EPILEPSY AND DAYCARE

KIT FOR PARENTS AND EDUCATORS

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.

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 !

EARLY CHILDHOOD

In complete safety

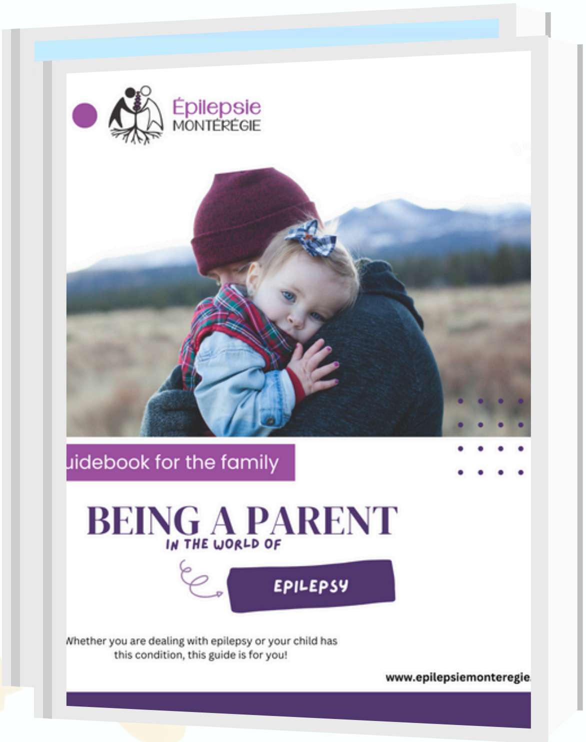
This kit is for you if you're planning to enroll your child living with epilepsy in daycare. Your child has special needs, you're worried and stressed about it, it's perfectly normal!

We're here to help!

In this document, you'll find solutions and suggestions for preparing your child's educator. With this kit, we hope to offer you a little peace of mind and contribute, in our own way, to the magic of childhood!

BEING A PARENTS IN THE WORLD OF EPILEPSY

Being a parent is the most noble and magnificent adventure of my life. My children are my treasures! Of course, I also come up against my limits and apprehensions. I imagine it's the same for you. However, when epilepsy gets involved, it's a big “WELCOME to a mysterious world of unpredictability”, isn't it? It's like living full-time with a sword of Damocles, because seizures can happen at any time, regardless of location, daily plans or safety!



Épilepsie
MONTÉRÉGIE

uidebook for the family

BEING A PARENT
IN THE WORLD OF
EPILEPSY

Whether you are dealing with epilepsy or your child has this condition, this guide is for you!

www.epilepsiemonteregie

If you'd like to read more about being a parent in the world of epilepsy, I recommend ***Being a parent in the World of Epilepsy***. The goal of this kit is to walk you through the possible emotions to unravel, and to present you with effective and helpful tools to help you cope better with this neurological disorder.

Email me at: anie@epilepsiemonteregie.org and I'll be happy to send you the document as well as more information.

It is also available on our website:
epilepsiemonteregie.org

Anie

> “Life is like climbing a staircase—each step teaches us something new.”
>
> -Melanie Klein

PLANNING

Epilepsy is an illness that often begins in children, even toddlers. Your child's daycare staff may have many questions. It's perfectly normal!

BEING WELL PREPARED

Childcare workers in family daycares have the skills and are used to welcoming and accompanying toddlers with atypical development*. However, certain complications can arise for children living with epilepsy.

Identifying your child's needs is essential to ensuring smooth integration at the daycare center.

So is **passing on information**. This preparation is necessary, and will provide peace of mind for both you and your child's educator, as well as **fostering a relationship of trust** between you and the daycare professionals.

The aim is to enable your child with epilepsy to participate safely in the activities offered by the environment.

The preparation we suggest is similar to that carried out for the start of the school year.

---

*Atypical children are those with a disorder, diagnosed or not: written language disorder (dyslexia, dysorthographia), oral language disorder (stuttering, dysphasia), hyperactivity, hypersensitivity, high intellectual potential/zebra/early, intellectual disability, attention deficit disorder, etc.

A BRIEF SUMMARY OF THE PREPARATION :

1-**Identify your allies;**
2-**Review the checklist;**
3-**Organize information about your child's epilepsy;**
4-**Transmit information to school personnel.** Establish a protocol with the teacher, nurse and principal. Ensure that information is passed on to the daycare supervisor, school bus driver, supervisors and other responsible adults. We encourage you to talk openly about your child's epilepsy and related concerns.

Journal de crises
0-17 en trois temps
0-5 ans
Épilepsie
Section
de Québec

HELPFUL DIARY

The aim of this diary is to help you to get to know your child better, and to keep track of their seizures so that you can quickly adjust treatment to optimize seizure control. It will facilitate the link and follow-up with the attending physician, pharmacist and nurse. It will also facilitate communication with those around you, while gaining their support.

This diary is your and your child's memory. Take it with you every time you visit your doctor or the emergency room.

http:// epilepsiequebec.com

Épilepsie
Section
de Québec

ALLIES

To create a safe space

Identifying your family's allies can reduce your worries about your child's safety when they are away from home. It's normal to wonder whether other adults will know how to handle a crisis, or whether they'll make the situation worse by overreacting.

The services we offer are aimed precisely at identifying and equipping your allies. **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 he or she needs the support of empathetic adults. Because episodes can occur suddenly, **staff need to be informed and supported.**

An ally is a kind, warm and reassuring person. This person listens and welcomes with as little judgment as possible. They help you to react better to uncertainties, risks and emotions.

YOUR ALLIES

Knowing them well is an important asset

EDUCATORS

A positive influence in your little treasure's life!

They are there to take care of your child. You need to give them the right tools and make sure they know what to do in a crisis.

The educator will speak softly to your child, maintain contact and provide a comforting, reassuring presence. This will enable your child to better situate the pre- and post-crisis periods.

OUR TEAM

Épilepsie Montérégie offers support, access to reliable information on epilepsy, listening, workshops, tools, tips, activities, sharing and more. The more you know, the more confident and capable you are as a family!

CHECKLIST ✓

Crisis needs :

- Detailed information on the child’s epilepsy;
- If your child has a seizure, they may need to rest afterwards. Is it possible to have a place to do this?
- Bring a change of clothes in case a seizure occurs during the day and there's a little damage.

List of typical epilepsy items to include in the backpack :

Small first-aid kit including :

- Detailed information on the child's epilepsy;
- A copy of the detachable form;
- Medical bracelet (on wrist or necklace);
- Magnet for vagus nerve stimulator;
- Medication to be given if necessary;
- Memory card (crisis intervention protocol);
- Sunscreen (increased photosensitivity with certain medications);
- Cap or hat (some children need to wear glasses - photosensitivity);
- Change of clothes;
- Other items.

APPENDIX

My child's epilepsy : Signs and symptoms

Did you know ?

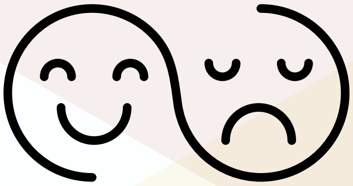
A sign is a clinical characteristic of an illness or condition that the doctor looks for and measures. **A symptom** is something your child feels or complains about.

YOUR CHILD IS AN EXPERT IN REGARDS OF THEIR 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 ______________________________



APPENDIX

My child's epilepsy : Signs and symptoms

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 ______________________________

A calm and reassuring presence is important !

REMOVABLE

APPENDIX

My child's epilepsy : Signs and symptoms

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!

Épilepsie Montérégie remains available for any further questions or to offer you the support you need. We look forward to hearing from you!

REMOVABLE

THE FORM

TO BE GIVEN TO THE PERSON IN CHARGE

NAME :

AGE :

PHONE NUMBER :

PARENT :

→ **My child's epilepsy looks like :**

→ **Possible triggers (if known) of a seizure for my child :**

→ **A list of symptoms that precede or follow my child's seizures:**

Precede :

Follow:

→ **Information about my child's medication :**

Épilepsie MONTÉRÉGIE

For more information : epilepsiemonteregie.org

REMOVABLE

THE FORM

TO BE GIVEN TO THE PERSON IN CHARGE

NAME :

PHONE NUMBER :

TYPE OF EPILEPSY :

→ **Support needed following the episode :**

→ **Describe what you think constitutes an emergency for your child. When to call the parent :**

→ **Other necessary information :**
Does your child have difficulty expressing feelings, asking for help or initiating conversation? Does he/she adapt easily to new people, activities or experiences?

Épilepsie Montérégie

For more information : epilepsiemonteregie.org

FOR THE EDUCATORS

This information is for you if you have a child living with epilepsy in your daycare. They may have special needs, and you may have concerns and questions. It's perfectly normal! In the next few pages, you'll find some ideas and suggestions for working together with parents.

With this information, 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.

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.**

There are several types of epilepsy

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.

Here are a few types:

- **The person's body stiffens, he falls to the ground and his body begins to shake;**
- **The person seems to stare into space for 6 to 7 seconds, then quickly resumes activity;**
- **The person begins to speak incoherently and seems to stagger, but does not fall to the ground.**

*Association Québécoise de l'épilepsie

Events for the little ones :

- Epileptic seizures in children can be relatively discreet:
    - Short break in contact (a few seconds to a few minutes);
    - Immobility of gaze (fixed) ;
    - Spasms ;
    - Loss of muscle tone;
    - Incomprehensible words spoken.
- The baby may be calm before and during the seizure, or may cry between spasms;
- **After a seizure, the child may be exhausted, moody or more alert.**

Here's a video showing an example of an epileptic seizure. The aim for parents is simply to raise awareness among people in the same situation and their loved ones.

- **Infantile spasms, epilepsy, 15 months;**
- Childhood epileptic seizures, 3 years and 8 months.

https://www.youtube.com/@toutpartdemoi/videos

Crisis triggers :

- High fever ;
- Fatigue, (lack of sleep) ;
- Strong emotion ;
- Other symptoms.

Here are some words that encourage self-regulation ex. “It's time to calm down”, “Try to think about something else”, “Count to five, then breathe out”, etc.

How to recognize 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

The generalized tonic-clonic seizure occurs in two phases:

- The tonic phase consists of a contraction of all the muscles, sometimes causing the tongue to bite. It may also be accompanied by a scream.
- The clonic phase is characterized by limb tremors and diffuse, irregular, involuntary muscle contractions.

EPILEPSY

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.

Explain...

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.

TALKING ABOUT EPILEPSY WITH YOUR TODDLER

Epilepsy is a disease that affects the brain!

The brain is the boss of your body and controls everything you do! Scratch your nose, talk to your friends or kick a ball around.

Our brain sends messages to our body. When we live with epilepsy, sometimes the messages get mixed up and a seizure occurs.

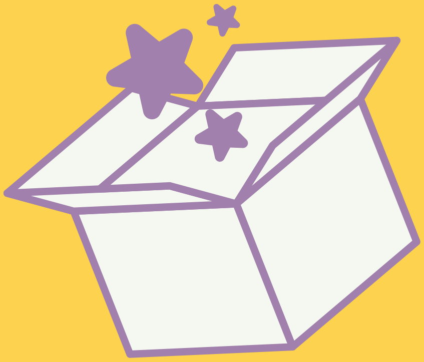
It's like a storm in the head! A big storm and then you lose control of your body. You're in the moonlight and can't move.

When this happens, you need to see a doctor and take medication to help you stay strong and healthy.

PSSST..... IT'S NOT CONTAGIOUS! YOU CAN'T CATCH IT LIKE A COLD.

MY TOOLBOX

EPILEPSIE IN PICTURES !



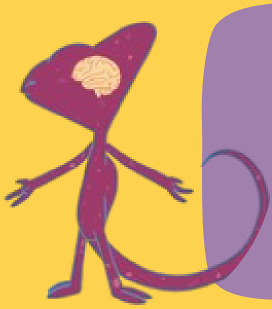
The plasma ball lamp
represents electricity
in the brain!
It's a must-have!

Un orage dans ma tête

L'épilepsie

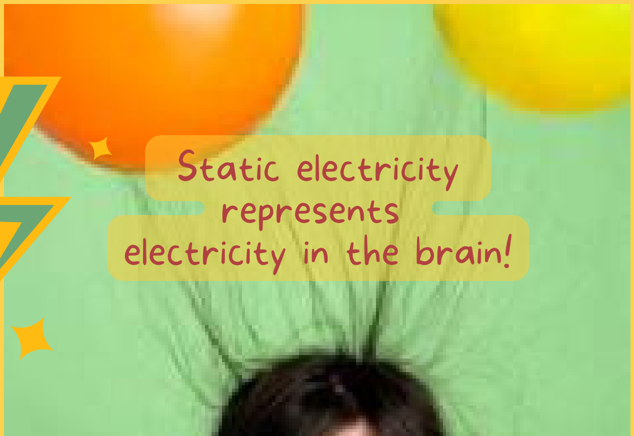
Bricolage !

Cauliflower or cabbage
represents the brain!



[The video Tic Doc about epilepsy (french content) :](https://www.tfo.org/regarder/lepilepsie/GP139586)

https://www.tfo.org/regarder/lepilepsie/GP139586



Static electricity
represents
electricity in the brain!

INDEX

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

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.

WELCOMING EARLY CHILDHOOD

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