

## CHILDREN WITH ESTABLISHED EPILEPSY

### **What is the difference between a seizure and epilepsy?**

A seizure is an abnormal surge of electrical activity originating in the brain. It can also be thought of as an “electrical thunderstorm of the brain.” Epilepsy applies to a variety of conditions which cause a patient to have the propensity to have spontaneous seizures. Approximately 5% of the world’s population will have a seizure during their lifetime, but only 1% of the world’s population will have epilepsy. Epilepsy syndromes come in two varieties. The first are generalized epilepsy syndromes which cause seizures that start over the entire brain at one time. The second are partial epilepsy syndromes which cause seizures that begin in one focal part of the brain and sometimes spread to other areas.

### **Can we discover the cause of my child’s epilepsy?**

There are many conditions which cause a child to have epilepsy. Some causes include structural abnormalities that can be seen on brain imaging, such as MRI. These abnormalities include things like head injuries, infections, brain malformations which the child was born with, and other causes. In some “epilepsy syndromes”, such as childhood absence epilepsy and juvenile myoclonic epilepsy, the brain looks normal. In these cases the nerve transmission from one brain cell to another is abnormal but the structure of the brain is not. It is frustrating that in a significant number of children the cause remains unknown despite extensive testing.

### **Will my other children have epilepsy too?**

The majority of siblings of children with epilepsy do not develop epilepsy. The actual risk of a sibling developing epilepsy depends on what causes the epilepsy. If it is caused by something that is acquired, such as a head injury, then siblings will not have a significant increased risk of seizures. If the cause is genetic then siblings may be at increased risk of having epilepsy. A few conditions are inherited in a dominant fashion so that there is a 50% risk that siblings will have epilepsy but this is very uncommon. Among common genetic epilepsies there is only a small risk that siblings will develop epilepsy.

### **Can my child have mental retardation associated with her seizures?**

Seizures do not cause mental retardation. However, many brain conditions that cause seizures also cause mental retardation which can vary from mild to severe. Developmental assessment and evaluation of school performance should be performed in children with epilepsy to determine whether cognitive and learning problems are present.

### **Can my child have learning problems?**

Learning difficulties can be associated with epilepsy and may range from mild to severe depending on diagnosis, age of seizure onset and seizure control. Some antiepileptic medications can also impact a child’s ability to learn. Educators, families, and medical providers should work together to address your child’s specific needs.

### **Will my child always have seizures?**

Some childhood epilepsy syndromes are age-limited and these children often stop having seizures after a particular age. Other types of epilepsy, however, require life-long treatment.

Although predicting whether epilepsy will resolve is difficult, you should discuss this with your neurologist.

### **How long will my child require medications?**

In the majority of cases, your child will remain on medications for as long as he or she has seizures. Most neurologists consider medication withdrawal only after a patient has been seizure free for at least 2 years. However, this decision depends on a number of factors the most important of which is the cause of your child's epilepsy. Medication withdrawal should never be done without first discussing this with your physician due to the risk of seizures.

### **What is epilepsy surgery?**

Epilepsy surgery is an option in children with partial epilepsy syndromes that have not responded to antiepileptic drugs. Epilepsy surgery involves the safe removal of the brain region that is causing seizures. In some cases, successful surgery renders over 50% of children seizure free. Serious problems such as stroke or death are extremely rare as part of surgery, occurring in less than 1% of people who have surgery. Approximately 15% experience temporary or mild side effects such as headaches, memory problems, or visual problems. An extensive evaluation is performed prior to surgery and may include outpatient EEGs, inpatient EEGs during which time the patient is admitted to the hospital with the goal of having seizures, brain imaging including MRIs as well as SPECT and PET scans, and at times additional testing such as neuropsychological memory testing.

### **What is the ketogenic diet?**

The ketogenic diet is a diet consisting of high fat content foods with very little protein or carbohydrate (sugar). Initiation and maintenance of the diet is done with the help of dietitians who are specially trained. Very strict adherence to the diet is required to maintain successful seizure control. The exact mechanism by which the diet controls seizures is unknown. The major side-effects of the diet are abdominal pain, diarrhea, dehydration, and elevated cholesterol levels.

### **Will my child be safe with a babysitter?**

It is imperative that your babysitter be aware of your child's epilepsy. You should instruct the sitter about what to do during a seizure. This usually means making sure the child is in a safe environment, turning the child onto his or her side if they are stiff or shaking, NEVER placing objects or fingers into the child's mouth, and monitoring respirations. The sitter should also be aware of standard seizure precautions as outlined in the **Patient Safety in Children** brochure. The child should NEVER be left alone while in the bath or while swimming, not even for a few seconds. A child who has a seizure in either of these settings is at a very high risk of drowning. Children should not be allowed to lock doors as this would make it difficult to get to the child during a seizure. Children should not be allowed to climb to heights due to the risk of falling during a seizure. Helmets are mandatory when riding a bicycle. It is MANDATORY that the babysitter has access to emergency phone numbers and knows to call 911 in the event that a seizure lasts longer than 4 to 5 minutes or if the child develops difficult breathing.

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