stress management
- ◆ Connecting you with peer supports and support groups
- ◆ Advocating for you and your family at schools and workplaces, and working to reduce stigma and discrimination related to epilepsy
- ◆ Helping you to access and navigate prescription drug programs and disability services



Community epilepsy agencies have locations all across Canada, including 14 in Ontario. Please visit **epilepsyontario.org/agency** or call **1-866-EPILEPSY** to be connected to your local agency.

TALKING TO YOUR DOCTOR

If you are not seizure-free after trying two different anti-seizure drugs, it is recommended that you talk to your doctor about other treatment options. Sometimes it can be hard to discuss this topic with your doctor. You may be worried that your doctor may feel insulted or get upset with you. But try to remember that your doctor is there to help you find the right treatment.

BEFORE YOUR APPOINTMENT:

It's a good idea to have a goal in mind for your appointment. Would you like to talk about changing your medication? About doing further testing? Would you like to talk about surgery? Write down your questions and bring them to your appointment.

STARTING THE CONVERSATION:

This is sometimes the most difficult part. If you are unsure about how to explore different treatment options, you could start by asking:

"So I have been taking these medications for (# of) years and they don't seem to be working. Could we discuss other treatment options?"

OR

"I've been experiencing a lot of side effects from my medication. I'd like to talk about other possible treatments."

If your doctor says that your seizures are under control, remember that the goal of epilepsy treatment is having no seizures and minimal side effects. If you are still having seizures once a month, or once a year, you are not seizure-free.

If you would like to talk about a specific treatment, such as surgery, you can ask:

"I'd like to talk about epilepsy surgery. I know it works for some people. Do you think I might be a candidate for surgery?"

If your doctor says that brain surgery is too risky or is a last resort, say that you would like information on both the risks and benefits so that you can discuss the decision with your friends and family.

If you have established that you would like a referral to a specialty centre, ask what the next step is.



Your doctor may be unaware that these guidelines exist. If this is the case, they may be unaware of your right to be referred to a specialty centre. You can approach this by saying (for example): *“The new epilepsy guidelines in Ontario say that if I’m not seizure-free after trying two different medications, I should be referred to a specialty centre. Does this apply to me?”*

DURING YOUR APPOINTMENT:

Here are some questions you can ask your doctor to find out if another treatment might be right for you. You may already know the answers to some of these, but if not, you can start at the beginning.

- ◆ *What type of seizures do I have?*
- ◆ *What is the cause of my seizures?*
- ◆ *Do the side effects of taking seizure medication outweigh the benefits for me?*
- ◆ *Do I have drug-resistant epilepsy?*
- ◆ *Should I visit an epilepsy center to see if other treatments might work for me?*
- ◆ *Is it possible that I have the kind of seizures that can be treated with surgery?*
- ◆ *If I try another treatment, how will it affect my lifestyle?*
- ◆ *If I try another treatment, how will it affect my overall health?*

If you would like to discuss a specific treatment, some questions that might be useful are:

- ◆ *How effective is this treatment?*
- ◆ *Would this treatment work for me (or my child)?*
- ◆ *What are the risks of this treatment?*
- ◆ *Where can I go for more information?*

TIPS:

- ✓ It’s a good idea to write down the information your doctor gives you, but it can be difficult to follow the conversation at the same time. Consider bringing a friend or family member along who can take notes.
- ✓ Remember that there are no silly questions. You can keep asking any questions you have if there is anything you do not understand, or if something does not make sense to you.
- ✓ Many doctors book very short appointments. If there is not enough time to ask your questions, tell your doctor that you would like another appointment so you can continue the discussion.
- ✓ Most doctors will listen to your concerns and try to help. If your doctor does not answer your questions to your satisfaction, you have a right to ask for a second opinion. You can ask your family doctor for a referral to another specialist, or you can find another family doctor. The Ontario government offers a service called Health Care Connect to assist you with finding a family doctor. Call 1-800-445-1822 for more information.

EPILEPSY EDUCATION CHECKLIST

This checklist can be used by both you and your health care providers to ensure that you and your family/caregivers have the information you need. Ideally, these topics should be discussed as soon as possible following your diagnosis.

Epilepsy Information

- Definition, seizure types, syndromes, potential causes
- Explanation of medical tests
- Prognosis
- Treatment options
- Seizure diary

Medications

- Choice of anti-seizure drug
- Side effects
- Compliance
- Drug interactions
- Missed doses or suddenly stopping medications
- Medication subsidies/drug plans
- Rescue medications

First Aid

- How to assist during a seizure
- When a seizure is a medical emergency

Women and Epilepsy

- Contraception
- Preconception
- Pregnancy and breastfeeding
- Pregnancy registry
- Menopause

Lifestyle

- Diet
- Exercise
- Sleep
- Alcohol and substance abuse
- Driving regulations
- Employment
- School

Safety and Risk Factors

- Injury prevention at home and in community
- Sudden Unexpected Death in Epilepsy (SUDEP)
- Medic Alert and identification jewellery

Possible Psychosocial Consequences

- Perceived stigma
- Memory loss
- Depression
- Anxiety
- Sexual difficulties
- Low self-esteem

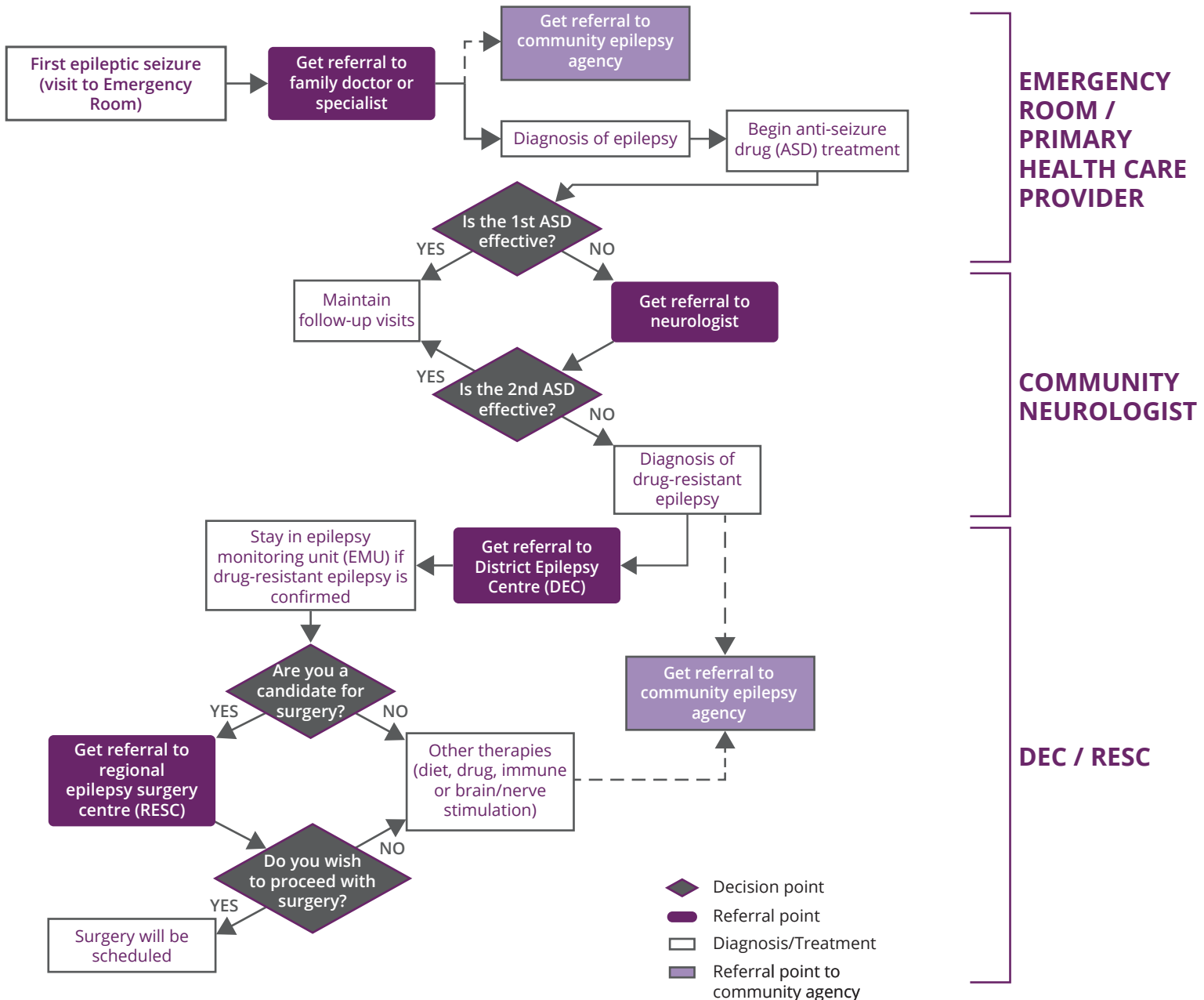
Community Supports

- Discussion about Community Epilepsy Agencies
- Call 1-866-EPILEPSY or find a list of local agencies at www.epilepsyontario.org/agency



DIAGNOSIS, TREATMENT & REFERRAL PATHWAY

This flow chart summarizes the recommended treatment and referral pathway if you have been diagnosed with epilepsy. At each stage, you and your health care providers can discuss treatment options to come to a decision that is best for you.



Adapted from the Epilepsy Guideline Series developed by Critical Care Services Ontario. The complete set of guidelines can be viewed at OntarioEpilepsyGuidelines.ca

ARE **YOU** LIVING WITH UNCONTROLLED SEIZURES?

Help is available.

Most people living with **epilepsy** have seizures that can be controlled by **anti-seizure drugs**



But **1 in 3** people continue to have seizures despite taking **anti-seizure drugs**

This is known as **drug-resistant epilepsy** and may require a different **type of treatment** for seizure control



If you are not seizure-free after trying **2 anti-seizure drugs**, you have the right to be referred to an **epilepsy specialist** to talk about your treatment options.

STEP 1

Diagnosed with epilepsy?



STEP 2

Try 1st drug. Still having seizures?



STEP 3

Try 2nd drug. Still having seizures?



STEP 4

Talk to your doctor about a referral to an epilepsy specialist.





GLOSSARY

Anti-seizure drugs	Medications that are taken to prevent the occurrence of seizures.
Autoimmune epilepsy	A type of epilepsy where the activity of the immune system causes seizures to occur.
Community Epilepsy Agency	A local organization that provides resources and support for all aspects of an epilepsy diagnosis.
Deep Brain Stimulation	A medical treatment where electrical impulses are delivered through electrodes implanted in the brain to help prevent seizures.
Discharge Package	Complete information about a child's medical history that is given to the family when leaving the pediatric health care system.
District Epilepsy Centre (DEC)	A specialized epilepsy centre that offers additional testing to learn more about your epilepsy.
Drug-resistant epilepsy	Occurs when seizure freedom is not achieved after trying two different anti-seizure drugs.
Electroencephalography (EEG)	A technique used to record electrical activity in the brain.
Epilepsy	A brain disease that causes repeated, unprovoked seizures.
Epilepsy Monitoring Unit (EMU)	A hospital unit that provides 24/7 monitoring and assessments for surgery and other treatments.
Epileptologist	A neurologist specializing in epilepsy.
Genetic test	A medical test to identify changes in DNA, genes or proteins that may be linked to seizures.
Generalized tonic-clonic seizure	A type of seizure that involves whole-body convulsions and a loss of awareness.
Guidelines	A series of recommendations for medical professionals based on current evidence.
Ketogenic Diet	A high-fat, low-carbohydrate, adequate protein diet used to reduce the occurrence of seizures.
Ketone bodies	Produced in the body when fats are broken down.
Magnetic Resonance Imaging (MRI)	A technique that produces high-quality images of the brain.

GLOSSARY

Medium Chain Triglycerides (MCT) Diet	A type of ketogenic diet where medium chain triglycerides, derived from oil, are the main sources of fat.
Modified Atkin's Diet	A limited carbohydrate diet with no restrictions on calories, fat or protein.
Neurologist	A doctor specializing in treating the brain and nervous system.
Regional Epilepsy Surgical Centre (RESC)	A specialized epilepsy centre that offers additional testing as well as epilepsy surgery.
Resective surgery	A procedure where the part of the brain that is causing seizures is removed.
Seizure	A sudden burst of electrical activity in the brain that can appear as a blank stare or uncontrolled body movements.
Seizure freedom	Having no seizures in the last 12 months (at minimum).
SUDEP (Sudden Unexpected Death in Epilepsy)	Occurs when a person with epilepsy dies suddenly and no cause of death can be found.
Vagus Nerve Stimulation	A medical treatment where electrical stimulation is delivered to the vagus nerve to help prevent seizures.

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of Critical Care Services Ontario

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www.OntarioEpilepsyGuidelines.ca



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