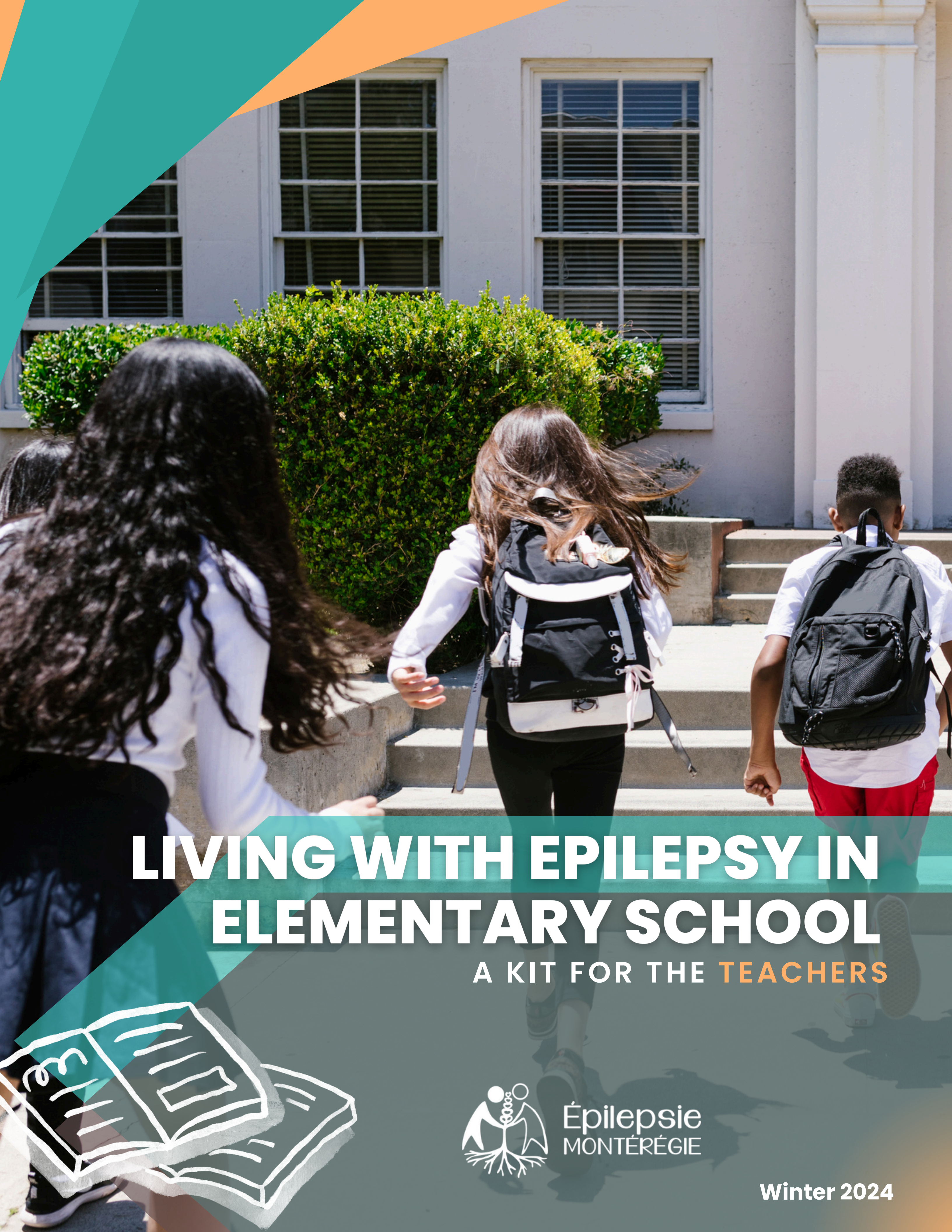


LIVING WITH EPILEPSY IN ELEMENTARY SCHOOL

A KIT FOR THE TEACHERS

Épilepsie
MONTÉRÉGIE

Winter 2024

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 !

TAKE ACTION IN COMPLETE SAFETY

This kit is for you if you have a child living with epilepsy in your class. Since this may be the first time you've experienced this situation, and your new 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 the condition can have on your student's progress at school. You'll also find strategies, solutions, classroom management tools and suggestions for teaming up with parents and your student.

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

With this kit, we hope to be an ally for you. With this kit, we hope to offer you a little peace of mind and contribute, in our own way, to your child's well-being in the classroom and to the magic of learning!

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.

Did you know ?

→ **Children living with epilepsy have the same range of skills as everyone else. When the disease is well managed, they can happily take part in all recreational activities.**

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.).

*Association Québécoise de l'épilepsie

THE WORLD OF EPILEPSY

IMPACT OF THE ILLNESS

“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).”

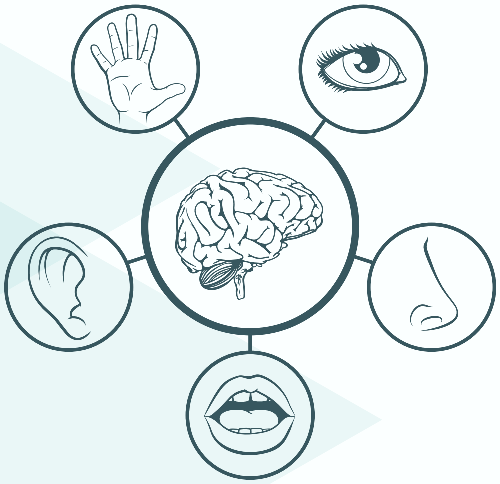
-Stéphane Auvin, Neuropediatrician, specialist in childhood and adolescent epilepsy

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.



> *"A child with epileptic seizures whose starting point is close to the language area of the brain is going to have more difficulties with language or reading."*
>
> -Stéphane Auvin

There's a link between epilepsy and ADHD

On the **CHU Sainte-Justine website**, we read that the risk of developing ADHD (attention deficit disorder with or without hyperactivity) in children with epilepsy is greater than in children without epilepsy. This link may be caused by different aspects of epilepsy, namely:

- Seizures;
- The age at which epilepsy begins;
- 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 and understands how to help when the child has a seizure. **We must remember that epilepsy is invisible**. We can't know that a child has epilepsy unless we witness a seizure, and this can be confusing for others. The tonic-clonic seizure is the most spectacular and can indeed be frightening and anxiety-provoking. It's important to reassure and inform peers.

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.

As the Canadian Epilepsy Alliance points out, it's important to stress that we all have unique characteristics that set us apart. These differences are part of life.

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."

-Canadienne Epilepsy Alliance

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

SUGGESTED KEYWORDS

MOST OFTEN, CHILDREN HAVE NO TABOOS. WE DO!

How to deal with epilepsy in the classroom

During an epileptic seizure, neurons discharge up to 500 times per second, compared with the usual 80 times. That's why we compare an epileptic seizure to a storm or a short circuit! Then, after a few seconds or minutes, the storm calms down and the brain resumes normal functioning.

Gabriel* has a ____________________epilepsy. This means that epilepsy affects the brain. When he has a seizure, it's because there's too much current at the same time.

→ **For tonic-clonic seizures:** his brain controls his whole body, everything he does, by passing small electrical currents. That's why his legs and arms move without his being able to control them.

→ **For absence seizures:** Gabriel seems lost in thought for a few seconds. It's as if we turned off the light in his head for a few minutes.

“The brain is used to move the body around: it organizes all voluntary movements according to the muscular apparatus, perceived information from the surrounding world and the goal to be achieved.”

After a crisis, here's a few sentences that helps self-regulation: “It's time to calm down”, “Try to think about something else”, “Count to ten, then breathe out”, etc.

- It's impossible to prevent a seizure from happening.
- Most seizures last a few seconds or several minutes and end naturally.
- Once the seizure is over, the student returns to normal life.
- It's not contagious! You can't catch it like a cold.

*fictional name

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.

INDEX

More content

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

Tic Doc, an informal video about epilepsy for children (french content)
https://www.tfo.org/regarder/lepilepsie/GP139586

The guide: *Being a Parent* created by Épilepsie Montérégie
epilepsiemonteregie.org

FIRST AID FOR SEIZURES

DURING THE SEIZURE

MAKE sure that your friend is in a safe place and position and is comfortable.

Anyone can help during a seizure!

Gently ROLL your friend onto his or her side. This position is called the recovery position.

DO NOT give anything to drink or put anything in the mouth of the person (such as a spoon).

The myth of a person having a seizure can swallow their tongue is false, so don't worry.

MAKE sure that the surroundings of your FRIEND is calm.

to your other friends that the person is having an epilepsy seizure.

If the seizure is still ongoing after 5 minutes, you must TAKE ACTION to prevent the seizure from evolving into a more severe condition.

Most of the time, seizures last only 1 or 2 minutes.

Remember to NOTE the start and end times of the seizure.

Call 911 or follow the instructions of an adult.

AFTER THE SEIZURE

- Talk reassuringly to the person, for they are probably confused.
- Stay with the person and explain to them what happened. They were unconscious during the seizure, so they won't remember what happened on their own.
- During a seizure, some people lose control of their bowels and of their bladder. Tell the person you knew they couldn't hold it.
- After the seizure, most people feel tired and need to rest: let them.

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 !

Content creator :
Anie Roy

Graphic designer :
Èva Perreault-Gagnon

Translation :
Èva Perreault-Gagnon

Editing :
Kaïlane Cook et
Sylvain Desruisseaux

Contact :
18, Court street, Granby,
QC J2G 4Y5
(450) 378-8876
anie@epilepsiemonteregie.org

@epilepsie.granby
@epilepsiemonteregie
@epilepsie_monteregie
@epilepsie_monteregie
www.epilepsiemonteregie.org