Recommendations for Care of Children with Epilepsy

Seeking the best treatment from the right doctor at the right time!
This booklet is to help parents and caregivers know when it is appropriate to seek treatment for a child experiencing seizures. For additional resources about epilepsy and tools to help manage your child’s condition, please visit www.epilepsyandmychild.org.
What Type of Doctors Treat Children with Epilepsy?

There are several types of doctors who treat epilepsy. For many children, epilepsy can be treated and successfully managed by a primary care physician, a family physician, or a pediatrician. This is often the case for those whose seizures are well controlled on one medication or who live in rural areas and must travel for hours to see an epilepsy specialist.

Most children with epilepsy under the age of 16 are treated by a pediatric neurologist. A pediatric neurologist specializes in childhood diseases of the brain, spinal cord, and nervous system. A pediatric neurologist learns about treating epilepsy in children and is involved in their care during residency.

A pediatric epileptologist is a neurologist who completes a one or two year subspecialty fellowship in clinical neurophysiology and/or epilepsy in addition to the training in epilepsy that a pediatric neurologist receives. A pediatric epileptologist typically has a medical/clinical practice which predominantly cares for children with epilepsy.

Epilepsy centers have epileptologists, psychologists, pharmacists, nurse-clinicians, nurse educators and other specially trained professionals to work with patients and their families to provide the services needed for optimal epilepsy care.
Children with New Onset Seizures

• Every year about 120,000 children in the United States experience their first seizure and 45,000 of them will be diagnosed with epilepsy. While seizures are most likely to begin in the first year of life, one percent of people in the U.S. will be diagnosed with epilepsy by age 20.

• Approximately 25-30% of seizures in children are caused by a sudden illness, brain infection (encephalitis) or spinal fluid infection (meningitis). This figure does not include febrile seizures, which are caused by a rapid rise in temperature (102 or higher) and most common in children around 18 months of age. Occurrence of febrile seizure(s) does not mean your child has epilepsy.

• Epilepsy is diagnosed when a child has recurring seizures and a significant risk of seizures in the future.

• If your child experiences a first seizure, he or she should be treated immediately in an ER. A physical examination and an assessment of cardiac, neurological and mental status are important. An eyewitness account of the seizure helps the doctor determine if your child has experienced an epileptic seizure.

• The ER physician may order a CT (computed tomography) scan to identify any brain abnormalities and blood tests for electrolytes (sodium and potassium), white blood cell count, glucose and calcium levels will help determine if a significant illness may have caused your child’s seizure. A lumbar puncture (spinal tap) may also be required if your child has an unexplained fever.

• You should follow up with your child’s primary care physician or pediatrician after a first seizure with no apparent cause, or a seizure resulting from a fever.

• An EEG (electroencephalograph) is a test that records the electrical activity created by the brain. One should be performed to evaluate children after their first unprovoked seizure to look for abnormal electrical discharges. This will help determine if it was an epileptic seizure.
• MRI (magnetic resonance imaging) is the preferred method of evaluating children with new onset seizures, especially if there are signs that the seizures start in a particular part of the brain.
• If seizures recur despite treatment with antiepileptic medication, your child should be referred to an epilepsy specialist as soon as possible.
• If a diagnosis cannot be made, get a referral to an epilepsy center.
Children Taking Epilepsy Medication

- Approximately 70% of children with epilepsy can have their seizures controlled with the use of antiepileptic medication. Side effects of seizure medications need to be reviewed in order to find the medication that offers the best seizure control with minimal side effects.
  - To control your child’s seizures, medications need to be taken as specifically prescribed every day.
  - Sleep and diet are also important for seizure control. A good night’s sleep, eating regularly and avoiding unusual stress or getting severely overheated will maximize seizure control in children. Regular medical evaluations and follow-up visits are important to monitor your child’s blood levels and medication. However, seizures may occur even when someone is doing everything he or she is supposed to do.
• Regular exercise and safety are important for any child’s health and well-being. Children with epilepsy should sleep on the bottom bunk when using bunk beds. Helmets are recommended for all children when riding bikes and skateboards. Children with epilepsy should engage in sports or recreational activities such as swimming or climbing with a buddy who is aware of their seizures and could help if needed.

• Most medications are well tolerated by children, but some children do experience side effects such as dizziness, fatigue, headaches, unsteadiness/balance issues, and weight gain or loss. Difficulty concentrating in school or remembering things may be a side effect of the medication, or it could be related to the child’s epilepsy. Speak to your doctor if your child is having side effects that impact his or her ability to learn or you see a change in normal behavior patterns. An adjustment in dosage or a change of medication may eliminate these side effects.

• Depression and attention difficulties are sometimes experienced by children with epilepsy. If your child shows signs of depression or other mood disorders and/or attention difficulties, please ask your doctor for a referral to a neuropsychologist or psychiatrist who can treat these conditions, if they do not appear to be directly related to introduction of a specific antiepileptic medication.

• If your child is being treated by a primary care physician, pediatrician or pediatric neurologist and seizures recur or your child is experiencing side effects that negatively affect quality of life, you should speak to the physician who is treating your child and request a referral to an epilepsy center. If treatment is already being coordinated by an epilepsy center, a discussion with your specialist about medication options and treatment alternatives is in order. To learn more about medication side effects and treatment options, go to www.nomoreseizures.org.
Children with Uncontrolled Seizures (Refractory Epilepsy)

**Medications**

- Epilepsy is often controlled by one of the first two medications that are tried, but about a third of children do not respond to the first few drugs and will require a long-term, ongoing effort to control seizures.
- Establishing an open and candid relationship with your child’s neurologist is important for establishing an effective treatment plan. If your child’s seizures do not respond to the first two medications tried, if their seizure control is not improving, or if the side effects impede their ability to learn and socialize, then it is time to ask to be referred to an epilepsy specialist.
- Keeping a diary of your child’s seizures to determine their frequency will help you know if the antiepileptic medication is working. Be sure to record any behavioral, learning or mood changes you observe or reported by your child’s teacher. Sharing this information with your child’s doctor at each visit will help you both determine if the medication is working, or if a change is needed.
- There are currently more than 20 medications available on the market to treat the various types of epilepsy. If your child does not respond to an adequate dose of one drug then another should be tried. To learn more about the various medications for epilepsy, dosages and potential side effects, go to www.nomoreseizures.org.

**Epilepsy Surgery**

- Epilepsy surgery should be considered for children who continue to have seizures that originate in one part of the brain after two appropriate antiepileptic medications fail when tried under the supervision of an epilepsy specialist. Sometimes, even children with generalized epilepsy benefit from epilepsy surgery. A partial list of epilepsy surgery centers can be found at www.naec.org.
- One type of epilepsy surgery removes the part of the brain where seizures begin. Other types of surgery can also reduce the frequency of seizures or limit spread of seizures and secondary injury (i.e., head trauma from drop attacks).
- Removal of part of the temporal lobe of the brain is the type of epilepsy surgery commonly performed in children. Sixty percent of children who undergo temporal lobe surgery become seizure-free following the procedure with continued medication. In children, epilepsy surgeries are commonly performed in other lobes in the brain to remove brain lesions (malformations, tumors and others).
Other Options

- Vagus nerve stimulation (VNS) may help control seizures. VNS stimulates the vagus nerve in the neck through wires that are fed from a generator implanted in the chest. VNS is about as effective as switching to a new drug but does not typically cause side effects like fatigue or drowsiness.

- In some children with refractory epilepsy, a dietary option (ketogenic diet) may be discussed and initiated. This usually needs to occur at an epilepsy center with experienced personnel who can initiate and guide parents in this process.
Making the Most of Your Child's Office Visit

Preparing for your child’s appointment at an epilepsy specialty clinic can help you achieve the best outcome. Seeing a new doctor can be stressful and people often forget important information. Keeping a seizure diary, writing down unusual behaviors, mood swings or unusual events in your child’s life are important information to understanding the course of your child’s epilepsy.

Some of the things you can do:

- Keep a seizure diary. When did the first seizure occur? When was your child diagnosed with epilepsy? What is the longest seizure-free period?
- List the antiepileptic medicines and the doses your child has been tried on, and the reasons the drugs were stopped.
- Bring your child’s current medicines with you (in the bottle with pharmacy label).
- Be able to describe your child’s seizures. Record in the seizure diary the seizure type (if they have more than one type of seizure). Did they have an aura or warning? What behavior did they have during each seizure? Did they have convulsions? How did they behave after each seizure? Did the seizure keep them out of school or result in an injury? It is important for you to accompany your child to the visit to describe the seizures to the doctor.
- Discuss with your child what you expect to accomplish at the clinic visit prior to going. Write down any questions either of you want to ask. If your child is old enough to participate in the conversation and treatment decisions, encourage them to do so. Communicate your expectations with the doctor at the beginning of your visit.
  - Bring any test reports or scans your child has had prior to the office visit.

Before you leave the office, ask the doctor:

- to write down instructions for changes in medications or tests that need to be scheduled
- about other resources that your doctor may be aware of such as a local Epilepsy Foundation affiliate or an epilepsy center
  - what type of seizures your child is having
  - to describe the possible side effects of the medications being prescribed
  - about an emergency treatment plan for those times when seizures are prolonged or repetitive.
Epilepsy Foundations throughout the country have additional materials and offer a variety of programs to help people understand this common disorder. For further information about epilepsy and the name of the Epilepsy Foundation near you, log on to www.epilepsyfoundation.org or call 800 332-1000.

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