



Epilepsy Checklist



For Teens

What do you know about your epilepsy?

You have been diagnosed with epilepsy. Epilepsy 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 epilepsy. It will help you ask the right questions about:

- Your epilepsy care team
- Seizures
- Anti-epileptic drugs
- Managing epilepsy at school
- Diagnosis and investigations
- Treatment options
- Living with epilepsy
- Accessing information and support



Your Epilepsy Care Team



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

- Neurologist
- Paediatrician/family doctor
- Nurse practitioner
- Neurology clinic nurse
- Social worker
- Pharmacist
- Others depending on your needs (e.g., dietitian, neuropsychologist, psychiatrist, neurosurgeon)

Who becomes part of your Epilepsy Care Team will depend on your needs.

**Do you
KNOW...**

- Who is part of your 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 person's epilepsy.

DO you
KNOW...

- What tests and investigations you have had (e.g., EEG, MRI)
- What caused you to have epilepsy



Treatment Options



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

**Do you
KNOW...**

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

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 you
KNOW...**

- What type or types of seizures you have**
- What your seizures look like and how long they usually last**
- What you should tell people to do if you have a seizure**
 - Seizure safety
 - When and how to give emergency medication
 - When to call 911
- When you should call your neurologist, nurse practitioner or neurology clinic nurse**

Seizures



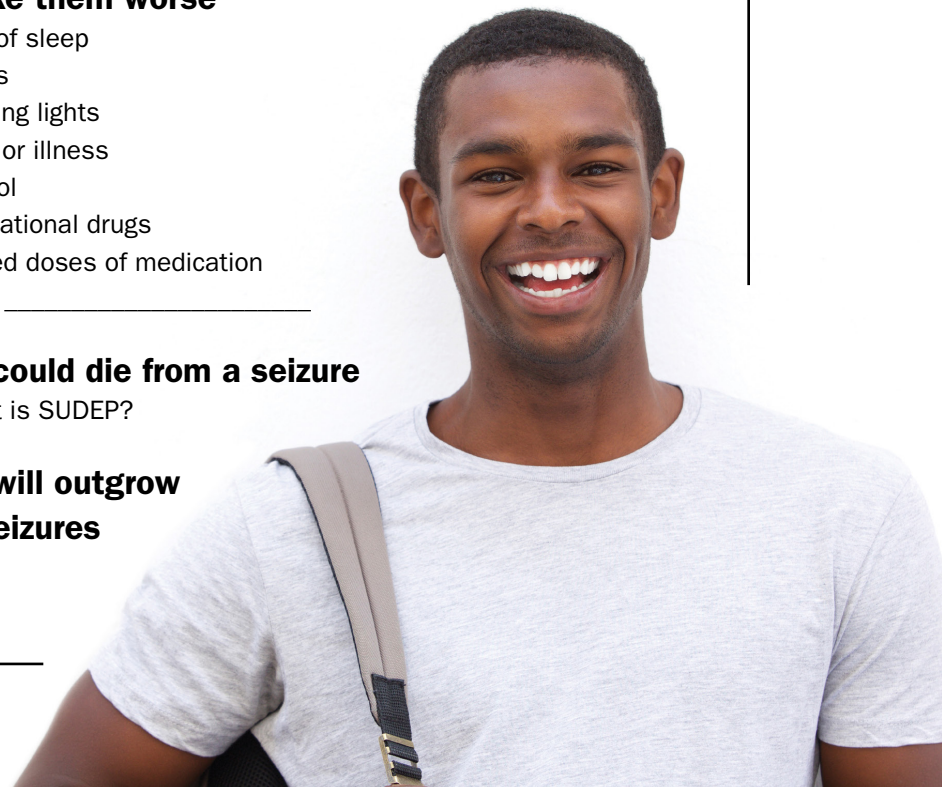
Do
KNOW...
you

- How to record a seizure**
 - What information is important to record
 - How to describe a seizure

- What might trigger your seizures or make them worse**
 - Lack of sleep
 - Stress
 - Flashing lights
 - Fever or illness
 - Alcohol
 - Recreational drugs
 - Missed doses of medication
 - Other _____

- If you could die from a seizure**
 - What is SUDEP?

- If you will outgrow your seizures**



Anti-Epileptic Drugs (AEDs)



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

**Do
KNOW...**
you

- The name and dose of your AEDs and when you should take them**
- Why it's important for you to take AEDs as prescribed**
- Why AEDs are introduced and withdrawn gradually**
 - What is the titration (increasing dose) schedule?
 - What is the weaning (decreasing dose) schedule?
- The possible side effects of your AEDs**
 - What are the common side effects?
 - What are the side effects I should be worried about?
 - Will the side effects go away?
 - What should I do if I experience any side effects?

Anti-Epileptic Drugs (AEDs)



Do you
KNOW...

- If you need to have your blood checked while taking an AED
- What to do if you:
 - Miss a dose
 - Take too much or too little medication
 - Are vomiting or have diarrhea
- What medications or supplements or homeopathic remedies might interact with your AEDs
- How AEDs can affect other medications



Living with Epilepsy



Living with epilepsy involves much more than simply trying to manage seizures. Teens with epilepsy often face challenges that other teens do not. What's safe for me to do? What's not safe for me to do? When you are diagnosed with epilepsy, it is important to find ways to cope with how epilepsy impacts you and make the adaptations necessary to ensure that you are safe but still enjoy life.

**Do you
KNOW...**

What safety precautions are needed for you while:

- At home
- At school
- Playing sports
- Participating in community activities or working at a job
- Traveling

What limitations you might have on:

- Driving
- Playing sports
- Drinking alcohol

What impact recreational drugs can have on your epilepsy

If you should wear a MedicAlert bracelet

- How to get one

Living with Epilepsy



DO you
KNOW...

- Who should know that you have epilepsy**
 - Family members
 - Teachers, school principal
 - Coaches
 - Friends
 - Employers and co-workers

- What to tell people about your epilepsy**

- How to deal with the impact epilepsy has on:**
 - Relationships with family and friends
 - Emotions and mood
 - Do you feel angry, sad or worried a lot?

- How epilepsy and its treatments might impact your sexual health**
 - Relationships, dating
 - Hormones
 - Birth control
 - Menstruation
 - Sexual function
 - Pregnancy
 - Reproduction and fertility

- Where you can find support to help you cope with your epilepsy**



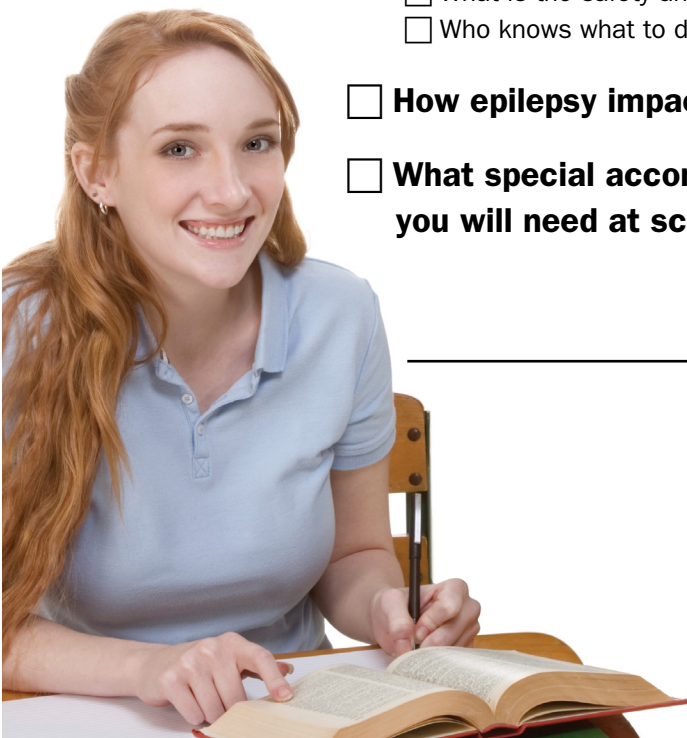
Managing Epilepsy at School



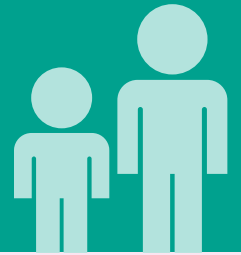
A large part of your day is spent at school. Ensuring that you can safely participate at school is important.

DO you
KNOW...

- What to tell the school about your epilepsy**
- What will happen if you have a seizure at school**
 - What is the safety and management plan?
 - Who knows what to do if I have a seizure?
- How epilepsy impacts your learning**
- What special accommodations you will need at school**



Becoming an Adult with Epilepsy



Many teens with epilepsy continue to have epilepsy as adults.
What does the future hold for you?

DO
KNOW...
you

- How adult epilepsy care is different from paediatric epilepsy care**
- What you need to do to prepare yourself for epilepsy care as an adult**
- Where you will receive adult epilepsy care**
- What your options are for:**
 - Post-secondary education
 - Employment
 - Living independently



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 Foundation – www.epilepsy.com
 - MedicAlert – www.medicalert.ca
 - StudentsFIRST
 - Online seizure diaries
 - Seizure Tracker – www.seizuretracker.com
 - My Epilepsy Diary – diary.epilepsy.com
 - Got Transition – <https://gottransition.org/resources-and-research/youth-and-families.cfm>
 - SUDEP Aware – www.sudep.news
- 



Developed by the SickKids Comprehensive Epilepsy Program

Photography is being used for illustrative purposes only and any person depicted in the Content is a model.