

Coordinated Care for People with Epilepsy

clinictocommunity.ca info@clinictocommunity.ca

Epilepsy Program at Children's Hospital of Western Ontario (London)

The Comprehensive Epilepsy Clinic (CEC)

The Comprehensive Epilepsy Clinic is a specially designed clinic as part of the Paediatric Epilepsy Program at the London Health Sciences Centre for children with Drug Resistance Epilepsy (DRE) or medically refractory epilepsy (meaning medication is not successful at controlling seizures).

The clinic provides advanced treatment alternatives, including the ketogenic diet, new medications, and surgical options.

The program aims to provide comprehensive, family centred care for children with severe epilepsies and to act as a Regional Centre of Excellence for epilepsy surgery. The CEC strives to support, advocate for, and inspire patients and their families.

The Team

The medical staff at the CEC consist of epileptologists, neurologists, medical geneticists, neurosurgeons, epilepsy fellows, neuropsychologists, registered nurse, paediatric EEG technologist, registered dietician, a child life specialist, social worker, transition specialist, and shared decision making coach.

- An epileptologist is a neurologist who has specialized training and experience in the management of epilepsy. After an initial consultation with you and your child, an individual plan of care is established.
- A medical geneticist is a doctor who specializes in genetic or inherited conditions. They use and interpret genetic information for the diagnosis and management of rare genetic diseases in individuals and provide counseling to their families about prognosis, implications for other members, recurrence risks, family planning, etc.
- The neurosurgeon is a surgeon who has had special training in brain surgery.
- A fellow is a paediatric neurologist who is getting additional formal training in epilepsy.
- A neuropsychologist provides comprehensive assessment of your child's thinking skills (intelligence, attention, learning, memory, language, visual-spatial skills, fine motor skills) and academic skills, as well as examination of their behaviour, emotions, and social skills.

- The registered nurse actively participates with your child's epilepsy team by acting as a liaison between you and your child's epilepsy team members and partners with community agencies to assist in addressing your child's relevant needs in the community.
- An electroencephalographic (EEG) technologist is a trained medical professional who uses specialized equipment to locate electrical brain abnormalities.

Location:

Zone B, 2nd floor (Smile Zone) Paediatric Medical Day Unit Victoria Hospital 800 Commissioners Rd. E. London, Ontario

Contact:

Telephone: 519-685-8332 Fax: 519-685-8350

- Within the epilepsy team, the registered dietitian manages and follows patients who are on the ketogenic diet.
- The child life specialist suggests coping techniques for procedures such as distraction, deep breathing and relaxation techniques.
- Families may benefit from discussing emotional, financial, family and other related concerns with a social worker as you try and understand, adjust, and cope with an epilepsy diagnosis and treatment.
- A transition specialist assists youth and their family with preparing a Transition Plan that incorporates funding supports and community based programs before entering the adult health care system.
- The decision making coach is available to help families in their decision making process for topics such as: medications, procedures, tests, and surgeries.

Referrals

Referrals to the CEC are for children with Drug Resistant Epilepsy (DRE) from paediatricians, family doctors, nurse practitioners, and paediatric neurologists. If you require a referral, please visit Referral Form (Ihsc.on.ca).

Treatment Options

Treatment options range from medications, Vagus Nerve Stimulators (VNS), ketogenic diet, and /or brain surgery.

Paediatric Epilepsy Monitoring Unit (PEMU)

The Paediatric Epilepsy Monitoring Unit monitors children to assist with diagnosing suspected epilepsy, assesses those with current epilepsy, and looks at potential surgical options. Children who are to have prolonged video EEGs are admitted to the PEMU at the Children's Hospital, LHSC. This will help neurologists and doctors to better understand the events or seizures your child has. This test may take several days, anywhere from one (1) day to one (1) week.

Preparation

- Wash your child's hair prior to going to the hospital.
 Refrain from using conditioner or hair products, as this may prevent the electrodes from sticking.
- Bring shirts that have a button or zipper in the front to allow for the EEG leads.
- Bring comfort items, such as games, toys, or electronics to keep the child occupied. Internet and television are available in the room.

- Meals will be provided; there is also a pantry, fridge, microwave, and toaster for the accompanying adult(s).
- You will be notified if medications need be changed.

What Happens to Your Child Whilst in Hospital?

- After registering your child on B2, you will be directed to the EEG department, where EEG technicians will attach electrodes to your child's head with a paste and secure them with a bandage. The leads are attached to a small computer that is portable and your child will carry it around in a small pouch.
- The EEG tech will assist you and your child to the EMU bed on B6-200 where instructions on using the seizure trigger device and how to record any events will be provided.
- Once the recording begins, your child will need to stay in their room with the video camera and microphones that are attached to the EEG machine.
- A doctor from the neurology team will admit your child and answer any questions as best as they can.
- The healthcare team will respond to any seizure or medical events, following the safety plans that are in place.
- Your child will be able to behave as usual, eat, sleep, and play.
- Your child can have sponge baths only and should stay in view of the camera at all times, except when using the washroom.

One parent or caregiver must always stay with your child (only one caregiver at the bedside). A bed is available for you to sleep on in the room and the Ronald McDonald house on the outpatient floor has facilities available for use (shower, kitchen, etc...).

For any questions, please contact the Neurology Office at the LHSC at 519-685-8332.







