



MY CHILD WITH EPILEPSY

Jessica is a five-year-old girl I saw in the emergency room for her first seizure. She and her grandmother sleep in the same bed. Her grandmother told me that Jessica began “jerking and gasping” at five o’clock in the morning. She was unresponsive and staring, and the jerking lasted about ten minutes. Jessica had been coughing a little for the past few days, but had no fever. After the convulsion, her right side seemed weak for a few minutes.

When I examined her, she had a low-grade temperature and slight wheezes in both lungs. Her strength had returned to normal. Jessica’s computed axial tomography (CAT or CT) scan was unremarkable. Her electroencephalogram (EEG) revealed large epileptic spikes on the left side of her brain.

I was able to reassure her distressed grandmother that Jessica had a benign focal epilepsy of childhood, Rolandic epilepsy, which she would outgrow. The seizure had probably been triggered by her bronchitis. Because the convulsion was so upsetting and prolonged, we decided to treat Jessica with antiepileptic medication until she no longer needed it.

143. Will my child grow out of her seizures?

Your neurologist can help you with prognosis by diagnosing the particular epileptic syndrome. The history, physical examination, brain imaging with computed axial tomography (CAT or CT) or magnetic resonance imaging (MRI), and particularly the

electroencephalogram (EEG) all help your doctor arrive at an accurate classification of your child's epilepsy.

For example, if your child has Rolandic epilepsy, also known as benign epilepsy with centrotemporal spikes (BECTS), the most common type of childhood epilepsy, she will likely outgrow it during adolescence. On the other hand, if she has Lennox-Gastaut syndrome, she probably will not.

Although epilepsy can rarely be cured, much can be gained by obtaining an accurate diagnosis. This helps guide treatment and molds expectations for the future. (Had Jessica not been evaluated in the emergency room, her grandmother would have worried needlessly that Jessica would suffer seizures all her life.)

144. What is a febrile seizure?

Small children can have convulsions related to a high fever. Febrile seizures are common, occurring in 4% of children. When a first seizure occurs with fever, the child should be evaluated by a physician. A respiratory infection or gastroenteritis often causes the elevated temperature. If the seizure is prolonged, anticonvulsants will be needed, the body has to be cooled, and the underlying cause of the fever must be treated. Most doctors do not prescribe daily anticonvulsants after a first febrile seizure. If one child has febrile seizures, the risk of other siblings developing febrile seizures is approximately 8%.

Children outgrow febrile seizures by the age of five or six years. The vast majority do **not** go on to develop epilepsy. Risk factors for epilepsy are a preexisting neurological abnormality, onset of febrile seizures before one year of age, multiple or prolonged febrile seizures, and a family history of epilepsy. If your child has none of these risk factors, the likelihood of epilepsy is only about 1%.

145. Why can't they find a cause for the seizure? They told me all her tests are normal!

In more than 50% of children with epilepsy, no brain tumor, cyst, malformation, or “scar” explains the occurrence of a seizure. However, an intermittent electrical malfunction in the child’s brain is responsible. Although the electroencephalogram (EEG) can be normal between seizures, the abnormal brain waves will usually be seen if a seizure occurs during an EEG.

When all the tests are normal and no cause is found, this is a good sign. These children’s seizures tend to be more easily controlled.

146. Do seizures cause brain damage?

Children with absence, or petit mal, seizures can have many spells without apparent ill effects. After a staring spell, they can pick up where they left off in a conversation. Their electroencephalogram (EEG) returns to normal immediately.

People with partial complex or generalized seizures, however, do not return to normal right away. The postictal period immediately after a seizure is characterized by confusion and fatigue. The EEG often slows down after a seizure, supporting the concept that the brain has not fully recovered.

We do know that brain injury can occur when seizures last longer than 30 minutes, a condition termed status epilepticus (Question #16). Two of my adult patients had persistent memory loss after episodes of status epilepticus.

Whether brief seizures cause brain injury is unknown. Much research is currently focused on answering this question. Many of my patients with intractable temporal lobe epilepsy complain of memory difficulties. Whether this problem stems from

their numerous seizures or the underlying cause of the epilepsy remains unclear.

It does appear prudent to control seizures when possible. Even though antiepileptic medications have potential side effects, they are usually a better choice than recurrent seizures.

147. What is the ketogenic diet?

Diet treatments for epilepsy have been prescribed for epilepsy since the time of Hippocrates. The diet that has been studied the longest and with the most research substantiating its effectiveness is the ketogenic diet. The ketogenic diet is usually prescribed for children who have not responded to treatment with antiepileptic medications.

Pioneered more than eighty-five years ago, the ketogenic diet is low in carbohydrate, has adequate protein, but is extremely high in fat. The diet contains up to five times more fat than protein and carbohydrates combined. It is what most adults would consider a very unhealthy diet. However, because of the slight calorie restriction, children do not gain excess weight. Fluids may also be restricted. In order to insure adequate nutrition, multivitamins, calcium, vitamin D, and other supplements may be given.

Because of its complexity, the ketogenic diet can only be followed under a neurologist's supervision with the assistance of a dietitian. The diet usually begins with a brief hospital admission for one to two days of fasting and meal preparation training. Many epilepsy centers are no longer fasting children, although the diet may work quicker if begun with a fast. The diet must be followed exactly. Each food portion is carefully weighed on a scale, and the entire meal must be eaten.

Exactly how the ketogenic diet controls seizures is largely unknown and remains a question under active investigation. We do know that the fat in the diet causes molecules called ketone

bodies to accumulate, which may play a role in decreasing seizure frequency. To make sure that the appropriate amount of ketone bodies is being produced by the diet, they may be easily measured at home or in the clinic with a urine dipstick.

When the ketogenic diet is carefully followed, about 10 to 15% of children become seizure-free, and another 30% have their seizure frequency dramatically reduced. If the diet is going to be effective, seizure frequency usually decreases within a month. After two years of successful seizure control, the diet may be discontinued without return of seizures in about one in five patients. If seizures are not completely eliminated, parents may still choose to keep their children on the ketogenic diet, sometimes for many years.

The ketogenic diet does not work in every child. It is not yet clear why the diet works in some children but not in others. Children who are tube fed and those with infantile spasms or tuberous sclerosis often do well. More research on the mechanisms of action of the ketogenic diet as well as identifying children who are likely to respond is ongoing.

Carrying out this diet requires a strong parental commitment and your child's daily cooperation. About one in six children will not tolerate the diet. Stomach upset is common, with symptoms such as nausea, vomiting, diarrhea, or constipation. Other complications may include acidosis, bone fractures, elevated cholesterol, kidney stones, and stunted growth. If you are interested in trying the diet, discuss the potential benefits and risks with your pediatric neurologist. Antiepileptic drugs are usually continued while on the diet, at least for the first month. Although the diet is not a medication, it is a sophisticated treatment. You may need to go to a comprehensive epilepsy center to find a dietitian familiar with this program. After starting the diet, your child will have periodic medical checks, including blood tests, to monitor for possible complications.

If you wish to learn more about the ketogenic diet, an excellent book has been written for parents, dietitians, and physicians that should answer your questions. *The Ketogenic Diet, A Treatment for Children and Others with Epilepsy*, Fourth Edition, John M. Freeman, MD, Eric H. Kossoff, MD, Jennifer B. Freeman, Millicent T. Kelly, RD, LD, can be obtained from Demos Medical Publishing, 386 Park Avenue South, New York, NY, 10016, (800) 532-8663 (www.demosmedpub.com).

Another diet that restricts carbohydrates, but is easier to follow and may be better tolerated, is the modified Atkins diet. The modified Atkins diet allows unlimited calories, fat, protein, and fluids and was created by a group of pediatric neurologists at Johns Hopkins Medical Center in 2002. Early studies have shown promise for the modified Atkins diet to decrease seizure frequency. There is no need for a hospital admission or preparatory fast. Ketosis, created by the high-fat and low-carbohydrate diet, does not seem to be as important in controlling the seizures. Stomach problems, increased cholesterol, weight loss, and other side effects may also occur. In some patients, it may be possible to substitute a modified Atkins diet for the more demanding ketogenic diet. The modified Atkins diet may also be effective in adults with intractable seizures.

Both the ketogenic diet and the modified Atkins diet should be carried out under the supervision of your neurologist with the assistance of a trained dietician.

148. Are epilepsy and attention deficit hyperactivity disorder (ADHD) related?

Epilepsy affects approximately 1% of children, while ADHD affects 3 to 5%. Since these disorders are relatively common, some children have both. Most children with ADHD do not have epilepsy. If there is any question about the diagnosis, bring your

child to see a pediatric neurologist who will take a detailed history, examine your child, and order an electroencephalogram (EEG).

However, many children with epilepsy may have symptoms consistent with ADHD. Problems paying attention and hyperactivity may result from epileptic activity between seizures (interictal), the seizures themselves (ictal), or brain dysfunction during the recovery period after seizures (postictal). Antiepileptic drugs may also contribute. In addition, it may be that the underlying cause of the epilepsy, such as a birth defect or brain injury, is also responsible for the symptoms of ADHD. ADHD symptoms affect one-third or more of children with epilepsy and are associated with decreased school performance and decreased quality of life.

Both behavioral and medication treatment are available for ADHD. Sometimes these problems may not be fully addressed in your visit with the neurologist because the focus is more on treating the epilepsy. If you suspect symptoms of ADHD in your child with epilepsy, discuss these concerns with your pediatric neurologist who can take steps to make a formal diagnosis and treatment plan.

149. Can video games cause seizures?

Less than 15% of people with epilepsy have seizures (called photosensitive epilepsy) in response to flashing lights. Children and adults with this type of seizure disorder need to avoid strobe lights, flickering television screens, and video games.

Sometimes children have their first seizure triggered by a video game, making it appear that the game caused their epilepsy. This is not the case. Children *without* epilepsy do not have seizures from video games.

Most children with epilepsy are not photosensitive. Before prohibiting your child from playing video games and watching television, ask your neurologist whether flashing lights present

a risk. Photosensitive epilepsy can be easily diagnosed during testing with flashing lights and an electroencephalogram (EEG). See Question #20 for more information.

150. Can my child participate in sports?

One of the biggest dangers of epilepsy in children is the overprotectiveness it fosters in parents. To develop normally, children need to face many challenges, academic, athletic, and social, among others. To have a full life, they need to test their limits (and probably yours!).

Children with frequent seizures should not swim alone, horseback ride, rock climb, high dive, do gymnastics above the ground on the balance beam and rings, or participate in other sports in which a sudden alteration of consciousness could result in serious injury. Baseball, soccer, football, tennis, volleyball, and playground sports are safer. Children with less frequent seizures can participate in most sports. Exercise rarely causes seizures.

There is always the possibility of injury when participating in sports, even for a child without epilepsy. As a parent, you will have to weigh the risk of injury against the risk of depriving your child of an important facet of life. If your child rides a bicycle, a helmet is a good precaution, as it is for all children. While boating, every child should wear a life jacket, whether they have epilepsy or not. In order to decide which sports are appropriate for your child, discuss safety concerns with your child, his teacher, coach, and physician. An epilepsy summer camp may be a good environment for your child to learn and participate in sports under supervision (Appendix F).

151. I want my child to know he isn't the only one with epilepsy. What can I do?

A local support group where your child can meet other children with seizures may be helpful. The Epilepsy Foundation

sponsors a School Alert program to provide epilepsy education. An educational puppet show, *Kids on the Block*, is available for children (www.kotb.com/). Contact the Epilepsy Foundation to see whether a program can be performed in your child's classroom. Knowledge of epilepsy can replace fear and provide a more supportive classroom environment for your child. Online communities such as www.epilepsy.com provide quality medical information and an opportunity to share personal experiences with epilepsy. Epilepsy.com has a special section for kids.

Over thirty summer camps are designed for children with epilepsy (Appendix F). Some are free of charge or scholarships may be available through the local affiliate. These camps provide an exposure to sports under supervision as well as an opportunity to interact with peers. Some camp counselors may have epilepsy as well and can serve as mentors and models for your child. Children with epilepsy who attend a special summer camp may experience an improvement in adaptive behaviors and social interactions. More information is available at www.efa.org.