EPILEPSY

INCLUSIVENESS

"People think that epilepsy is divine simply because they don’t have any idea what causes epilepsy. But I believe that someday we will understand what causes epilepsy, and at that moment, we will cease to believe that it’s divine. And so it is with everything in the universe."

- Hippocrates

The Aim of Scouting is to promote the development of individuals, enabling them to grow and take their place in society as active citizens. As we move forward with the Canadian Path we are much more aware of each individual’s personal progression, inclusive of their varying abilities. This inclusiveness within Scouting uniquely positions us to play an important role in modifying community attitudes and behaviour towards individuals with identified needs; it starts with Scouts.

Please use this guide for a better understanding of youth with Epilepsy; how as Scouters, we can make a difference through simple interventions, program modifications and knowing where to get help when needed.

DESCRIPTION

Epilepsy is a disorder that takes the form of recurring seizures. Seizures are sudden uncontrolled episodes of electrochemical activity in the brain. Brain cells normally communicate with each other in a coordinated way to control our conscious state and body movements. During a seizure this communication is temporarily disturbed and becomes un-coordinated. There are many different types of seizures and although they can sometimes look frightening they rarely cause any damage to the brain.

Epilepsy is not infectious and others cannot catch it by contact or association! Nor is it a mental illness.

CHARACTERISTICS/BEHAVIOURS

There are over forty different types of epileptic seizures. Seizures can be classified as partial or generalized - partial seizures involve epileptic activity in part of the brain and generalized seizures involve epileptic activity in the whole brain.

Generalised seizures may then take one of the following forms:

**Tonic Clonic Seizure**

Sometimes these are referred to as Grand Mal Seizures, the most common generalised seizure involving the whole brain. The person goes stiff, falls to the ground, their limbs jerk, after which they may become still before regaining consciousness. These seizures result in all the muscles contracting. The body stiffens and the person will fall over if not supported.

**Absence Seizures**

Previously called Petit Mal Seizures, it appears to onlookers that the person is daydreaming or switching off. However, in an Absence Seize the person cannot be alerted or woken up, they are momentarily unconscious and therefore totally unaware of what is happening around them. These seizures occur most commonly in youth between the ages of 6-12 (girls being more prone than boys).

**Atonic Seizures**

Sometimes called Akinetic Seizures, are the opposite of Tonic Clonic Seizures; the muscle tone is lost and the person drops to the ground - sometimes referred to as ‘drop’ attacks. When the body goes limp it inevitably falls to the floor, and there is an increased risk of head injury when the individual falls.

**Myoclonic Seizures**

Myoclonic Seizures are abrupt jerking of the limbs, which occur most frequently in the morning. Although the seizures are brief, they can be extremely frustrating. As in Absence Seizures, the person is not conscious, but the seizure is so brief that the person appears to remain fully conscious.


IN A SCOUTING SITUATION

• All Scouters must be thoroughly familiar with both youth and adult members Program Participant Enrolment Forms, paying particular attention to the Information For Medical Emergencies section, and have a copy available at all times.
• Collaborate, on an on-going basis, with the youth and parents to fully comprehend the concerns on how to proceed and how best to work with the youth to provide for the best Scouting experience.
• Know as much as possible about the type of epilepsy and how it is controlled.
• Ensure that the Information For Medical Emergencies is kept up to date; as youth grow, their medication may change - it is important that Scouters continue to dialogue with the youth and parents, as they need to be aware of changes in medication or condition.
• Monitor the youth’s requirements for medication intake - what medication is used and at what time is it administered, often within a one hour window.
• If a youth is experiencing an epileptic seizure, a Scouter must move other youth away, allowing for space for recovery.
• Scouters supporting the youth experiencing an epileptic seizure need to present as calm, displaying no fear or panic.
• You don’t need to call an ambulance when someone has an epileptic episode unless it lasts longer than 5 minutes, however, report incidents to the parents or guardians.

PROGRAM MODIFICATION SUGGESTIONS

• For the activity being undertaken, consider whether additional precautions are required; where it might be important to ensure there is a Scouter nearby. If so, use these precautions for ALL youth members. Don’t single out anyone.
• Know which activities are prohibited and which need extra supervision - ensure that the youth member is given the same opportunities and experiences as every other member.
• Careful program planning is essential pertaining to high adventure activities especially with water based activities.
• With youth and parental permission, ensure that everyone is aware of the youth’s condition, the first aid protocol and what to do in the event of a seizure.
• When planning, consider emergency treatment; how it will be accessed, for example, if hiking or canoeing - how can an ambulance be called, how will the ambulance be able to find you?
• Be aware of known or suspected triggers of a seizure:
  • Lack of sleep
  • Medication trials
  • Bright lights
  • Stress
  • Heat
  • Alcohol

IN THE EVENT OF SEIZURE

Do:

• Protect the youth from injury and keep them away from potential hazard.
• Loosen tight clothing around the neck.
• Put a piece of soft clothing or pillow under their head.
• Provide calm reassurance as the youth regains consciousness.
• Following the seizure, lay the youth on their side, in the First Aid “recovery position.”
• Remain with the youth until the seizure has completely ended.

Note:

• Seizure movements are not to be restrained.
• Do not place anything in their mouth.
• Only move them if they are in danger.
• Do not strive to bring them to consciousness.
• No food or drink is to be given until recovery is complete.

Immediately Get Medical Help If:

• It is the person’s first seizure.
• If the duration of the seizure extends beyond 5 minutes.
• Injury occurs during the seizure.
• Urgent medical assistance is deemed to be required.

FURTHER ASSISTANCE

This Info Sheet is a resource guide only and is not intended to be therapeutic, diagnostic, medical, or legal advice. Our best source of assistance for youth with identified needs is the youth’s parents or caregivers; the information provided is designed to support the relationship that exists between a youth and his/her parents or healthcare providers and the Scouters involved with the youth.

SOURCES

www.webmd.com/epilepsy/guide/epilepsy-seizure-symptoms, www.epilepsy.ca, and material adapted and used by permission of The Scout Association (UK), Scouts Australia, Scouting Ireland and Epilepsy Canada.