

# **Epilepsy & Seizure Disorder Management Protocol**

**2009**

## **Recognition of Committee Members:**

The following are thanked for their dedication and expertise in developing the Epilepsy and Seizure Disorder Management Protocol for the Public and Catholic elementary and secondary schools in the Halton Region.

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## **INTRODUCTION:**

Epilepsy, also known as a seizure disorder –the terms are used interchangeably, is not often talked about in public. Misconceptions and fears persist that are sometimes more burdensome to persons living with seizure disorders than the seizures themselves. The fact is epilepsy is not a disease but a common neurological disorder affecting one out of every one hundred Canadians. Anyone can develop a seizure disorder at any time without a known cause. Most often diagnosed in children and in seniors, the seizure disorder affects each person differently. Many people with seizure disorders successfully control their seizures with medication and are able to enjoy healthy and fulfilling lives.

## **Rationale for a Seizure Management Protocol:**

The goal of this protocol is to educate school personnel about epilepsy, its causes, symptoms and treatments so that a child diagnosed with a seizure disorder can have the support needed in the school setting or on a school trip to successfully participate in their education.

## **RESPONSIBILITY TO PROVIDE A SAFE ENVIRONMENT FOR PUPILS WITH EPILEPSY AND SEIZURE DISORDERS: LEGAL CONTEXT**

### **DUTY OF CARE:**

This Epilepsy and Seizure Disorder Management Protocol for school administrators, teachers and other employees has been developed to meet the requirements of:

#### ***Education Act:***

- s. 265 (1) Duties of principals:
- j) care of pupils and property – to give assiduous attention to the health and comfort of the pupils,

#### ***Regulation 298:***

- s. 20 Duties of teachers:
- g) ensure that all reasonable safety procedures are carried out in courses and activities for which the teacher is responsible,

The Board's liability policy provides coverage for employees acting within the scope of their duties with the board. Thus, all school staff that administer first aid to a student who is experiencing a seizure within the school or during a school activity are covered.

*This protocol recognizes the Accessibility for Ontarians with Disabilities Act, 2005 and the Ontario Human Rights Code both in spirit and intent.*

## What is a Seizure Disorder?

Epilepsy or seizure disorder is a neurological disorder caused by sudden, brief changes in how the brain works, e.g. when the normal electrical balance in the brain is lost. Seizures are the physical effects of unusual burst of electrical energy in the brain and may include muscle spasms, mental confusion, loss of consciousness, uncontrolled or aimless body movement, incontinence and vomiting.

Note:

- Seizures are not contagious
- Seizures are not the child's fault
- Many seizures are hidden
- Seizures are not dangerous to others
- One seizure does not lead to a seizure diagnosis

The type of seizure depends on where in the brain the discharge begins.

### Myths: Common Misconceptions – Epilepsy Ontario

1. *You can swallow your tongue during a seizure.* It is physically impossible to swallow your tongue.
2. *You should force something into the mouth of someone having a seizure.* Absolutely not! That is a good way to chip teeth, puncture gums, or even break someone's jaw. The correct first aid is simple: just gently roll the person onto their side and put something soft under the head to protect from injury.
3. *You should restrain someone having a seizure.* Never use restraint! The seizure will run its course and you cannot stop it.
4. *see appendix B for more myths explained.*

Children with inherited disorders or brain injury may have epilepsy among their symptoms.

Many factors can lead to seizures, but 75% of the time, the exact cause is unknown or "idiopathic". Common causes include:

- Head injury – severe head blows from falls, car or bicycle accidents.
- Brain Injury caused by tumour, stroke, trauma or infectious diseases – viral encephalitis, meningitis or even measles
- Poisoning due to substance abuse, e.g. drug or alcohol use
- Brain injury can occur in utero, during childbirth or later in infancy/life
- Fevers leading to febrile convulsion in young children.

In most cases, epilepsy is not inherited. Everyone inherits a "seizure threshold" – when brain cells are irritated beyond this point, we will have a seizure. People with a low seizure threshold tend to develop seizures more easily than others.

## **SCHOOL ADMINISTRATORS' RESPONSIBILITIES CHECKLIST**

- School is to develop a process for identifying students with a Seizure Disorder e.g.:
  - School Registration
  - Notification (survey) home to parents
- Provide parents /guardians with information about the Epilepsy and Seizure Disorder Management Protocol, school's responsibilities, parent responsibilities, child's responsibilities and forms to be completed.

### **PARENT/GUARDIAN SEIZURE DISORDER PACKAGE**

- Package provided to parents/guardians on day of registration or last week of June. The following forms to be completed and returned to the school prior to the students first day of school (e.g. last week of August):
  - Epilepsy & Seizure Disorder Management Plan
  - Parent Request and Consent for Seizure Disorder Interventions and for Staff to administer prescribed medication
  - Parent/Guardian Epilepsy and Seizure Disorder Package available in the Office
- Collect EPILEPSY and SEIZURE DISORDER MANAGEMENT PLAN forms e.g. as soon as possible after registration or last week of August:
  - Develop a Seizure Disorder binder where copies of each the following forms are kept.
    - Epilepsy and Seizure Disorder Management Plan
    - Seizure Incident Record
    - Parent Request and consent for Seizure Disorder Interventions and staff to administer prescribed medication
  - Provide a copy of the Epilepsy and Seizure Disorder Management Plan to:
    - the classroom teacher to be kept in Occasional Teacher folder on teacher desk.
    - Post a copy of the Epilepsy & Seizure Disorder Management Plan with child's picture in a high traffic area for staff (e.g. staff room)
- Where needed, the school administrator arranges a meeting to gather medical information and management procedures related to the seizure disorder condition of the student and participants may include:
  - Principal/designate
  - Parent/Guardian

- Classroom teacher (coaches, other staff where relevant)
- Other relevant medical personnel/information e.g. a letter from a neurologist, paediatrician or other physician if student needs emergency medication such as lorazepam (Ativan) to stop a seizure.

**In service staff in September:**

**Resources to assist:** Canadian Epilepsy Alliance – [www.epilepsymatters.ca](http://www.epilepsymatters.ca) – see resource list page 16

- Identify student(s) in the school with seizure disorder.
- Provide classroom teachers with a student with a seizure disorder with a copy of:
  - Classroom Teacher Responsibilities Checklist.
  - Provide other teachers and those that come in contact with the student on a regular basis with a copy of: Staff Member Seizure Disorder Responsibilities Checklist.

**Provide the following Seizure Disorder Information: see Appendices**

**Instruct teachers to communicate with:**

- Support staff and volunteers of students in their class with seizure disorder.
- *Classroom students: (In discussion with child's parents) Provide information to the class about the child's seizure disorder in age appropriate terminology. A careful explanation of the seizure would alleviate the fears of the children about the disorder. Make students aware seizure disorders are not contagious, the child cannot control it, and is not dangerous to others.*
- **Occasional Teacher:**
  - Identify student on the School Board's Occasional Teacher contact system (Smart Find/ Harri).
  - Locate the student's **Epilepsy & Seizure Disorder Management Plan** in the Occasional Teacher folder on the teacher's desk.

**Outline to teachers specific plans to be taken for students with a seizure disorder when going on field trips.**

- When taking student off school site it is important that there is communication with the parent/guardian to develop a careful and clear plan of expectations to meet the needs of the student with a seizure disorder (e.g. Parent invited on trip as a supervisor).
- Parents need to know the itinerary and anticipated activities.

- Child with a seizure disorder to be assigned to an informed adult who knows what do in case of a seizure and what to do in case of an emergency e.g. parent or classroom teacher.
- The child should be wearing a medical alert identification.
- The child should have sufficient medication for the entire trip and maybe extra in case of travel problems.
- Field trip location (e.g. trip to rural setting, Outdoor Education camp, or trip to urban centre (Ottawa):  
The trip provider and/or the campsite manager needs to be contacted with information about the student with seizure disorder to check if the provider/site manager can guarantee they can accommodate the student's requirements for safe participation in the program. If the safe participation for the student with a seizure disorder cannot safely be accommodation, teachers must choose an alternate trip location that is accessible for the student.
- Teacher in charge of trip to inform other teachers, volunteers, bus driver of identity of child with a seizure disorder and review emergency plans.
- Copy of the Epilepsy & Seizure Disorder Management Plan should accompany the student on the trip along with phone numbers of parents, caregivers, emergency services and the nearest medical facility – 911.

**Conduct an Emergency Drill:**

- Simulate a seizure disorder emergency – similar to a fire drill – to ensure that all elements of the emergency treatment plan is in place and that everyone knows their role and what to do.

**Informing Secondary Schools:**

- Have a process in place to identify the Grade 8 students with Seizure Disorders transferring to secondary schools in September. Provide the secondary school with the student's Epilepsy & Seizure Disorder Management Plan.

**Informing Summer School Staff:**

- Have a process in place to identify students with Seizure Disorders taking summer school programs with the Board. Provide the summer school administrator with the student's Epilepsy & Seizure Disorder Management Plan.

**TEACHERS' RESPONSIBILITIES CHECKLIST**

- Know the identity of students in the class with a seizure disorder
- Be knowledgeable about the student's plan
- Have a process in place for informing the Occasional Teacher about the student's management plan.

- ❑ Where applicable, attend meeting arranged by the school administrator to gather information related to the student's seizure disorder. Participants may include Principal/designate, parent/guardian and medical personnel
- ❑ Be familiar with the following seizure disorder information posted in appendix A.
- ❑ Using the student's Epilepsy & Seizure Disorder Management Plan
  - Know the triggers to the student's seizure activity
  - Know the signs and symptoms of the student's seizure
  - Know if and when to provide medication
  - Know if and when to call parents/emergency contacts after a seizure.
- ❑ Communicating information about the student's seizure disorder to others;
  - Provide information to support staff and volunteers working with a student with a seizure disorder
  - With the student's parent permission encourage the sharing of information about seizure disorders with the class in age-appropriate terms. Students must be aware that seizure disorders are not contagious, the child cannot control the seizure and seizing is not dangerous to others.
- ❑ Develop open lines of communication with the student and encourage the student to inform you when he/she feels the first symptoms of a seizure or a general feeling of unwellness
- ❑ Develop open lines of communication with the parents/guardians, e.g. phone calls, a communication book, behaviour changes that may be due to medications, etc.
- ❑ If a student is prone to Tonic Clonic seizures, have their desk placed so that if they fall, there is room for the seizure to run its course.
- ❑ Where appropriate, have a buddy system in place so that the student is not alone in the washrooms or hallways.
- ❑ See pages 8 and 12 for field trip information.

### **Coaches, Co-Curricular Supervisors, Volunteers' Responsibility Checklist**

- ❑ Provide appropriate first aid to students exhibiting signs and symptoms of a seizure – refer to page 14.
- ❑ When you are coaching and/or supervising an activity or club, have access and be knowledgeable about the student's Epilepsy & Seizure Disorder Management Plan
- ❑ Using the student's plan
  - Know the triggers to the student's seizure activity

- Know the signs and symptoms of the student's seizure
- Know if and when to provide medication
- Know if and when to call parents/emergency contacts after a seizure.
- Communicating information about the student's seizure disorder to others;
  - Provide information to support staff and volunteers working with a student with a seizure disorder
- Develop open lines of communication with the student and encourage the student to inform you when he/she feels the first symptoms of a seizure or a general feeling of unwellness
- Develop open lines of communication with the parents/guardians, e.g. phone calls, behaviour changes that may be due to medications, etc.

## **Tips for Teachers - Implications on Learning**

### **Possible Triggers**

- Improper medication balance
- Stress- both excitement and emotional upset
- Lack of sleep
- Illness
- Poor diet
- Menstrual cycle
- Change in weather
- Televisions, videos, flashing lights (including flickering overhead lights)
- Inactivity

### **Side Effects of Medications Taken for Seizure Disorders**

- Concentration concerns
- Short term memory loss
- Fatigue/drowsiness
- Hyperactivity
- Motor capacity can be affected: eye-hand coordination, balance, speech coordination
- General well-being can be affected: dizziness, unsteadiness, vomiting
- Mood changes: depression, aggressiveness, anti-social behaviours
- Toxicity: liver damage, anemia

### **Possible Outcomes/Concerns**

- Safety risks
- Possible behaviour issues
- Social issues
- Chronic absenteeism

- Feelings of lack of control
- Poor self-image
- Academic performance can be affected

### **How Can Learning Be Affected**

- Intermittent disruptions caused by seizures may impact learning and the student's ability to attend. This can change from day to day or within the day.
- Medications may slow down the processing of information or may induce fatigue
- Seizures themselves during the day may cause disruptions in the student's memory of what was just learned.
- "Invisible" or absence seizures may result in slower processing, consolidation and retrieval of information
- Night time seizures may leave a student feeling fatigued and less attentive in class the next day
- Possible academic problems with reading, writing, and math as well as difficulty with comprehension and speech may result
- Impaired working memory
- Disorientation
- Disorganization
- Possible difficulty with time management

### **Some Suggested Teaching Strategies and Accommodations**

- Repeat instructions several times or use a "step by step" strategy to help the student who has "blanked out" during a seizure
- Have student repeat the instructions back to the teacher as necessary
- Establish a buddy system so the child can ask the buddy questions and receive missed class work
- Use visual instructions/tools so that the student can refer to them as required i.e. wall calendars, activity lists
- Use visual and verbal prompts to keep the student oriented
- Label items around the class
- Minimize written output as required
- Allow extra time for tests and assignment when required
- Cue the student ahead of an expected response
- Allow extra response time
- Encourage the student to work in a small group
- Make use of a weekly list of deadlines and activities (agenda)
- Use tape recorded textbooks or scanned documents as required
- Use consistent expectations and routines

## **Other Considerations**

- Ensure during physical activities, where climbing is involved, that the student is properly assisted and does not climb to great heights
- Ensure fluorescent light fixtures in classroom/school are working correctly (not flickering)
- Minimize the use of videos in class, if possible
- Avoid loud noises (gym) as much as possible
- Avoid using the “lights out” technique for class control
- Ensure that plans left for a supply teacher includes a picture of the student with a seizure disorder, as well as the Seizure Protocol that is in place
- If calling into Harri for an absence, ensure that you leave instructions as to where to find the information regarding the student with the seizure disorder.

## **Field Trips and Special Events**

Students with a seizure disorder should be encouraged to participate in school activities and extra curricular activities. See page 8 for guidelines about field trips.

For school events such as a dance, ensure that the family is aware that the music will be louder than normal and refrain from using any type of strobe lights. If the student is attending a sports event where they may need to climb a set of bleachers for seating, arrangements should be made to ensure that an area is left open near the lower seats for this student and some friends.

## **Additional Supports**

In some cases, where seizures are not under control, and are considered “drop seizures” or in the case of epilepsy- tonic-clonic seizures, which may happen at any time, the student’s occupational or physical therapist may prescribe specific equipment, e.g. soft helmet, face piece, a gait trainer harness, etc. to ensure the student’s safety.

Remember, it is essential to involve parents in all of these decisions.

You may want to consider having a community health expert speak to the class and staff about seizures. This should be done with both parental and student permission. In some cases, the entire class is encouraged to take on a specific role in the event of a seizure, which empowers the other students and helps them to understand what is happening during a seizure. This is a school-based decision.

## Epilepsy and Seizure Disorder Management Plan



<b>Student:</b>	<b>Date of Birth:</b>
<b>School:</b>	
<b>Teacher:</b>	<b>Date Revised:</b>
<b>Parent contact:</b>	<b>Emergency contact:</b>

**Goal:** guidelines for seizure activity while in school or on school-sponsored activities

**Health/Diagnostic Information:** include information about type of medication, dosage and frequency; note the possibility of incontinence and/or enuresis during loss of consciousness. Ensure a blanket and pillow are available.

<b>Triggers Preceding a Seizure</b> (if known):	<b>Frequency of Seizure Activity</b> (if known):

<b>Description of Seizure (Convulsive)</b>	<b>Action</b>
[insert]	[insert]
<b>Description of Seizure (Non-Convulsive)</b>	<b>Action</b>
[insert]	<p>For direction to administer medication contact the parent <b>[name of parent]</b> at <b>[insert phone number]</b>, if not available contact the care giver <b>[name]</b> at <b>[insert phone number]</b>,</p> <p>Specific direction to administer <b>[insert the name of medication]</b> will be provided by parent/care giver; rectal suppositories will not be administered by board staff</p> <p>* <b>see attached First Aid Treatment</b></p> <p>* <b>complete the Seizure Incident Record</b></p> <p>If contact is not made or direction is not given and/or seizure lasts longer than 5 minutes, call 911</p>

## **FIRST AID FOR SEIZURES:**

### **WHEN TO CALL 911 – EMERGENCY MEDICAL SERVICES:**

**☐ STUDENTS NOT DIAGNOSED with EPILEPSY AND SEIZURE DISORDER :**

- **CALL 911 IMMEDIATELY.**

**☐ GENERALIZED CONVULSIVE SEIZURE ( e.g. Tonic Clonic Seizure):**

- **CALL 911 IMMEDIATELY.**

(The only time ambulance is NOT called immediately is when you are aware of a different protocol for this student as outlined in the student's Epilepsy and Seizure Disorder Management Plan. )

- **IF IN DOUBT – CALL 911**

### **STEPS IN MANAGING AN INDIVIDUAL EXPERIENCING A SEIZURE:**

#### **PARTIAL NON- CONVULSIVE SEIZURES – RESPONSE:**

**1. KEEP CALM. STAY WITH THE PERSON.**

- Do not try to stop the seizure, let the seizure take its course.
- Talk gently and reassure the person that everything is ok and you are there to help.
- The person will be unaware of his/her actions and may or may not hear you.
- Using a light touch, guide the student away from hazards.

#### **GENERALIZED CONVULSIVE SEIZURES – RESPONSE:**

**1 KEEP CALM. STAY WITH THE PERSON**

- Take note of the time when seizure begins. Record time on Seizure Incident Record Form.

**2. DO NOT RESTRAIN OR INTERFERE WITH THE PERSON'S MOVEMENTS**

- Do not try to stop the seizure, let the seizure take its course.

**3. PROTECT FROM FURTHER INJURY WHERE POSSIBLE**

- Move hard or sharp objects away.
- Place something soft under the head e.g. pillow, article of clothing.
- Loosen tight clothing especially at the neck.

**4. DO NOT PLACE OR FORCE ANYTHING IN THE PERSON'S MOUTH**

- Doing so may cause harm to the teeth, gums or even break someone's jaw.
- It is physically impossible to swallow the tongue.
- The person may bite their tongue and/or inside of their mouth.

**5. ROLL THE PERSON TO THEIR SIDE AS SOON AS POSSIBLE:**

- Sometimes during and after a seizure a person may vomit or drool a lot. To prevent choking, simply roll the person on their side. That way, fluids will drain out instead of blocking off the throat and airway.
- DO NOT BE FRIGHTENED if a person having a seizure appears to stop breathing momentarily.

***AFTER ALL TYPES OF SEIZURES*** (The student will be groggy and disoriented).

- Talk gently to comfort and reassure the person that everything is ok.
- Stay with them until they become re-oriented.
- Provide a place where the student can rest before returning to regular activity





## Resources

Epilepsy Canada	<a href="http://www.epilepsy.ca">http://www.epilepsy.ca</a>
Canadian Epilepsy Alliance	<a href="http://www.epilepsymatters.com">http://www.epilepsymatters.com</a>
Epilepsy Ontario	<a href="http://www.epilepsyontario.org">http://www.epilepsyontario.org</a>
Local agencies to assist families	<a href="http://www.advanceinepilepsy.com">http://www.advanceinepilepsy.com</a>
Epilepsy Classroom	<a href="http://www.epilepsyclassroom.com">http://www.epilepsyclassroom.com</a>
Epilepsy Support Centre	<a href="http://www.epilepsysupportcentre.com/">http://www.epilepsysupportcentre.com/</a> Click on About Epilepsy tab, scroll to the bottom of the screen and click on School programs for grades 5 and 12 – handouts, curriculum and much more –both public and catholic curriculum posted.

Be Aware of Ketogenic Diet  
<http://www.epilepsyfoundation.org/answerplace/Medical/treatment/diet>

## Videos

Glen's Journey <http://www.destinymaker.org>

Dr. Henry Hasson, MD, Paediatric Neurology explains seizures  
<http://www.youtube.com/watch?v=NxeMr2PSwdQ>

Reuber, M., Schachter, s., Elger, c., Altrup, v. (2009). *Epilepsy Explained: A book for People Who want to Know More*. Toronto, ON: Oxford University Press. ISBNL 978-0-19-537953-2

Epilepsy Foundation <http://shop.epilepsyfoundation.org> has several videos at reasonable prices.

A) *Seizure Disorder and the School I (elementary school) and Seizure Disorder and the School II (secondary school)* – designed to improve understanding of epilepsy for teachers, administrators and other school personnel. The videos show actual seizures in children, describe first aid and management in the classroom and stress the importance of early recognition. Fears and concerns of school personnel are addressed. Details how epilepsy may affect learning and discusses how the teacher can make the school experience a positive one. Reviews the importance of promoting self-esteem, assuring full inclusion of the child in all school activities and responding to the reactions and questions of other students.

B) *Out of the Shadows: Teens with Epilepsy Take Charge* is a fast-paced, documentary-style program that shares the stories of four teens living with epilepsy.

## Types of Seizures

Some children have just one type of seizure but it is not unusual for more than one type of seizure to occur in the same child. There are more than 40 types of seizures but most are classified into two main types of seizures. If the electrical discharge disturbs the whole brain, the seizure is called generalized. If the seizure disturbs only part of the brain, it is called partial.

### IMPORTANT

***Status Epilepticus** is a state of prolonged seizure or repeated seizures without time for recovery and may exist for any seizure type. Tonic-clonic status is a medical emergency. It can lead to severe brain damage and even loss of life. If a tonic-clonic seizure lasts longer than 5 minutes, the individual needs immediate medical care. CALL 911!*

### Generalized Seizures – types:

- a) **Absence Seizures**, formerly petit mal seizures, are brief periods of complete loss of awareness. The child may stare into space – completely unaware of surroundings and unable to respond. These seizures start and end abruptly, without warning. They last only a few seconds. The child may stop suddenly in mid-sentence, stare blankly, then continue talking without realizing that anything has happened. Rapid blinking, mouth or arm movement may occur.

During absence seizures, the child is not day dreaming, forgetting to pay attention or deliberately ignoring your instructions. These seizures happen many times a day, interrupting attention and concentration. Absence seizures often disappear before adolescence

- b) **Tonic-clonic Seizures**, formerly known as grand mal seizures, are general convulsions with two parts. First, in the tonic phase, the child may give a loud cry or groan. The child loses consciousness and falls as the body grows rigid. Second, in the clonic phase, the child's muscles jerk and twitch. Sometimes the whole body is involved; at other times, just the face and arms. Shallow breathing, bluish skin or lips, heavy drooling and loss of bladder or bowel control may occur. These seizures usually last 1 to 3 minutes. Afterwards, consciousness returns slowly and the child may feel groggy and want to sleep. The child will not remember the seizure.
- c) **Infantile Spasms** are rare. They occur in clusters in babies usually before six months of age. The baby may look startled or in pain, suddenly

drawing up the knees and raising both arms as if reaching for support. If sitting, the infant's head may suddenly slump forward, the arms flex forward and the body flexes at the waist. Spasms last only a few seconds but often repeat in a series of 5 to 50 or more many times a day. They often occur when the baby is drowsy, on awakening or going to sleep.

- d) **Atypical Absence Seizures** involve pronounced jerking or automatic movements, a duration of longer than 20 seconds, incomplete loss of awareness.
- e) **Myoclonic Seizures** involves a sudden, shocking jerk of the muscles in the arms, legs, neck and trunk. This usually involves both sides of the body at the same time and the student may fall over.
- f) **Atonic Seizures** last a few seconds. The neck, arms, legs or trunk muscles suddenly lose tone or loss of tone without warning. The head drops, the arms lose their grip, the legs lose strength or the person falls to the ground. Students with atonic seizures may have to wear a helmet to protect their head from injury during a fall. Child's surroundings may need to be altered to ensure safety.

### **Partial Seizures –types:**

- a) **Simple Partial Seizures**, formerly known as focal seizures, cause strange and unusual sensations, distorting the way things look, sound, taste or smell. Consciousness is unaffected – the child stays awake but cannot control sudden, jerky movements or one part of the body.
- b) **Complex Partial Seizures**, formerly known as psychomotor or temporal lobe seizures, alter the child's awareness of what is going on during the seizure. The child is dazed and confused and seems to be in a dream or trance. The child is unable to respond to directions. The child may repeat simple actions over and over e.g. head turning, mumbling, pulling at clothing, smacking lips, make random arm or leg movements or walk randomly. The seizure lasts only a minute or two but the child may feel confused or upset for some time and may feel tired or want to sleep after the seizure.

## **Treatment Protocol**

### **Will the Child have a Warning?**

Some children have a strange sensation before a seizure. This "aura" acts as a warning that a seizure is about to occur. Sometimes it helps the child to prepare

for the seizure by lying down to prevent injury from a fall. The aura varies from one child to another. Children may have a change in body temperature or feeling of anxiety. Some experience a strange taste, striking odour or musical sound. An aura may occur before partial or tonic-clonic seizures. An aura is not always followed by a seizure, in fact, the aura is a simple partial seizure. Ask the child's parent if there are signs of an impending seizure.

## Medications

Complexity:

Many seizures may be partly or fully controlled by medication (up to 80%) and there are many drugs available which may control different types of seizures. The challenge is to match the type and dose of medication(s) to the individual and what (s)he is experiencing.

The goal is for **one** medication to control the seizures of an individual with negligible side effects. Unfortunately this is often not the case. Finding a suitable regimen of medications often involves not just one medication, but a combination of 2 or more different meds, each with its own attributes and side effects. In reality, many medications have side effects ranging from nuisance to dangerous. The process of identifying and balancing the appropriate mix and balance of medications may be one of considerable complexity, and could be ongoing over a lengthy period. During the process, there may be uncertainty surrounding seizure control (possibly including different types of seizures) and the accompanying side effects.

Patience and ongoing consultation are critical.

Seizure disorders are usually treated with drugs called anti-epileptics or anticonvulsants. These drugs are designed to control seizures. Some drugs control just one or two types of seizure while others have a broad range. In some children, these drugs work so well that no seizures occur. For those on these drugs, seizures are eliminated in about 50% of cases. Drugs reduce the frequency or intensity of seizures in another 30%. The remaining 20% of people have seizures that cannot be brought under control by conventional drug therapy.

Some children may experience the following side effects of drug treatments.

- Learning capacity: concentration, short term memory loss
- Alertness: hyperactivity, drowsiness, fatigue
- Motor capacity: hand, eye, balance, speech coordination
- General well-being: unsteadiness, vomiting, dizziness
- Mood changes: depression, aggressiveness, anti-social behaviours
- Toxicity: liver damage, anaemia

## **Diet as a Treatment**

The Ketogenic Diet is used to treat a small number of children with intractable epilepsy who do not respond to standard therapies. It is an extreme, multi-year, high-fat diet that is challenging to administer and maintain. There is no way to predict whether it will be successful, but a significant percentage of children who are placed on the Ketogenic Diet achieve significant reduction in intensity and frequency of seizures. This type of diet is physician-monitored.

## **Brain Surgery**

Brain surgery for epilepsy is performed, but only in a small percentage of cases, and only when all other treatment fail to adequately control seizures. The last decade has seen significant advances in the surgical treatment of epilepsy. The area of the brain with abnormally discharging neurons (the seizure focus) is surgically removed, if it is possible to identify this area and remove it safely. In certain patients without a well-defined epilepsy focus, surgically disconnecting or isolating the abnormal area so that seizures no longer spread to the neighbouring normal brain can help. As with any operation, there are risks to epilepsy surgery. In patients with an identified seizure focus, the success rate of surgery is up to 80%. For some children who experience seizures, their seizure activity may occur/increase with times of stress e.g. illness, fever, fatigue, dehydration, heat, bright and/or flashing lights.

## **Vagus Nerve Stimulation Therapy**

The vagus nerve stimulator has been approved to treat hard to control seizures. The device is a small, pacemaker-like generator which is surgically implanted near the collarbone to deliver small burst of electrical energy to the brain via the vagus nerve in the neck. So far, research has shown that vagus nerve stimulation may reduce seizures by at least 50% in about half the study participants.

## Common Misconceptions

*MYTH: Epilepsy is contagious.*

About as contagious as a gun-shot wound! You simply can't catch epilepsy from another person.

*MYTH: Only kids get epilepsy.*

Epilepsy happens to people over age 75 more often than it does to children aged 10 and under. Seizures in the elderly are often the after effect of other health problems like stroke and heart disease.

*MYTH: People with epilepsy are disabled and can't work.*

People living with the condition have the same range of abilities and intelligence as the rest of the population. Some have severe seizures and cannot work; others are successful and productive in challenging careers.

*MYTH: People with epilepsy shouldn't be in jobs of responsibility and stress.*

People with seizure disorders are found in all walks of life and at all levels in business, government, the arts and other professions. We aren't always aware of them because many people, even today, do not talk about having epilepsy for fear of what others might think.

*MYTH: With today's medication, epilepsy is largely a solved problem.*

Epilepsy is a chronic medical problem that for many people can be successfully treated. Unfortunately, pharmaceutical treatment doesn't work for everyone and there's a critical need for more research.

*MYTH: Epilepsy is rare and there aren't many people who have it.*

There are more than twice as many people with epilepsy in Canada as the number of people with cerebral palsy, muscular dystrophy, multiple sclerosis and cystic fibrosis combined. Epilepsy can occur as a single condition, or may accompany other conditions affecting the brain, such as cerebral palsy, mental retardation, autism, Alzheimer's disease, and traumatic brain injury.

*MYTH: You can't die from epilepsy.*

Epilepsy is a very serious medical condition and individuals do die of it. Epilepsy as a direct cause of death can be divided in different categories.

- Seizure-related deaths, such as from accidental drowning, auto accidents, etc.
- Death due to prolonged seizures ([status epilepticus](#))
- [Sudden Unexplained Death in Epilepsy](#) (SUDEP)

*MYTH: You can't tell what a person might do during a seizure.*

Seizures usually take a characteristic form: the individual will do much the same thing during each episode. Although the behaviour may be "inappropriate" for the time and place, it is unlikely to cause harm to anyone and should not be seen as an embarrassment to anyone.

*MYTH: People with epilepsy are physically limited in what they can do.*

In most cases, epilepsy isn't a barrier to physical achievement, although some individuals are more severely affected and may be limited in what they can do. Professional sports players with epilepsy include Greg Walker (baseball, Chicago White Sox), Bobby Jones (basketball, Denver Nuggets and Philadelphia '76ers), and Gary Howatt (hockey, New York Islanders).