Medical Conditions Package

Epilepsy & Seizure Disorder Protocol

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The Epilepsy/Seizure Disorder Protocol has been amended to comply with Policy/Program Memorandum No. 161 Supporting Children and Students with Prevalent Medical Conditions (Anaphylaxis, Asthma, Diabetes and/or Epilepsy) in schools. The following Epilepsy/Seizure Disorder Protocol addresses the components outlined in PPM 161, www.edu.gov.on.ca/extra/eng/ppm/ppm161.pdf
Rationale for an Epilepsy and Seizure Disorder Management Protocol
The goal of this protocol is to educate school personnel about epilepsy and seizure disorders, 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 be safe and successfully participate in their education.

What is Epilepsy/Seizure Disorder?
Epilepsy:
A disorder of the central nervous system, specifically the brain, characterized by spontaneous, repeated seizures. Epilepsy, also known as a seizure disorder, is not often talked about in public. Misconceptions and fears persist that are sometimes more burdensome to persons living with epilepsy 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 epilepsy at any time without a known cause. Most often diagnosed in children and in seniors, epilepsy affects each person differently. Many people with epilepsy successfully control their seizures with medication and are able to enjoy healthy and fulfilling lives.

Seizure:
A seizure occurs when the normal electrical balance in the brain is lost. The brain’s nerve cells misfire: they fire either when they shouldn’t, or don’t fire with they should. The result is a sudden, brief, uncontrolled burst of abnormal electrical activity in the brain. Seizures are the physical effects of such unusual bursts 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

Conditions that may cause seizures:
a) Epilepsy
b) Medical conditions where seizures may be among the symptoms, such as:
   - Cerebral Palsy (25%-35% of the population has seizure occurrence)
   - Intellectual disability (as much as 1/3 of the population can have seizure occurrence)
   - Angelman’s Syndrome

c) Physical trauma/injuries to the head and/or brain

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

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

Status Epilepticus is a state of prolonged seizure (longer than 30 minutes) or repeated seizures without time for recovery and can happen with any type of seizure. Status epilepticus is a medical emergency.

Generalized Seizures
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

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.

Myths: Common Misconceptions – Epilepsy Ontario

• You can swallow your tongue during a seizure. It is physically impossible to swallow your tongue.
• 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.
• You should restrain someone having a seizure. Never use restraint! The seizure will run its course and you cannot stop it.

Causes of Seizures:
• For 60% - 75% of all cases there is no known or idiopathic causes.
• 40% are caused by abnormality in the brain that interfere with electrical workings. For example:
  • Brain injury (caused by tumor, stroke or trauma)
  • Birth trauma (e.g. lack of oxygen during labour)
  • Poisoning from substance abuse or environmental contaminants (e.g. lead)
  • Aftermath of infection (e.g. meningitis, encephalitis, measles)
  • Alteration in blood sugar (e.g. hypoglycaemia)
• 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.

Potential Triggers of Epilepsy/Seizure Disorder
• 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
• Improper medication balance

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

Education Act
Education Act 265 (1): Duties of Principals
  j) care of pupils and property – to give assiduous attention to the health and comfort the pupils

Education Act, Regulations: Reg. 298, S20:Duties Of Teachers
  g) ensure that all reasonable safety procedures are carried out in courses and activities for which the teacher is responsible

Common Law Duties Owed by Teachers:
To assist or allow a student to seek medical attention as a ‘careful parent’ would. The board’s liability policy provides coverage for employees acting within the scope of their duties with the board. Thus, all school staff who administer first aid to a student who is suffering from a seizure within the school or during a school activity, are covered.

Communication of Information on Epilepsy/Seizure Disorder
The Board Public Webpage (www.hcdsb.org) offers resources that include information about epilepsy/seizure disorder that can be shared with all parents/guardians, students, employees, volunteers, coaches and other persons who have direct contact with a student with epilepsy/seizure disorder. School administrators are asked to consider including these links in School Newsletters, on the school website or in other pertinent areas, (www.hcdsb.org → Parents tab → Safe, Healthy and Inclusive Schools →
Medical Conditions ➔ Epilepsy/Seizure Disorder) or in a letter home to all parents/guardians at the beginning of the school year.

This information is intended to assist people in understanding epilepsy/seizure disorders

The school principal/designate shall work with staff and families to help ensure that an epilepsy/seizure disorder friendly school environment exists that is safe and supportive for all students.

**Identification**

Have a process in place where children with an epilepsy/seizure disorder condition are identified to the school system by parents/guardians and requested to supply information on the epilepsy/seizure disorder condition.

- **Students, new to the school, during registration**
  
  (e.g. Question on registration form: *specifically asking whether or not their child has epilepsy/seizure disorder*)

  Epilepsy/Seizure Disorder Student Plan of Care provided to parents/guardians for further information regarding epilepsy/seizure disorder triggers, etc.

- **Students presently registered at school (e.g. Verification form)**
  
  At the beginning of each school year, the school principal/designate shall have a process in place of requesting parent/guardian/adult student to identify if there is a new diagnosis of epilepsy/seizure disorder (throughout the school year)

- Ensure student’s medical condition(s) are entered into the Board’s student database system.

**Development of the Epilepsy/Seizure Disorder Student Plan of Care**

The parent/guardian in consultation with the principal shall create, review and update the student plan of care during the last week of August, or on the date as requested by the school administrator.

The plan shall be reviewed by the principal/designate in consultation with the parent/guardian/adult student, following the HCDSB Epilepsy/Seizure Disorder Protocol, on an annual basis or when there is a change in the child’s condition or changes to the prescribed medication. Where appropriate, the classroom teacher is to be part of the information sharing process.

The child’s epilepsy/seizure disorder triggers are to be identified and avoidance strategies are to be developed and implemented.

**Instructions for Managing a Seizure**

**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**

**UNLESS:** you are aware of a different protocol for this student as outlined in the student’s Epilepsy and Seizure Disorder Student Plan of Care

- **IF IN DOUBT – CALL 911**

**Steps in Managing an Individual Experiencing a Seizure:**

*Generalized Convulsive Seizures – Response:*
1. **Keep calm. Stay with the person**
   - Take note of the time when seizure begins and length of seizure (e.g. stopwatch). Record time on Seizure Incident Record Form. (Available on StaffNet)

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 after the seizure subsides:**
   - 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

**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

**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

**Note:** School administrators should consider simulating an anaphylactic emergency, with all staff, similar to a fire drill, to review and check to see that all elements of the school’s emergency protocol are in place and everyone knows their role.

**Field Trips and Students with Epilepsy/Seizure Disorder Procedures (Day Trips, Overnight Trips, Extensive Trips and Exchange Programs)**

- **Process in place to identify students diagnosed with epilepsy/seizure disorder.**

- **Trip site and activities are to be checked for potential hazards.** Where possible a pre-activity inspection of the site and activities by the in charge teacher supervisor to investigate safety conditions is to be done.

- **Communicate with the child’s parents/guardians** during the initial planning stages of the trip informing them of the destination, mode of travel and activities students are to participate in. This will allow for parent/guardian input in the school developing a clear set of expectations and accommodations to meet their child’s medical needs on the trip. Knowing the trip expectations and
accommodations the parents will be able to provide an informed decision as to their child’s participation. You may consider inviting the parents on the trip as a supervisor.

- **MEDICATION:** For overnight, extensive or exchange programs parents are to be consulted on:
  - amount, when taken, how it is administered, dosage
  - how medication is to be transported
  - how medication is to be stored

- **Tour operator and/or activity provider:**
  - In charge teacher to provide tour operator/activity provider with list of students that need to be accommodated on the trip for epilepsy/seizure disorder.
  - Request operator to provide you with their plans and procedures as to how they are going to accommodate for students with epilepsy/seizure disorder.
  - Compare tour operator’s plans for accommodations with school board expectations for accommodations for one of its students.
  - Adjust operator’s accommodation plans accordingly to the needs of the student. Follow the plans wherever there is a higher standard.
  - If trip provider does not have a pre-existing plan for the student’s medical condition develop one of your own based on school board expectations and parent input and provide the operator with a copy.
  - Based on listed accommodations for the student can the tour operator provide:
    - accommodations during travel to destination
    - safe facilities, safe programming
    - ready access to a doctor, clinic or hospital where you are going

- **An emergency action plan for epilepsy/seizure disorder on the trip must be prepared** by the in charge teacher supervisor and communicated to all staff and volunteers on the trip.

- **Student forms on the trip** – copy of the student's Epilepsy Seizure Disorder Plan of Care along with trip accommodations, where appropriate, are to be taken on the trip.

- **Grouping of student(s):** student is to be assigned to a group with staff member who is knowledgeable about managing seizures.

- **Buddy system:** In situations where the teacher/supervisor is providing ‘in the area supervision’ teacher is to assign a ‘buddy’ to the student. The ‘buddy’s’ responsibility is to assist the student and to access the teacher supervisors in case of an emergency.

- **A suitable means of communication** (e.g. cell phone) to be taken on the trip and/or an easily accessible phone is available at the site. Ensure you have the correct and proper change if using pay phones.

- **Trip supervisor is to meet students** with epilepsy and provide them with the following information (age appropriate):
  - Never go off alone when feeling unwell, or about to have a seizure. Always inform an adult (‘buddy’) on the trip.
  - Communicate clearly to adults/those in authority on the trip that s/he has a seizure disorder, when feeling a reaction or generally feeling unwell.
Treatment Protocols

Warning Sign: ‘AURA’
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 tonicclonic 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
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 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. 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.