

# Doctors who Treat Epilepsy

An initial diagnosis of epilepsy will probably come from your family doctor or paediatrician. While they can diagnose and treat epilepsy, all children with serious, ongoing epilepsy should be seen by a paediatric neurologist. The neurologist may then refer the child back to the paediatrician for ongoing therapy. For a teenager, you may want to consider a neurologist who treats adults. A list of neurologists and paediatric neurologists with phone numbers can be obtained from your local epilepsy organization.

In a majority of cases, the medical treatment of epilepsy goes well. Occasionally, parents may feel that they want a second opinion about their child's condition. If you ask, most doctors will be very willing to refer your child for a second opinion. It is a good idea to consult the doctor who is currently treating your child before seeking a second opinion. Working in partnership with your doctors will help to achieve the best care for your child.

## Choosing a Neurologist

- ∅ Ask a doctor you respect — your family doctor or paediatrician — to recommend a neurologist.
- ∅ Find out what hospital affiliation the neurologist has. If possible, you may want your child to be treated by a doctor affiliated with one of the teaching hospitals.
- ∅ Look for a neurologist with whom you feel you can talk, who answers your questions and who is willing to seek a second opinion if necessary.
- ∅ Become a member of your local epilepsy organization and attend awareness events where you can talk with local neurologists and parents of the children they treat.
- ∅ Remember, you can be referred to a neurologist only by another doctor.

## How You can Help your Doctor

Doctors need to determine the type of seizures your child has before they can prescribe the right medication or other treatment. Because they often do not actually see the seizures, they rely on your description to distinguish among the possible seizure types. The better you describe the seizures, the better your doctor's diagnosis will be.

- ∅ Keep written records. Your local epilepsy organization can provide check lists for this purpose.
- ∅ Use a video camera. A recording of your child's seizures may help your doctor. Your local epilepsy organization may be able to assist with this.

## Preparing for your Appointment with the Doctor

Your appointment with the doctor will go better if you make some preparations in advance.

- ∅ Confirm your appointment time earlier that day so you are not inconvenienced.
- ∅ If your child is to have diagnostic tests, such as a sleep-deprived EEG, make sure that you understand the doctor's instructions and follow them carefully.
- ∅ Make written notes before your visit so that you will not forget the questions you want to ask. If your appointments with the doctor are rushed, you might even send your questions ahead of time in letter so that the doctor has a chance to consider them.
- ∅ Bring all of your child's medications (in the bottles) and dose schedule to the appointment. You should also have a medication calendar in which you record any untoward events that have happened and blood levels if you know them.
- ∅ Be prepared to give the doctor your pharmacy's phone number.
- ∅ Bring to the doctor's attention any problems that have occurred, even if you feel that they are trivial. Any change in your child's status may be relevant.

## Questions the Doctor may Ask You

In addition to your child's full medical history, you should try to be ready to answer the following questions.

- ∅ What was your child doing at the time of the seizure?
- ∅ What was the exact time of day?
- ∅ What took place before the seizure?
- ∅ What called your attention to the seizure (cry out, fall, stare, turn the head)?
- ∅ Did your child's body become rigid?
- ∅ Were there jerks or twitches? What part of the body moved first? Next?
- ∅ Did your child's eyelids or eyes roll? To which side?
- ∅ Did your child's skin show changes (flushed, clammy, blue, etc.)?
- ∅ Did the breathing change?
- ∅ Did your child talk or perform any actions during the seizure?
- ∅ Did your child urinate or defecate during the seizure?
- ∅ How long did the seizure last? Time the seizures with a watch or clock. This is difficult to remember during a seizure, but it helps the doctor.
- ∅ Could you make contact with your child during the seizure? Did s/he respond?
- ∅ What was your child's behaviour after the seizure (alert, drowsy, confused, fearful, any memory of what happened, etc.)?
- ∅ Did your child report any unusual feelings, sensations or perceptions which occurred before the seizure?
- ∅ If your child is taking medication, when was the last dose?

## **Clinical Programs for Children with Epilepsy**

With appropriate medication, the majority of seizures can be controlled. Some types of seizures, however, resist control by anticonvulsant medication. Sometimes, these seizures are associated with developmental delay or with behavioural problems.

If your child continues to have seizures despite good medical treatment, your doctor may wish to refer him or her to a centre which specializes in the treatment of drug-resistant epilepsy. Many major centres across Canada have clinics and hospitals which treat childhood epilepsy. Information about the various programs may be obtained from your doctor or from your local epilepsy organization. To be admitted, your child must be referred by a medical doctor.