Seizure Disorders

Caring for Children with Seizure Disorders in a Community Program

Unified Referral and Intake System (URIS)
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INTRODUCTION

Unified Referral and Intake System

The Unified Referral and Intake System (URIS) is a collaboration among various government departments, health services organizations, school divisions, and child caring organizations. URIS supports community programs in the care of children with specific health care needs. Community programs that are eligible for URIS support include schools, licensed child care facilities and respite services.

URIS provides a standard means of classifying the complexity of health care needs and establishes the level of qualification required by personnel to support children with these health care needs. Health care needs that are classified as 'Group B' can be delegated to non-health care personnel who receive training and monitoring by a registered nurse. For children with 'Group B' health need s (e.g., seizure disorder), the nurse provides the following support:

- develops and maintains a written health care plan;
- provides training to community program personnel that are responsible for the child; and
- monitors community program personnel that receive training.

URIS Group B Support for Children with Seizure Disorders

A child is eligible for URIS Group B support if he/she is diagnosed with a seizure disorder by a physician. URIS Group B support may be discontinued when the child's anti-seizure medication has been discontinued and the child has not experienced seizure activity for a minimum of two years.

This document provides standard clinical information that is relevant to the care of children with seizure disorders in community program settings. Supplemental documents are also provided to assist the nurse in the development of health care plans and training and monitoring of community program personnel.

CLINICAL INFORMATION

The following information is considered 'best practice' in community program settings and is the basis for all seizure disorder information contained in this document and its supplements.

Seizures

The brain controls and regulates the body including movements, sensations, thoughts and emotions. It contains billions of nerve cells that communicate with each other through electrical signals. In a seizure, the brain sends out an abnormal burst of electrical signals. These signals can change a person's movement, behavior or state of awareness. A seizure is often very brief, lasting from a few seconds to a few minutes. Under certain conditions, anyone can have a seizure.

When a person has had more than one seizure, they may have a seizure disorder or epilepsy. Epilepsy is not contagious. Approximately 1% of Canadians have epilepsy (Epilepsy Canada). Epilepsy is the most common chronic brain disorder.

Causes

Common causes of seizures

- Problems with brain development before birth
- Lack of oxygen or damage to the brain during birth or after birth
- Brain injury (e.g., car accident)
- Brain infections (e.g., meningitis, encephalitis)
- Metabolic conditions (e.g., mitochondrial disease)
- Interruption in blood flow to the brain (e.g., stroke)
- Brain tumor

Less frequent causes are progressive degenerative disease (e.g., Huntington's disease) and poisons that can produce seizures (e.g., alcohol).

Triggers

Not all seizures are preventable, but recognizing triggers may help to minimize the number of seizures that a person experiences. There is not always an obvious trigger. Triggers will also vary from person to person.

Factors that may trigger seizures in children:

- Missing a regular dosage of anti-seizure medication
- Stress, excitement
- Lack of sleep
- Poor lifestyle habits (e.g., prolonged fasting)
- Illness, fever
- Flickering lights, such as white lights in a dark room, strobe lights, disco lights and video or computer games. Flickering lights are usually a trigger for children who are photosensitive.
- Hyperventilation can be a trigger for absence seizures

- Extreme emotions
- Heat, humidity
- Hormonal changes during puberty or at the time of menstrual periods

Types of Seizures

There are different types of seizures. The two main types of seizures are generalized and partial. Generalized seizures occur in the whole brain. Partial seizures occur in one part of the brain. Seizures that start in one part of the brain and spread to the whole brain are partial seizures that become secondarily generalized.

An individual may have one type of seizure or a mixture of different types. Seizures can also differ in the same person in terms of length, frequency and severity.

Tonic-clonic seizures (generalized seizure) are the type of seizure with which people are most familiar. The length, intensity and duration of tonic-clonic seizures can vary, but most seizures do not last more than one to three minutes.

- The child suddenly loses consciousness. If sitting or standing, the child will fall to the ground.
- The whole body stiffens (tonic phase). Then the body begins to jerk repeatedly (clonic phase).
- The child may cry out, clench teeth, bite tongue, drool or have increased salivation.
- The child may have changes in breathing.
- The child's skin may turn pale or blue-grey.
- The child may lose bladder or bowel control.
- The child will be confused after the seizure.

During the seizure

1. Note the time when you become aware of the seizure.
2. Put the child on the floor in a side-lying position immediately. This position helps to keep the airway open and clear, which is the primary concern during a tonic-clonic seizure.
3. Move any harmful objects out of the child's way to prevent injury. Loosen tight clothing around the neck.
4. Stay with the child and ensure he/she remains in the side-lying position until awake and alert.

After the seizure

1. Reassure and comfort the child. The child may be tired and need to sleep for several hours.
2. Inform the parent/guardian that the seizure occurred.

DO NOT

- Leave the child unattended after a seizure.
- Restrain the child.
- Put anything in the child's mouth as it could cause teeth and jaw damage. The child will not swallow his/her tongue.
- Offer the child anything to eat or drink until he/she is fully awake.
- Place anything large under the child's head as it may affect the airway. The head and neck may be cushioned with something soft and small (e.g., jacket).

When a child in a wheelchair is experiencing a seizure and is unresponsive, he/she should be removed from the wheelchair and placed on the floor in a side-lying position to keep the airway open. If it is not physically safe to remove the child from the wheelchair, the following actions are recommended:

- Recline the chair and turn the child's head to one side to prevent saliva or vomit from entering the airway.
- Ensure the wheelchair is secure.
- Protect the child from falling.

Absence seizures (generalized seizure) are often very brief. They begin and end abruptly. This type of seizure can occur many times a day. They may go unnoticed or be mistaken for daydreaming or inattentiveness. Absence seizures may cause attentional and academic problems for a child.

- Loss of awareness occurs but the child usually will not fall.
- The child stares blankly for a few seconds.
- The child may have eye blinking, fluttering or upward rolling eyes. The head may bob.
- The child may drop held objects.
- The child may not be aware that the seizure occurred.

During the seizure

1. Stay with the child.
2. Move the child only if in an unsafe place (e.g., staircase, playground equipment, busy roadway). Absence seizures can place a child at risk for accidental injury.

After the seizure

1. Reorient the child to surroundings (e.g., repeat instructions).

Myoclonic seizures (generalized seizure) involves a sudden increase in muscle tone. They usually occur with children who have a developmental delay but can also occur in children who have other seizure types. They are very brief and usually occur without warning. They occur most frequently when falling asleep or upon awakening. They may occur in succession.

- The child has sudden muscle jerks that may be mild and affect only part of the body, such as arms, face or neck. Sometimes the whole body is involved and may be intense enough that the child falls to the floor or sustains injury.
- There is no apparent loss of consciousness.

- The child recovers within seconds.

During the seizure

1. Stay with the child.
2. Move the child only if in an unsafe place (e.g., staircase, playground equipment, busy roadway).

After the seizure

1. Check for injuries. Wearing a helmet may be recommended for the child who is currently experiencing myoclonic seizures. The parent /guardian, in consultation with the physician, will determine the need for a helmet.
2. Reassure and comfort the child.

Atonic seizures (generalized seizure) involves a sudden loss of muscle tone. They are a form of drop seizures. They usually occur with children who have a developmental delay and can occur in children who have other seizure types. They can cause a child to fall and drop. They are very brief and usually occur without warning.

- If the seizure is mild, you may only see the child's head drop. If standing, the child may fall to the ground. If severe, dramatic loss of muscle tone occurs with significant risk of injury.
- Loss of awareness occurs.
- The child is not usually tired after the seizure.

During the seizure

1. Stay with the child.
2. Move the child only if in an unsafe place (e.g., staircase, playground equipment, busy roadway).

After the seizure

1. Check for injuries. Wearing a helmet may be recommended for the child who is currently experiencing myoclonic seizures. The parent /guardian, in consultation with the physician, will determine the need for a helmet.
2. Reassure and comfort the child.

Simple partial seizures affect body movement, sensations or emotions. Awareness is not altered.

- The child may have jerking movements that occur in one part or one side of the body.
- The child may see or hear things that are not there.
- The child may appear sad, afraid, angry or laugh out loud.
- The child may experience a loss of sensation, tingling, pain or nausea.
- The child is awake and aware.

Complex partial seizures affect motor action and awareness is altered.

An aura may occur which is a sensation that occurs at the beginning of a seizure, such as seeing spots, hearing ringing or smelling an odor. It is the onset of a seizure that is localized in one area of the brain. The type of aura experienced varies from person to person. It is determined by the location of the discharges.

- The child may stare or appear dazed. The child may be unaware of his/her actions and surroundings.
- The child may make repeated motions (automatisms) such as chewing movements, picking at clothes or lip smacking.
- The child may appear dizzy, confused, anxious, scared or angry.
- The child may experience abdominal pain or an unusual taste or odor.
- The child may respond inappropriately.
- The child may be confused and tired after the seizure.

During the seizure

1. Note the time when you become aware of the seizure.
2. Stay with the child and guide him/her away from hazards. Do not move the child unless an immediate danger threatens the child's safety. The child may struggle and lash out as he/she does not recognize you.
3. If the seizure progresses to a secondarily generalized seizure (partial seizures that spread throughout the brain to become a generalized), implement the response for tonic-clonic seizures.

After the seizure

1. Reassure and comfort the child.
2. Reorient the child to surroundings (e.g., repeat instructions).

Emergency Response Plan

Seizures usually end after a few seconds or few minutes, but on rare occasions a seizure does not stop on its' own. This can occur with any type of seizure and may result in severe brain damage or death. Status epilepticus is a state of prolonged or recurrent seizures in-between which consciousness does not return. It is considered a medical emergency as often these seizures will not stop on their own. When a seizure lasts longer than five minutes, the child may be at risk of status epilepticus.

The emergency response plan described below should be implemented in the following situations:

- Seizure lasts more than five minutes.
  The length of time may be less than five minutes depending on the child's specific need or other factors such as the response time of EMS. However, the amount of time should never exceed five minutes.
- Repetitive seizures which occur every few minutes without sign of recovery in between.
- Evidence of serious injury as a result of the seizure.
- Other medical concerns (e.g., airway obstruction, choking).

- Child is pregnant or has diabetes.

1. Activate 911/EMS. Delegate this task to a responsible person. Do not leave the child alone.
2. Contact the child's parent/guardian. This can also be delegated to a responsible person.
3. Stay with the child until EMS personnel arrive.

If a child does not have a history of seizures and is experiencing seizure activity for the first time, 911/EMS should be called immediately.

Observation of Seizures

It is important to observe the seizure and record relevant information as it can assist in identifying trends or changes in the child's seizures. It is always important to communicate relevant information to the child's parent/guardian. A seizure log or diary may be used if seizures are frequent and the parent/guardian can be given a copy for doctors' visits.

Observation of a seizure may include the following:

- Length of the seizure
- Time and date that the seizure occurred
- Activities child was participating in when the seizure occurred (e.g., location, event)
- Exposure to possible triggers (e.g., fatigue, illness, flickering lights, stress, missed dose of anti-seizure medication)
- A chronological description of what is seen during and after the seizure. Do not try to determine the type of seizure the child experienced. Some questions to consider when describing seizure activity are listed below:
  - What happened first?
  - Did the seizure start on one side of the body? Which side?
  - Did the child lose consciousness?
  - Were the eyes involved? Did they roll back?
  - Did the eyes and head move to one side? Did the eyelids twitch?
  - Did the child change color?
  - Did the child have frothing from the mouth?
  - How did you know when the seizure was over?
  - Did the child lose bladder or bowel control?
  - Was the child sleepy, confused or restless after the seizure?
  - When did the child resume activity?
  - Was the child aware that he/she had a seizure?

Treatment

Anti-seizure Medication

Daily anti-seizure medication is the most common treatment for seizures. Different medications control different types of seizures. The goal is to control the seizures with one medication. When more than one medication is used, the potential for side effects increases. The dose of medication is increased gradually until a maintenance level is reached. It is important to follow the physician's instructions as to when and how much medication should be taken. Medication can achieve good control of seizures for most children. However, for 20-25% of children medication does not provide adequate control of their seizures.

Common side effects of anti-seizure medication are drowsiness, fatigue, change in attentiveness and appetite, mood swings, altered balance and decreased coordination. All of these can adversely affect the child's behavior and performance. Other potential side effects include rashes and liver and bone marrow changes.

Daily anti-seizure medication is usually taken at home. It is helpful for the community program to be made aware of changes in medication as this can affect the child's behavior and performance.

Rescue Medication

Rescue medications, such as Lorazepam and Midazolam, are used to try to stop a seizure or to prevent further seizures occurring in a cluster. It is usually given after five minutes of seizure activity. Diastat is a rescue medication that is administered rectally and, therefore, not recommended for use in community program settings.

Rescue medication has sedative properties which can affect breathing and heart rate. Therefore, only one dose can be administered in a 24-hour period at the community program.

Lorazepam is prescribed in the sublingual form. It is placed in the cheek pocket, to be absorbed into the blood stream through the mucosal membrane. It is in tablet form and comes in three strengths: 0.5 mg (green), 1.0 mg (white) and 2.0 mg (blue). It is placed between the cheek and the gum as the jaw will be clenched. It dissolves in about 20 seconds and is absorbed into the bloodstream. If it is swallowed, the effect of the drug will occur too late. It starts to work in 2-3 minutes, is the strongest at 60 minutes and lasts for 6-8 hours. Lorazepam should be stored at room temperature, away from moisture and heat.

1. Administer the medication as prescribed by the physician.
   - Place Lorazepam between the inner cheek and lower gum.
   - Massage cheek gently.
2. Contact the child's parent/guardian. Delegate this task to a responsible person.
3. Activate 911/EMS if seizure does not stop after the specified amount of time. The length of time may be less than five minutes as order by the physician

and/or parent/guardian request. However, the amount of time should never exceed five minutes.

4. Stay with child until EMS personnel arrive. Advise EMS personnel that rescue medication was given, including time and amount.

Midazolam is given intranasally, using a 1 ml syringe. The syringe can be attached to a mucosal atomizer device (MAD) to allow the medication to be sprayed farther up the nasal cavity. When using the syringe alone, point it toward the nasal septum. Sometimes, the dosage is divided into two nostrils, which will be indicated on the child's prescription bottle.

It is recommended that Midazolam is provided to the community program in a pre-drawn syringe or vial. Certain dosages of Midazolam are manufactured in glass ampules only. If Midazolam is removed from the ampule and placed in a syringe or vial, it is stable for 36 days and then must be replaced. It is the responsibility of the parent/guardian to replace expired medication.

1. Fill 1 ml syringe with prescribed dose of Midazolam (if not already pre-drawn).
2. Remove air from syringe.
3. Connect the mucosal atomizer device (MAD®) to the syringe, if available.
4. Tilt head back.
5. If using the MAD®, place the tip in the nostril. If using a syringe only, place the end of the syringe in the nostril, pointing it toward the nasal septum.
6. Administer the medication into the nostril(s) as prescribed by the physician. The medication is administered in one or both nostrils, as prescribed by the physician.
7. Contact the child's parent/guardian. Delegate this task to a responsible person.
8. Activate 911/EMS if seizure does not stop after the specified amount of time, as ordered by the child's physician. The length of time may be less than five minutes as order by the physician and/or parent/guardian request. However, the amount of time should never exceed five minutes.
9. Stay with the child until EMS personnel arrive. Advise EMS personnel that rescue medication was given, including time and amount.

If you did NOT witness the start of the seizure, administer rescue medication immediately as you do not know how much time has already gone by. You will not harm the child by giving the rescue medication too early.

Other Treatments

Other treatments for seizure disorders include epilepsy surgery, ketogenic diet, vagus nerve stimulation and specific vitamin supplements.

Epilepsy Surgery occurs most often for children who have partial seizures. For some children who have successfully undergone epilepsy surgery, medication can eventually be tapered and discontinued. However, the majority of children continue to require anti-seizure medication after epilepsy surgery.

Ketogenic Diet is a strict therapeutic diet used to treat certain types of seizures. It may help to control seizures, but anti-seizure medication is still required for most children. Not all children can tolerate the diet as it is nonpalatable due to its ratio of high fat to decreased carbohydrates and proteins. The ketogenic diet causes the body to burn fats rather than carbohydrates. When there is very little carbohydrate in the diet, the liver converts fat into fatty acids and ketone bodies. The ketone bodies pass into the brain and replace glucose as an energy source. An elevated level of ketone bodies in the blood, a state known as ketosis, can lead to a reduction in the frequency of seizures.

Vagus Nerve Stimulator (VNS) may be used for a child whose seizures are refractory (i.e., cannot be controlled by medications and/or other treatments).

VNS therapy works to control seizures by intermittently stimulating the vagal nerve which then sends signals to the brain. These signals help to reduce the rate and duration of seizures.

The pulse generator is located under the skin of the upper chest. It is connected to the lead in the neck which connects the pulse generator to the vagal nerve. The physician programs the VNS generator to deliver regular, brief intermittent stimulation throughout 24 hours.

A magnet is available to provide additional stimulation, when needed, at the time of a seizure or aura. Use of the magnet is not necessary to receive VNS therapy, but is an added benefit that service two functions. Holding the magnet over the pulse generator will provide an extra dose of stimulation that may stop or shorten the seizure, decrease the intensity of it and ease recovery once the seizure has ended. It can also be used to stop stimulation temporarily for the purpose of eliminating side effects of stimulation during certain activities.

In community program settings, the magnet may be used when the child is having an aura, when a seizure begins and/or during a seizure. However, the parent/guardian may choose NOT to provide the magnet for use during attendance at the community program.

The child's health care plan should specify when to use the magnet. The magnet should not be held over the pulse generator for more than two seconds**.** The magnet can be used more than once during a seizure. Using the magnet more than once will NOT harm the child or the generator. The child will also not be harmed if the magnet is used for an event that is not a seizure. The magnet should be kept with the child so it can be accessed quickly for use as necessary.

The magnet should not be dropped as it can break if dropped on a hard surface. The pulse generator should be kept at least 25 cm away from credit cards, televisions, computers, microwave ovens and other magnet devices.

Non-traditional Therapy
Other therapies, such as vitamin, minerals, herbal therapies, acupuncture, chiropractic, massage therapy, guided imagery, biofeedback, aromatherapy, yoga, therapeutic touch, homeopathy, hyperbaric oxygen, carbon dioxide therapy and cerebellar stimulation may be used to complement, or as an alternative to, medical treatment. The use of alternative therapies at the community program is not recommended as sufficient scientific evidence of their effectiveness is currently not available.

Febrile Seizures are usually generalized and occur in children and infants when they have a fever. In many cases, anti-seizure medication is not prescribed on a long-term basis. Instead, the fever is treated in an attempt to lower the body temperature and prevent seizure activity from occurring. Most children outgrow febrile seizures by six years of age.

1. Call parent/guardian is child is experiencing signs of fever such as:
    - hot dry skin
    - child is flushed or pale
    - sweating, shivering or goose bumps
    - temperature above normal (37.5°C or 98.6°F). The safest and easiest way to take a child's temperature is under the armpit.
2. Give acetaminophen if written consent from parent/guardian has been obtained. Do not give aspirin.
3. Dress the child lightly. Give clear cool fluids to drink. Keep room cool, but not cold.
4. If child has seizure, implement the response for tonic-clonic seizures as described above.

Epilepsy Syndromes

Infantile Spasms occur in infants less than one year old. The spasms may occur as single event or in clusters. Spasms appear as sudden muscle contractions that include flexing of the head or body at the waist. The arms may come up in a startle-like reaction and the knees draw up. The infant may cry out as part of the seizure. These episodes usually last 2-10 seconds and may occur in a series. Infantile spasms often occur when the infant is falling asleep, drowsy, or upon wakening. Infantile spasms most commonly begin between four and eights months of age).

Juvenile Myoclonic Epilepsy (also known as Janz Syndrome) can occur anytime from age eight to 30 but usually develops during, or shortly after, puberty. It involves myoclonic jerks that frequently occur in a series or upon waking. The jerking may increase and result in a tonic clonic seizure. Some children may also have absence seizures.

Benign Rolandic Epilepsy often starts at the age of three and is usually outgrown by adolescence. Seizures often start upon the child beginning to wake up or during sleep. They begin with a tingly sensation on one side of the mouth and may involve the throat which can result in garbled speech and make the child hard to understand. The child may make gurgling noises and drool. Seizures may cause twitching movements and stiffness on the side of the face being affected, and may then spread to the rest of that side of the body. Sometimes the seizure will spread to the whole body, causing a generalized tonic-clonic seizure. Seizures are often infrequent and may not be treated with medication.

Landau Kleffner Syndrome (also known as Acquired Epileptic Aphasia in Childhood) is a relatively rare disorder which develops in children usually between the ages of three to seven years old, during the time a child is developing language recognition and speech. The first indication of Landau Kleffner Syndrome is usually seen as the child developing difficulty in understanding what is said to them, as well as the ability to put their own thoughts into words. Seizures will usually follow within a few weeks of the development of the language problems and can include both tonic-clonic and complex partial seizures. Some patients do not develop seizures.

Lennox Gastaut Syndrome is one of the most severe of the childhood epilepsy syndromes. It is characterized by very frequent seizures of several different types. The most common seizure types are atonic, absence and tonic seizures. However, other types can occur. This syndrome is difficult to treat and often does not respond to typical epilepsy medications. A very small percent will outgrow their seizures and attain normal, or near normal, intelligence and abilities. For others, treatments, such as the ketogenic diet, vagus nerve stimulation or surgery, have been utilized with varying degrees of effectiveness.

Syncope
Syncope, or fainting, may be mistaken for seizure activity. It is generally caused by insufficient blood getting to the brain and not by abnormal electrical activity in the brain.

Non-epileptic Seizures
Non-epilepetic seizures, also called pseudo seizures, can resemble seizures but are not the result of abnormal electrical activity in the brain. They are considered to be of psychological origin rather than physical. They can be challenging to diagnose and treat.

Precautions
A seizure disorder should not interfere with a child's ability to enjoy a wide range of activities. Precautions may be required for a child whose seizures are not well controlled. Weighing the risks and benefits of an activity will help to determine if a child should participate. Some activities that require precautionary measures include swimming, cycling, climbing and bathing. Swimming is acceptable as long as the child is carefully supervised. Pool swimming is safer than lake swimming because of the risks associated with water depth and visibility. The child with a seizure disorder should

always swim with a responsible adult who is no further than an arm's length away and capable of rescuing them. The child should not swim if feeling unwell, anti-seizure medication has been missed or the child's physician recommends against it. *Guidelines for Management of Seizure Activity in Water* provides guidelines for the community programs in the management of seizure activities during water activities such as swimming. It is included as a supplement to this document.

The main goal in managing a seizure that occurs in the water is to prevent physical injury and maintain an open airway. When a seizure occurs in water:

- Support the person in the water with the head tilted so the face and head stay above the surface.
- Remove the person from the water as soon as safely possible.
- Lorazepam should be administered with a dry hand as it will begin to dissolve immediately if it becomes wet.
- When a child has a tonic-clonic seizure in the water, 911/EMS should be initiated immediately due to the potential risk of aspirating water.

A child with a seizure disorder may participate in cycling when precautions are implemented, such as wearing a helmet, not cycling alone and avoiding busy intersections.

Climbing, that involves moderate heights, is acceptable if the child is supervised and/or wearing a helmet. The parent/guardian, in consultation with the physician, will determine the need for a helmet.

Any child with a seizure disorder, regardless of age, should be supervised while in the bathtub.

Psychosocial Impact of Seizure Disorders

A child with a seizure disorder can, and should, live a normal life. Children with seizure disorders have the same psychosocial needs as other children. However, it can be a challenge to balance these needs with safety concerns. Some of the factors related to the psychosocial impact of seizure disorders include the following:

- Seizure frequency and unpredictability of occurrence
- Daytime seizures can have greater psychological impact than nocturnal (nighttime) seizures
- Drug side effects can affect lifestyle
- Poor self-esteem, anger, aggression and isolation may occur
- Parental overprotection and overindulgence are common
- For adolescence, denial is common. This may be dangerous if the adolescent suddenly stops taking anti-seizure medication as it could cause severe or prolonged seizures. They may also have difficulty in making new relationships. Fear of intimacy, loss of control and excitement may inhibit expressions of sexuality.

Most children with seizures test in the average IQ range. Some children may test lower than their potential due to effects of anti-seizure medication, unrecognized seizure activity or an underlying neurological condition.

Helping Peers Understand

Providing factual information that is age-sensitive can assist peers in understanding a child's seizure disorder. If children have witnessed a seizure, they may need reassurance that the child who experienced the seizure will be "ok" and the adults responsible for him/her know how to keep him/her safe.

It is not appropriate to share a child's personal health information with peers unless parent/guardian permission has been provided.

HEALTH CARE PLAN

When a community program receives URIS Group B support for children with URIS 'Group B' health care needs, a written health care plan is developed and maintained by a registered nurse on an annual basis, minimally. The development and implementation of the health care plan should reflect the principles of inclusion, normalization and independence. From a practical standpoint, these principles mean:

- A child with a seizure disorder is foremost a child within a family, child-care facility, classroom or other community program.
- The environment should be changed to support the child, not the child changed to suit the environment.
- Interventions should be as non-intrusive as possible and be delivered in a manner that respects the child's dignity and privacy as well as the normal routines and patterns of the community program.
- The parent/guardian and child have rights and obligations and should be actively encouraged to participate in decisions affecting themselves and their children.

Consultation with the parent/guardian and community program is required to develop a health care plan that is relevant to the child's needs and the community program setting. For some children, the management of their seizure disorder within the community program may be complex and require consultation with health care professionals who are involved in the management of the child's seizure disorder.

When a child has multiple health care needs, all relevant information should be integrated into one comprehensive plan. The format of the health care plan should be user-friendly and provide the community program with the information required to safely manage the child's health care needs.

The health care plan should be kept in a location that is secure and accessible at the community program. All community program personnel that may be responsible for a child with a seizure disorder should be aware of the location of the health care plan. It should also accompany the child on excursions outside the facility.

Content

The following information is included in the seizure disorder health care plan. The *Seizure Disorder Health Care Plan(s)* contains this information and is included as a supplement to this document:

Demographic information

- Child name
- Birth date
- Community program name
- Parent/guardian name and phone number(s)
- Alternate emergency contact name and phone number(s)
- Physician(s)

- Neurologist and phone number
- Family physician/pediatrician and phone number

Medical information

- Medical diagnoses and other relevant conditions
- Known allergies
- Availability of Medic-Alert® identification
- Prescribed medications
  - If anti-seizure medication is administered at home, name of medication is required only.
  - If anti-seizure medication is administered at the community program, additional information is required. See *When anti-seizure medication is administered at the community program* (below) for more details.
  - If rescue medication is prescribed and available at the community program, additional information is required. *See When rescue medication is prescribed and available at the community program* (below) for more details.

Seizure information

- Seizure type (if known)
- History
  - First diagnosed
  - History of seizure activity
  - Last known seizure
- Typical frequency and length of seizures
- Triggers, if known
- Safety precautions, if applicable (e.g., use of helmet)
- Activity restrictions, if applicable
- Other treatments prescribed (e.g., ketogenic diet, vagus nerve stimulator)
  - If child has a vagus nerve stimulator, additional information is required. See *Vagus Nerve Stimulator* (below) for more details.

Responding to seizures

- Description of seizure experienced by child
- Actions to implement during and after seizure
- Tonic clonic seizure
  - Description of seizure activity
  - Actions to implement during and after seizure
- Emergency Response Plan
  - Description of emergency situations

- Actions to implement in emergency situations

Documentation

- Template for recording seizure activity observed by community program personnel
  - Date and time of seizure
  - Length of seizure
  - Description of seizure activity
  - Activity child was participating in when seizure occurred
  - Exposure to triggers, if known
- Template for recording interventions and actions performed by nurse and/or community program personnel (e.g., communication, actions taken)
- Signatures & dates
  - Nurse signature & date(s) of health care plan development/review
  - Parent/guardian signature & date

When anti-seizure medication is administered at the community program

When anti-seizure medication is administered to the child during attendance at the community program, the health care plan also includes the following information. The *Administration of Anti-seizure Medication* contains this information and is included as a supplement to this document:

- Name of medication
- Dosage
- Time of administration
- Route of administration
- Location of medication at community program
- Steps in administering medication
- Written record for administration of medication
  - Date/time of administration
  - Initial/signature of community program personnel that administered medication
  - If administration not complete, indicate reason

When rescue medication is prescribed and available at the community program

When rescue medication is prescribed and available at the community program, the health care plan also includes the following information. The *Seizure Disorder Health Care Plan – Lorazepam* and *Seizure Disorder Health Care Plan – Midazolam* contain this information and are included as a supplement to this document:

- Name of medication
- Dosage

- Route of administration
- Location of medication at community program
- When to administer medication
- Steps in administering medication
- When to call 911/EMS
- Written record for administration of medication
    - Date/time of administration
    - Initial/signature of community program personnel that administered medication

When child has a Vagus Nerve Stimulator (VNS)

When the child has a VNS and the magnet is used in the community program, the health care plan also includes the following information. The *Seizure Disorder Health Care Plan – Vagus Nerve Stimulator* contains this information and is included as a supplement to this document:

- Care of pulse generator and magnet
- When to use magnet
- When to call parent/guardian
- When to call 911/EMS

The parent/guardian may choose to use the VNS at home only. When the child has a vagus nerve stimulator; but the magnet is not used at the community program, the following information is included in the health care plan:

- Care of pulse generator
- When to call parent/guardian
- When to call 911/EMS

When child has febrile seizures

When a child has febrile seizures, the health care plan also includes the following information. The *Febrile Seizures Health Care Plan* contains this information and is included as a supplement to this document:

- Signs of fever
- Responding to fever

TRAINING

When a community program receives URIS Group B support, training is provided to community program personnel by a registered nurse. Training is provided on an annual basis, minimally. The training of community program personnel should reflect the principles of adult learning. From a practical standpoint, these principles mean:

- Identifying and integrating the learning needs of participants into the training session.
- Information should be applicable to the participants' responsibilities and focus on what is most useful to them.
- Adults have accumulated a foundation of life experiences and knowledge and need to connect learning to this knowledge/experience base.
- An organized training session with clearly defined elements assists participants in identifying and attaining learning goals.

It is recommended that all community program personnel that may be responsible for a child with a seizure disorder attend the training session. As an example, community program personnel that may be responsible for a child with a seizure disorder may include:

- in schools - teachers, teaching assistants, school administrators, office staff, substitute teachers, bus drivers, lunch room supervisors;
- in licensed child care facilities - child care providers, child care directors; and
- in recreational programs – staff members, administrators, volunteers.

The community program is responsible to ensure personnel that may be responsible for a child with a seizure disorder attend the training session. It is recommended to keep a written record that indicates community program personnel in attendance and date that training occurred.

Adequate time should be scheduled for training to ensure community program personnel obtain the knowledge and skill necessary to safely respond to the needs of children with seizure disorders in their facility. The amount of time required to train community program personnel will vary depending on several factors, such as the existing knowledge of community program personnel, number of personnel attending the session and format of training resources used (e.g., PowerPoint, Worksheet).

Whenever possible, training should be scheduled when all community program personnel can attend to ensure service is provided in an efficient manner. If the training session is poorly attended (i.e., there is not an adequate number of community program personnel to safely address the child's seizure disorder), additional training should be scheduled. If subsequent training sessions are also poorly attended, alternate strategies should be discussed with the community program to ensure training is provided in an efficient manner.

When the community program has not received training, a child with a seizure disorder may attend the community program. In such situations, the community program's internal policy for emergency situations (e.g., call 911/EMS) is implemented, if required.

Content

The following clinical information and child-specific information is included in the training session:

Clinical information

- Seizure disorders
- Causes of seizures
- Triggers for seizures
- Description of seizure type(s) and experienced by child and how to respond
- Tonic-clonic seizures and how to respond
- Emergency situations and how to respond
- Treatment of seizure disorders
  - Anti-seizure medication
  - Rescue medication
  - Other treatments
- Precautions
- Observation and documentation of seizure activity
- Psychosocial impact of seizures

Child specific information

- Seizure type/activity experienced by child
- History
  - First diagnosed
  - History of seizure activity
  - Last seizure
  - Typical frequency and length of seizures
- Triggers, if known
- Safety precautions, if applicable
- Activity restrictions, if applicable
- Treatments prescribed
  - If child is prescribed rescue medication and it is available at the community program, additional information is provided at training session. See below for more details.
  - If child has a vagus nerve stimulator, additional information is required. See below for more details.

- Actions to implement during and after seizure activity, if differs from standard response
- Emergency situations and how to respond, if differs from standard response

When Lorazepam is prescribed and available at the community program
It is recommended that all community program personnel who may be responsible for the child receive training on the administration of Lorazepam. The following information is included in the training session:

- Dosage prescribed
- Location of medication at community program
- Steps in administering medication
- When to administer medication
- When to call 911/EMS
- Recording administration of medication

When Midazolam is prescribed and available at the community program
It is recommended that 2-3 community program personnel receive training on the administration of intranasal Midazolam. The following information is included in the training session:

- Dosage prescribed
- Location of medication at community program
- When to administer medication
- When to call 911/EMS
- Recording administration of rescue medication
- Demonstration and return demonstration of administering rescue medication
    - A vial of saline solution and needle/syringe is used for demonstration purposes. A mucosal atomizer device (MAD) should also be used during training if used to administer midazolam to the child.

When child has a Vagus Nerve Stimulator (VNS)
If the child has a VNS and the magnet is used at the community program, it is recommended that 2-3 community program personnel receive training. The following information is included in the training session:

- Care of the pulse generator and magnet
- When to use magnet
- When to call parent/guardian
- When to call 911/EMS
- Demonstration and return demonstration on use of the magnet

If the child has a VNS and the magnet is NOT used at the community program, it is recommended that 2-3 community program personnel receive training on the following information.

- Care of the pulse generator
- When to call parent/guardian
- When to call 911/EMS

Training Resources

The following resources are included as supplements to this document. If alternate resources are used, it is the responsibility of the nurse to ensure its content is consistent with the clinical information included in this document.

- *Seizure Disorder Handout*
- *Seizure Disorder PowerPoint*
- *Seizure Disorder Worksheet* (Word and PowerPoint version) is recommended for community program personnel that have previously attended a seizure disorder training session. The Microsoft Word version may be better suited for individuals or small groups. The Microsoft PowerPoint version may be more suitable for large group settings.

On-site training by a registered nurse is required to delegate the knowledge and skill to community program personnel in the management of seizure disorders. Other teaching strategies may be used as supplements to on-site training at the discretion of the nurse. The following on-line resources may be useful for teaching purposes.

- Epilepsy & Seizure Information for Schools (DVD) – 22 minutes or 7 minutes
  BC Epilepsy Society - www.bcepilepsy.com
- Seizure Training for School Personnel (PowerPoint presentation, 18 minute video and learning assessment tool)
  Epilepsy Foundation - www.epilepsyfoundation.org

MONITORING

Monitoring of trained community program personnel by a nurse is required to ensure that the knowledge and skill necessary to safely care for children with seizure disorders has been acquired and/or retained. Monitoring is required on an annual basis, minimally.

The frequency and timing of monitoring is based on the professional judgment of the nurse as well as the complexity of information taught, maturational issues and the skill demonstrated by community program personnel. The following strategies may be used for monitoring purposes.

- Completion of the *Seizure Disorder Training Session Evaluation Form* by community program personnel that attend training, included as a supplement to this manual;
- Observation of community program personnel performing a return demonstration (i.e., administration of midazolam) at the training session.
- Asking community program personnel questions during the training session to assess their knowledge of seizure disorders. The *Seizure Disorder Worksheet* is included as a supplement to this document.

REFERENCES

BC Epilepsy Society website

Canadian Epilepsy Alliance website

Devinsky, Orrin *Epilepsy: Patient and Family Guide* (*3rd Edition*). Demos Medical Publishing, New York, 2008.

Epilepsy Canada website

Epilepsy Foundation website

Epilepsy Ontario website

Epilepsy & Seizure Association of Manitoba (ESAM) website

Freeman, John M., Vining, Eileen P.G., Pillas, Diana J. *Seizures and epilepsy in childhood: a guide for parents (3rd edition).* John Hopkins University Press, Baltimore, 2002.

Lagae, Lieven, *The treatment of acute convulsive seizures in children,* European Journal of Pediatrics (2011), vol170, page 413-418.

RESOURCES

The following list includes resources that may be relevant to community programs in the care of children with seizure disorders. The purpose of these agencies/organizations may not be consistent with the purpose and content of this manual.

BC Epilepsy Society
www.bcepilepsy.com

Canadian Epilepsy Alliance website
www.epilepsymatters.com

Epilepsy Canada website
www.epilepsy.ca

Epilepsy Foundation
www.epilepsyfoundation.org
Information for Parents and teachers - www.epilepsyclassroom.com

Epilepsy Ontario website
www.epilepsyontario.org

Epilepsy & Seizure Association of Manitoba (ESAM) website
www.manitobaepilepsy.org