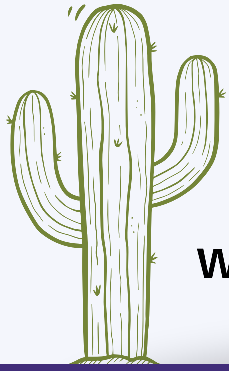
LIVING WITH EPILEPSY IN HIGH SCHOOL

A KIT FOR THE TEACHERS



WINTER 2024

Épilepsie
MONTÉRÉGIE

ABOUT US

My name is Anie, and I've been a psychosocial counsellor for epilepsy for the past ten years. My focus is on the day-to-day life of people living with the condition, on the impact of the disease on their lives and those of their loved ones. I'm a neurotypical, mother of 3 young adults including a non-binary child with ASD and generalized anxiety disorder, and have been a caregiver for over 20 years to one of my parents. I understand the worries that parents can have. My goal? To optimize the tools available to ensure your child's well-being, and by extension, your own!

WE’RE LISTENING

I offer to be your ally in this adventure by providing family guidance. I offer my support to you, your children and their siblings. I can come to you to meet your family's needs.

SCHOOL SUPPORT

Hello, my name is Sylvain Desruisseaux and I'm very happy to be part of the “Épilepsie Montérégie” team as a liaison officer.

My primary role is to create harmonious links with families and the school community, as my expertise comes from the education field as a pedagogue and school principal. Concerned about the well-being of others, my mandate is to provide support to parents, but also to accompany children, teenagers and adults on their educational journey.

I look forward to working with you!

AWARENESS

I've chosen to use the epilepsy diagnosis I received in a positive way by working to raise awareness. I'm always happy to create content that many people can relate to. Videos, podcasts, posters and many other tools to help people who, like me, live with the condition. I hope you find this kit as reassuring as I do.

-Èva

I AM YOUR HOST TODAY !

With Lou

Èva's twin sister

Épilepsie Montérégie has developed a playful and striking approach to raising epilepsy awareness.

Whether it's for schools, day camps, families, events or any other occasions, the puppet is an important ally. This character lives with epilepsy and shares information through her perspective.

The impact is different when the information is transmitted by Lou. The puppet encourages openness, emotional sharing and adds a touch of magic! Lou is a powerful tool for children and adults alike!

We offer educational workshops !

EPILEPSY

Listen differently, see differently and, above all, speak openly!

This kit is for you if you have a student living with epilepsy in your class. Since this may be the first time you've experienced this situation, and your student may have special needs, it's perfectly normal for you to have concerns or questions. We're here to help you and to meet your needs!

In this document, you'll find important information to help you better understand epilepsy and the impact of the condition on your student's educational progress. You'll also find strategies, solutions and tools for managing your classroom.

Collaboration between parents and teachers contributes greatly to your teenager's well-being. **The challenge is to reconcile the concerns and values of parents, those of the school and your own.**

With this kit, we hope to be an ally for you.

FACTS ABOUT EPILEPSY

What is epilepsy?

Epilepsy is a brain condition characterized by recurrent, unprovoked seizures. It presents itself as an "electrical storm" of variable duration. Seizures can take many forms, from a brief cessation of activity to a loss of consciousness and motor convulsions*.

1 %

OF QUEBECERS LIVE WITH EPILEPSY

50% to 70% of people living with epilepsy have first manifested symptoms in childhood or adolescence.

Seizures take many forms: brief suspension of consciousness (absence), tremors - spasms in one arm, convulsions (tonic-clonic). The form the seizure depends on where in the brain the excessive electrical discharge occurs.

- 1% of the population lives with the condition;
- More often children and the elderly (65 and over);
- 70% control their condition with medication;
- Manifestations, frequency, duration and severity vary from person to person;
- Coping with epilepsy is possible (managing illness and emotions, organization, etc.).

> ***"Puberty and the transition to adolescence:***
> *In addition to puberty, the onset of adolescence also coincides with a new school environment and a new network of acquaintances (not to mention the need to free oneself from one's parents). Hormonal changes and chronic stress are conducive to changes in seizure frequency. The transition to adolescence may require a readjustment of anti-seizure medication, and may even mean the cessation of seizures".*
>
> -Association québécoise de l'épilepsie

*Association Québécoise de l'épilepsie

Screens, video games and photosensitivity

- Predominantly present in young people aged 9 to 15, photosensitive epilepsy remains a relatively uncommon form of the condition (less than 5 cases in 100). *

*Association Québécoise de l'Épilepsie

Photosensitivity is the brain's visual hypersensitivity to flickering light sources or patterns that can trigger epileptic seizures. Among the most likely triggers of a photosensitive epileptic seizure are:

- strobe lights ;
- stage lighting ;
- certain video games;
- the sun's reflection on water or snow;
- high-contrast or rapidly oscillating patterns on screens;
- car headlights.

THE WORLD OF EPILEPSY

“One child in two living with epilepsy has issues at school: absenteeism, relationships with others and learning difficulties (sometimes all three at the same time).”

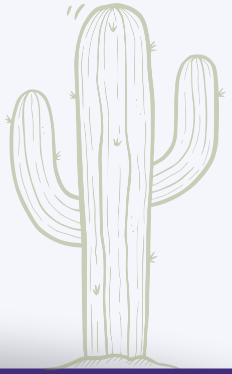
-Stéphane Auvin, Neuropediatrician, specialist in childhood and adolescent epilepsy

IMPACT OF THE ILLNESS

It's important to note that students living with epilepsy experience far more learning problems and difficulties at school than others.

Certain factors may explain this phenomenon:

- **Anti-seizure medication*** can affect learning. The side-effects of medication such as fatigue, drowsiness, reduced speed of information processing, concentration and memory problems, represent a challenge for the teacher-child duo;
- **Anxiety disorders.** Anxiety can, among other things, lead to lower motivation at school;
- Seizures accompanied by **loss of consciousness** disrupt mental functioning during the episode, and this effect may persist for several days;
- **Absence seizures** appear to disrupt short-term memory such as the events that occurred immediately prior to the episode. For example, a student who has absence seizures throughout the day will have learning difficulties;
- Seizures: **age - frequency of seizures - type of epilepsy, etc**;
- **Socio-familial and psychological factors**;
- **Memory impairment** is a major cognitive problem in children with epilepsy.



Not all children feel the same side effects of medication.

Good to know

- Some children have **nocturnal seizures**. This can affect both the psychological and physical aspects of the child. It can cause anxiety, irritability, headaches and difficulty being functional the next day.
- Children with epilepsy can be teased or even bullied by other children. **Social anxiety and prejudice** are more detrimental to a student's quality of life at school than the disease itself. That's why we offer awareness workshops that really make a difference.
- **Absenteeism** may be higher: either to recover from an episode, for medical appointments or to set up new treatments.
- **Extra time may be needed** to understand instructions or finish exams, especially in the days following a seizure.
- A change in emotions or personality. After the onset of seizures, **some people may be more emotional** than before, while others may be calmer.

STRATEGIES

Make sure the class knows what to expect when your teenager has a seizure and understands how to help. Tonic-clonic seizures are the most spectacular and can be frightening and anxiety-provoking. Students need to be reassured and informed.

The generalized tonic-clonic seizure occurs in two phases:
The tonic phase consists of a contraction of all muscles, sometimes causing the tongue to bite. It may also be accompanied by a scream.
The clonic phase is characterized by jerking limbs and diffuse, irregular, involuntary muscle contractions.

How do you recognize when a child is having an absence seizure?

"Absence seizures are much like brief episodes of blank staring or daydreaming. When a child is daydreaming, you can get his attention by touching his shoulder or calling his name. But when a child is having an absence seizure, you won't be able to "wake him up" or get his attention. Be patient and the crisis will soon be over. Reassure the child and repeat the instructions you gave during the seizure."

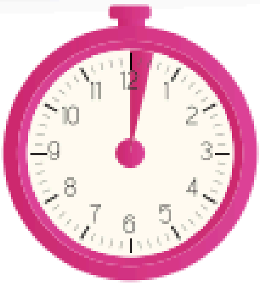
-Association québécoise de l'épilepsie

Minimize classroom triggers such as heat, dehydration, intermittent light and stress.

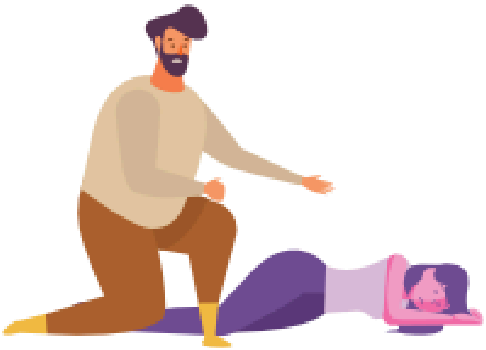
A calm and reassuring presence is important !

EPILEPSY

FIRST AID FOR SEIZURES



1. **STAY CALM.** Let the seizure take its course.
2. **TIME** the seizure.
3. **PROTECT FROM INJURY.** If necessary, ease the person to the floor. Move hard or sharp objects out of the way. Place something soft under the head.



4. **LOOSEN** anything tight around the neck. Check for medical identification.
5. **DO NOT** restrain the person.
6. **DO NOT** put anything in their mouth. It is impossible for the person to swallow their tongue.

7. Gently **ROLL** the person onto their side when the convulsions have stopped, after making sure they are breathing to allow saliva and other fluids to drain from the airway.

8. If the seizure is still ongoing after 5 minutes, you must **TAKE ACTION** to prevent the seizure from evolving into a more severe condition. Call 911.
9. If the person has a nonconvulsive seizure, stay with them to prevent injury. Don't try to wake them up, just let the seizure proceed normally.

AFTER THE SEIZURE

Talk to the person reassuringly. Do not leave until the person is reoriented. The person may need to sleep or rest.

INDEX

Pour des compléments d’information

Association Québécoise de l’Épilepsie (french content)
https://www.associationquebecoiseepilepsie.com/

Canadian Epilepsy Alliance
https://www.canadianepilepsyalliance.org/

Plateforme ÉPITAVIE (french content)
A virtual intervention to better understand epilepsy.
https://www.crsi.umontreal.ca/section-patients/liste-des-tavies/epi-tavie

CHU Sainte-Justine: Epilepsy
https://www.chusj.org/soins-services/E/Epilepsie

TONIC, le Podcast (french content)
Dr. Guillaume Lafortune, neurologist at Granby Hospital, explains epilepsy from a medical point of view.
https://open.spotify.com/episode/2uxZYdStWnWS0hfCtkbwBG?si=4lfKslUhRSCVeWzTCasLOw

Guide: Being a parent in the world of epilepsy par Épilepsie Montérégie.
epilepsiemonteregie.org

Trousse “Classification *des crises*” par Épilepsie Montérégie (french content).
epilepsiemonteregie.org

Centre d’étude sur le stress humain
https://www.stresshumain.ca/

OUR SERVICES

Épilepsie Montérégie is a community organization whose objectives are to provide information, raise awareness about epilepsy and promote the rights of people living with the disease.

DOCUMENTATION

We have a wealth of information available to help you better understand all aspects of epilepsy.

AWARENESS

We raise awareness to demystify epilepsy and change people's beliefs about the condition.

TOOLS

We have many tools available to help your child live better with epilepsy.

SUPPORT

Our counsellor is available to accompany you and offer support as needed.

HAPPY SCHOOL YEAR !

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