



Epilepsy Checklist



What do you know about your child's epilepsy?

Your child

has been diagnosed with epilepsy. Epilepsy is a common neurological disorder that affects about one in every 100 people. Someone who has repeated seizures is considered to have epilepsy.

This checklist will help you to access the information and support you need to manage your child's epilepsy. It will help you ask the right questions about:

- Your child's epilepsy care team
- Diagnosis and investigations
- Seizures
- Treatment options
- Anti-epileptic drugs
- Living with epilepsy
- Managing epilepsy in a school or day care
- Accessing information and support



Your Child's Epilepsy Care Team



There are many health care professionals available to support you as you learn to manage your child's epilepsy.

- Neurologist
- Clinical nurse specialist
- Neuropsychologist
- Primary care doctor
- Social worker
- Psychiatrist
- Nurse practitioner
- Pharmacist
- Neurosurgeon
- Epilepsy clinic nurse
- Dietitian

Who becomes a part of your child's epilepsy care team will depend on the needs of your child and family.

DO you
KNOW...

- Who is part of your child's epilepsy care team
- How to contact the team members



Diagnosis and Investigations



Tests and investigations are done to confirm the diagnosis of epilepsy and to help determine what has caused the epilepsy. Note that sometimes we cannot find a cause for a child's epilepsy.

DO
KNOW...
you

- What caused your child to have epilepsy**
- What tests and investigations your child has had (e.g., EEG, MRI, genetic tests)**



Seizures



A seizure is caused by a sudden electrical disturbance in the brain. The type and frequency of seizures, triggers for seizures and the care required for a seizure is different for every person.

DO
KNOW...
you

- What type or types of seizures your child has**
- What to do if your child has a seizure**
 - Seizure safety
 - When and how to give emergency medication
 - When you should call 911
- When you should call your child's neurologist or neurology clinic nurse**
- How to record a seizure**
 - What information is important to record
 - How to describe a seizure
- What might trigger your child's seizures or make them worse**
- If your child could die from a seizure**
 - What is SUDEP?
 - Should I learn how to do cardiopulmonary resuscitation (CPR)?
- How you will know if your child has a seizure at night**
- If your child will outgrow his or her seizures**



Treatment Options



There are a variety of treatment options available to manage epilepsy.

**Do you
KNOW...**

- The epilepsy treatment options available for your child**
 - Medication
 - Surgery
 - Ketogenic diet
- What treatment has been recommended for your child**
- What will happen if the current treatment option is not working**
- If it is safe to give your child complementary or alternative treatments such as vitamins, supplements or homeopathic/naturopathic remedies**



Anti-Epileptic Drugs (AEDs)



Most children diagnosed with epilepsy are treated with anti-epileptic drugs (AEDs). How well the AEDs work, the side effects and the number of drugs required to treat epilepsy varies from child to child. The goal of treatment with AEDs is to maximize the control of seizures while causing no or few and mild side effects.



- The name and dose of your child's AEDs and when they need to be given**
- Why it's important for your child to take AEDs as prescribed**
- Why AEDs are introduced and withdrawn gradually**
 - What is the titration (increasing) schedule?
 - What is the weaning (decreasing) schedule?
- The possible side effects of the AEDs your child is taking**
 - Common side effects
 - Side effects you should be worried about
 - If the side effects go away
 - What you should do if your child experiences any side effects
- If your child needs to have his or her blood checked while taking an AED**
- What to do if your child:**
 - Misses a dose of medication
 - Takes too much or too little medication
 - Is vomiting or has diarrhea
- What medications or supplements or homeopathic remedies might interact with your child's AEDs**
- How AEDs can affect other medications**



Living with Epilepsy



Living with epilepsy involves much more than simply trying to manage seizures. Children with epilepsy often face challenges that other children do not. When a child is diagnosed with epilepsy, it is important for families to find ways to cope with how epilepsy impacts their lives. They need to ensure their child is safe, but still has a good quality of life.



What safety precautions are needed for your child while:

- At home
- At school or day care
- Playing sports
- Participating in community activities
- Traveling

If there are any limitations on what your child can do

If your child should wear a MedicAlert bracelet

- How do I get one?

Who should know that your child has epilepsy

What you should tell others about your child's epilepsy

How to talk to your child about his or her epilepsy

How to promote independence in your child while still keeping him or her safe

How to deal with the impact epilepsy has on your child's:

- Emotions and mood
- Behaviour
- Social interactions

Where you can find support to help you, your child and your family cope with your child's epilepsy

Managing Epilepsy in a School or Day Care



A large part of a child's day may be spent at school or in a day care. Ensuring that your child can be safely cared for in these environments is important.



- What to tell the school or day care about your child's epilepsy**
- What will happen if your child has a seizure at school or day care**
 - What is the safety and management plan?
 - How will classmates be prepared?
 - What if your child gets teased about having seizures at school?
- How epilepsy impacts your child's:**
 - Learning
 - Behaviour
 - Interactions with peers
- What special accommodations your child will need at school or in the day care**
- What you can do if your child is not getting the support he or she needs at school**



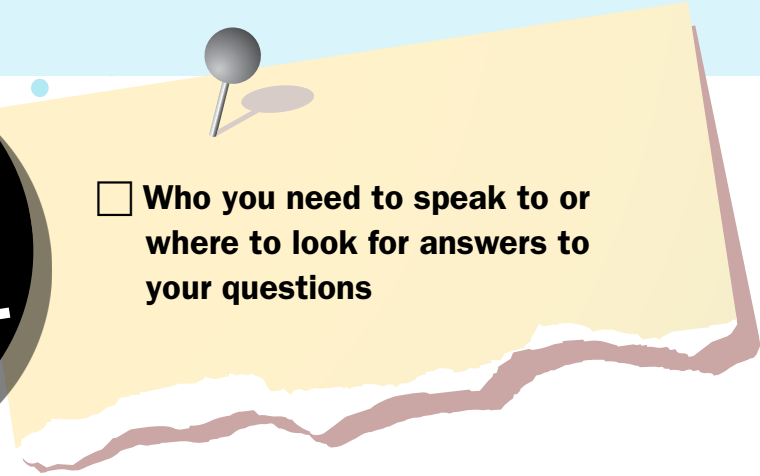
Accessing Information and Support



There are many people, community agencies and websites that can offer you information and support about epilepsy.

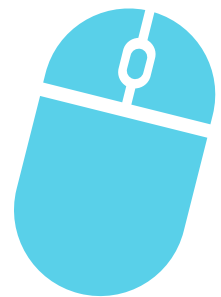


DO YOU KNOW...

- 
- Who you need to speak to or where to look for answers to your questions

Have you checked out these websites?

- AboutKidsHealth Epilepsy Learning Hub – www.aboutkidshealth.ca/epilepsy
- Epilepsy Ontario – www.epilepsyontario.org
- Epilepsy Canada – www.epilepsy.ca
- Epilepsy Toronto – Children and Youth Services – www.epilepsytoronto.org
- Canadian Epilepsy Alliance – canadianepilepsyalliance.org
- Epilepsy Action – kids.epilepsy.org.uk
- Epilepsy Foundation – www.epilepsy.com
- MedicAlert – www.medicalert.ca
 - StudentsFIRST
 - No Child Without
- Online seizure diaries
 - Seizure Tracker – www.seizuretracker.com
 - My Epilepsy Diary – diary.epilepsy.com
- SUDEP Aware – www.sudep.news





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