

LIVING WITH EPILEPSY IN DAY CAMPS

A KIT FOR THE PARENTS

Épilepsie MONTÉRÉGIE

Summer 2023

SUMMER IS COMING!

ENJOYING YOURSELF SAFELY

This kit is for you if you are planning to enroll your child in a day camp or summer camp and your little one has epilepsy. They have special needs, and this causes you concern and stress, which is completely normal!

We are here to support you!

In this document, you will find possible solutions and suggestions for preparing day camp counselors. With this kit, we hope to offer you some peace of mind and contribute, in our own way, to the magic of summer!



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 !

PLANNING

Prepare well

To ensure a smooth transition into day camp, it is essential to identify your child's needs. Sharing this information is also important. **This preparation is necessary and will provide peace of mind for both you and your child's counselor.**

The goal is to enable your child, who lives with epilepsy, to safely participate in the sports, cultural, and outdoor activities offered at summer camps and day camps.

The preparation we offer is similar to that done for the start of the school year.



PREPARATION IN A NUTSHELL

1. **Identify your allies;**
2. **Organize information about epilepsy** (see attached sheets—what is epilepsy, what is a seizure, what is the treatment for my child, what to do in case of a seizure, etc.);
3. **Go through the checklist;**
4. **Pass on the information to those in charge.** Establish a protocol with those in charge, which means: talk openly about your child's epilepsy and any concerns you and your child may have. Suggest a workshop offered by the organization Épilepsie Montérégie.

ALLIES

CREATING 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!

COUNSELLORS



A positive influence in the life of your little treasure!

They are there to take care of your child. It is therefore important to give them the right tools to do so and to ensure that they know what to do in the event of a seizure. In addition, your child may be tempted to hide their epilepsy or may be anxious about having a seizure. The reassuring presence of their counsellor is necessary.

Discuss with your child a plan of action, a way to talk about it with the counselor.



A HEALTHY, WELL-BALANCED LIFESTYLE

A healthy and balanced lifestyle (sleep, diet, and being active).

Try to maintain regular bedtimes and mealtimes to minimize the stress and fatigue caused by activities. Fatigue can increase the risk of seizures for some children. Kids living with this neurological disorder need plenty of sleep.

YOUR ALLIES

Knowing them well is an important asset!

YOU



It's a challenge to be a good parent! Even if your child has epileptic seizures, he or she should not be overprotected. However, overprotecting your child in the world of epilepsy could make him or her feel vulnerable or dependent on others, and could eventually affect his or her self-esteem. Your child needs to explore his or her environment. Activities can be adapted according to the degree of risk. By wanting to avoid the slightest injury, pain or ordeal at all costs, you are over-protecting your child.

Invite your child to take part in discussions about his or her epilepsy experience. It's also a way of giving him back his power after a seizure.

For his or her development, it's a good idea to encourage your child to try out new experiences that will greatly boost his or her self-esteem and self-confidence.

Praise them for their perseverance and efforts!

OUR TEAM





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

We also provide information sessions!

CHECKLIST

Safety in sports :

- Ask your doctor if there are any activities your child should avoid for their safety.
  - Reading (french content) : CHU, Safety management in sports

Crisis needs :

The school nurse is responsible for informing school staff about the various illnesses. Generally, a meeting is organized to explain the different characteristics of epilepsy, i.e. how to recognize a seizure and how to manage it. This meeting should be for all school staff, since seizures can occur at any time and in any place.

To plan ahead :

- Detailed information on child's epilepsy;
- If your child has a seizure, they may need to rest afterwards. Ask if it possible to have a place to rest?
- Provide a change of clothes in case a seizure occurs during the day and there's a little damage;
- Suggestion: You can agree with your child on a key word to be spoken if they sense a crisis coming, so that you can intervene immediately and inform those in charge.

List of typical epilepsy items :

Small first-aid kit includes :

- Detailed information about the child's epilepsy;
- A copy of the detachable form;
- The medical bracelet (worn on the wrist or neck);
- The magnet for the Vagus Nerve Stimulator;
- Medication to be administered as needed;
- The memory card (action plan in the event of a seizure);
- Sunscreen (increased photosensitivity with certain medications);
- Cap or hat (some children must wear sunglasses—photosensitivity);
- Change of clothes;
- Other items.

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

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 :

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?



For more information : epilepsiemonteregie.org

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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 _____



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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 !

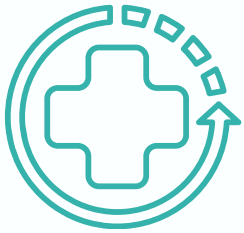
REMOVABLE

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

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

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.



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





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

Remember to NOTE the start and end times of the 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.



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.

HAVE A GREAT SUMMER!

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