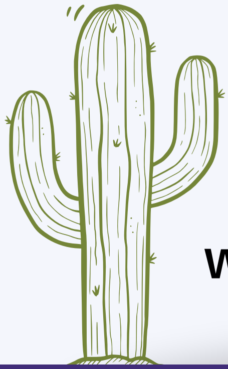
LIVING WITH EPILEPSY IN HIGH SCHOOL

A KIT FOR THE PARENTS



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 your teenager is living with epilepsy and attending high school. They have special needs, and you're worried and stressed about it - it's perfectly normal!

We're here to help!

In this document, you'll find information, solutions and suggestions for teaming up with your child's teachers and school staff. You'll also find a section for school staff and one for your teenager. With this kit, we'd like to offer you a little peace of mind and contribute, in our own way, to your child's well-being in high school.

Adolescence is like a cactus....

-Anaïs Nin

Adolescence and the transition to adulthood are often difficult times, especially when epilepsy is involved. Life is bubbling up inside your teenager, and they want to have exciting experiences. However, epilepsy is bound to impose its limits and create worries. For your part, you may be “taking in” their frustrations with patience and concern.

If you'd like to read more on the subject of adolescence in the world of epilepsy, we suggest the **TONIC** project. It's an 8-episode **mini-series** that follows the journey of a 22-year-old woman coping with epilepsy in different situations in her life. There's also the **TONIC Podcast**, a series of interviews linked to each episode of the **TONIC web series**. And finally, you can read the **Recharging Kit**! A kit that offers information on various topics (hormonal changes, driver's license, dating, work, etc.) and tools to help you get through the teenage years in optimal conditions.

TONIC demystifies epilepsy and encourages open dialogue!

www **epilepsiemonteregie.org**

TONIC

SCHOOL ENVIRONMENT IN COMPLETE SAFETY

TEACHERS

Teachers wear many hats. They are role models, mentors, caregivers and helpers. Teachers have a major impact on your teenager's life. In the context of epilepsy, it's important to pass on information, give the right tools and make sure the person knows what to do in the event of a seizure.

What's more, your teen may be tempted to hide the fact that they are diagnosed with epilepsy, or may be anxious about having an episode.

As we often say, **the unpredictability of a seizure can increase stress level and the feeling of anxiety.** The reaction of those around the person can also have an impact on the person. They will be more nervous if there is agitation during the crisis. On the other hand, if those around them remain calm and know how to react appropriately, the stress level will be lower. I encourage you to discuss a possible scenario with your teenager, for possible discussion with their teachers.

In the next few pages, you'll find useful and relevant information to share with school staff. Facts about epilepsy, how to write down “your” epilepsy, a form to give to those in charge, the impact of epilepsy in the classroom, strategies for coping with epilepsy in the classroom, suggestions for adapted services in the school environment, thoughts and references.

A WEALTH OF INFORMATION

It is important to inform the resource people around your teenager.

Understanding epilepsy and its cognitive, psychological and social consequences makes a difference for everyone. No matter how independently your child copes with the disease, we understand that they need the support of empathetic adults. Since episodes can occur suddenly, school personnel need to be informed and supported.

INTERVENTION PROTOCOL

Drawing up an intervention protocol puts measures in place to ensure your child's safety, and ensures that school personnel are properly trained to respond quickly in the event of an emergency.

The protocol should include the following points:

- Basic information about your adolescent's type of epilepsy (see form);
- What to do during a seizure;
- When to call a relative;
- When to call an ambulance.

Theoretically, the intervention protocol should be developed by your teenager, you and, if necessary, in consultation with your child's doctor or members of the epilepsy care team. You can then discuss it with school staff.

DESCRIBE EPILEPSY

Did you know ?

A sign is a clinical characteristic of an illness or condition that the doctor looks for and measures. **A symptom** is something your child feels or complains about.

THE PERSON LIVING WITH EPILEPSY IS AN EXPERT WHEN IT COMES TO HIS OR HER OWN SYMPTOMS.

BEFORE THE SEIZURE

Warning signs or unusual sensations (symptoms) :

☐ Hearing or smelling something that is not actually there (visual and/or auditory distortion);
☐ A particular smell or taste;
☐ A scream;
☐ Sudden emotions, for no apparent reason, such as fear, depression, rage or joy;
☐ A feeling of being outside one's own body;
☐ illusions of déjà-vu or knowledge of the future (already lived);
☐ An upset stomach;
☐ Palpitations;
☐ Needle prick (tingling) or numbness in any part of the body;
☐ Goose bumps;
☐ Tingling, prickling or abnormal sensations in one hand;
☐ Reddening or paling;
☐ Others ________________________

DURING THE SEIZURE

Signs and manifestations :

☐ Loss of consciousness ;
☐ Excessive saliva ;
☐ Bitter, acidic taste in the mouth;
☐ Inability to speak;
☐ Noisy breathing ;
☐ Revulsed eyes ;
☐ Trembling ;
☐ Staring ;
☐ Stiffness - rigidity ;
☐ Incomprehensible language ;
☐ Spasms in arms and legs;
☐ Insensitivity to immediate environment ;
☐ Insensitivity to touch ;
☐ Head nodding ;
☐ Automatisms such as licking or swallowing, or hand movements;
☐ Sudden loss of muscle tone;
☐ The child cries or moans loudly;
☐ Loss of bowel or bladder control;
☐ Others ______________________________

Epilepsy symptoms are unique and affect young people differently.

AFTER THE SEIZURE

Signs of the recovery phase :

☐ Memory problems ;
☐ Head and muscle pain;
☐ Sleep ;
☐ Confusion (disoriented for some time) ;
☐ Weakness ;
☐ Nausea or vomiting ;
☐ Fatigue ;
☐ Anxiety (feeling of fear, shame or sadness) ;
☐ Difficulty finding names or words;
☐ Others ______________________________

The need for neuron recovery!

Drawing up a portrait of “your” epilepsy is a must.

Being able to describe what epilepsy means to you is a major step in learning to live with this neurological disorder. The time invested in recognizing the symptoms that occur before, during and after a seizure helps to identify possible solutions. What's more, becoming aware of our most vivid emotions, needs, obstacles and limitations in relation to the disease helps us to discover the issues and impacts of epilepsy on our lives and those of our loved ones. This is all the more important as it also identifies our allies!

THE FORM

TO BE GIVEN TO THE PERSON IN CHARGE

NAME :

AGE :

PHONE NUMBER :

PARENT :

My epilepsy looks like :

Possible triggers (if known) of a seizure :

A list of symptoms that precede or follow my seizure:

Precede

Follow:

Information about my medication, if necessary :

Épilepsie MONTÉRÉGIE

THE FORM

TO BE GIVEN TO THE PERSON IN CHARGE

NAME :

PHONE NUMBER :

TYPE OF EPILEPSY :

Support needed following the episode :

This is an emergency for me, the time to call my loved ones:

Other necessary information :
Do you have difficulty expressing your feelings, asking for help or starting a conversation? Other relevant information...

For more information : epilepsiemonteregie.org

FOR THE TEACHER

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?

1 %

OF QUEBECERS LIVE WITH EPILEPSY

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

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*.

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

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*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.

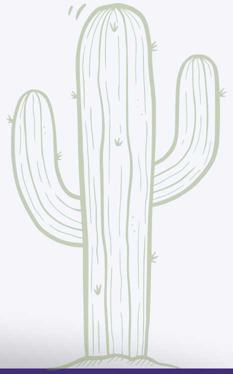
THE WORLD OF EPILEPSY

> *“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*

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.

TO PASS ON TO YOUR TEENAGER

STUDENT ACCESSIBILITY SERVICES

In schools (high school, CEGEP and university), there are **accomodations** that can help with the educational process. It is your responsibility to notify your school of your intention to use these services. The person in charge will discuss your learning needs with you.

As we saw earlier, the school should have an **intervention protocol** that includes the following information: the name of your doctor, the name of your medications, your allergies, your other medical conditions, how to intervene and who to contact in the event of a crisis.

To have access to accommodations and adapted services
You'll need to provide a medical certificate or summary report, and possibly an evaluation report from a neuropsychologist, which, depending on your situation, will mention your needs to help you learn.

LIST OF SERVICES AVAILABLE:

- Note-taking service;
- Extra time on exams;
- Access to an adapted room;
- An adapted schedule (depending on medication intake);
- Adapted pedagogical support (homework help, assignment supervision, etc.);
- Use of a digital tape recorder;
- Mentoring;
- Systemic meetings with the teacher.

For any student, **the exam period generates a lot of stress, which can influence the frequency of your seizures**, so ask for accommodations!

Source :
www.abouthkidshealth
www.cegep-ste-foy.qc.ca (Services adaptés)

IN FRONT OF THE SCREENS

Breaks are essential

Take a break of at least **5 minutes every hour** if you work intensively on a screen, or **15 minutes every 2 hours** if you work less intensively. During these breaks, it's a good idea to leave your workstation and move around to “break” the static posture!

Studies show that spending too much time in front of a screen also increases the risk of cognitive disorders, including concentration problems and sleep disruption.

Suggestions for avoiding eyestrain

Anti-blue-light glasses are designed to reduce the risk of eyestrain and improve sleep quality when you spend hours behind the screen, as they reflect between 20% and 40% of this light. They reduce exposure to blue-violet and UV light rays, while letting through turquoise light, which is good for your health. However, a study shows that their effectiveness is questionable. It's up to you!

Monofocal or unifocal glasses are designed for screen work and provide distance-appropriate visual correction, separating the eyes from the screen. These glasses allow you to see the whole screen, while minimizing up-and-down head movements.

Eye exercices :
https://youtu.be/Y2-IwPdZlWI?si=_63dOj7rHQmJE1NC

SHARED REFLECTIONS

Your future...

Studying has a different impact on everyone's life.

For some, it will be an enthusiastic experience, while for others, it will be a little more difficult. Many teenagers and young adults go through a period of denial and anger when faced with epilepsy.

When you live with this neurological disorder, the choice of studies can be a major concern, especially if you have learning problems.

Believing that nothing is possible....

If your epilepsy is not stabilized, it's true that it can be more complicated for you to project yourself into the future. Some jobs are not suitable and can be dangerous. Envisioning your future can be painful, and you may be inclined to censor yourself. However, start with your desires and then look at the contraindications. A touching and winning formula.

To facilitate the process, you need to start thinking about your abilities and limitations, which will help guide and direct your career choice.

Here are a few ideas to get you thinking:

- What are your constraints and/or limitations in relation to epilepsy?
- How might these constraints influence your decisions?
- Are your expectations and goals regarding your studies and your career choice achievable?
- Do you need special help or adaptation to achieve your goals?

Talk to people you trust.

To Each his Own Pace

To you who live with epilepsy,

Even today, epilepsy is a frightening disease, surrounded by misunderstanding and prejudice. I encourage you to take the time you need to face the diagnosis of epilepsy. Take the time to think about what it means to you to live with epilepsy, and do your best to identify the impact of the disease on your life.

I know that coping with epilepsy, its inequalities and unexpected events is a daily challenge. I'm sure that this disease will disrupt your daily routine.

I want you to know that I admire the perseverance and willpower you have shown to tame the gray areas of this disease. There's no such thing as a sure thing with epilepsy!

One thing I am sure of is that your journey is unique, because it's yours!

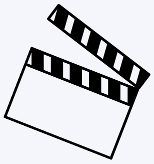
“To each his own pace.“

It's important to be indulgent with yourself and also with those around you who are also going through upheavals.

You're doing the best you can!

I'm here if you want to talk about it.

If you want to know more, check out the TONIC project!



Anie

http:// **epilepsiemonteregie.org/serie-tonic/**

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

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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