

Understanding Epilepsy: A Parent's Guide

Introduction

As a parent, you may have many questions regarding your child's epilepsy diagnosis. As you look for answers, you may encounter information about epilepsy, its causes, and possible treatments. All of these different opinions can make it challenging for a family to organize options and begin to choose a treatment plan that best fits the family.

We hope that this packet will help better prepare you to understand the information you receive about treatments for seizures, as well as give you the chance to look over the most recent professional opinions about epilepsy.

Westside Regional Center anticipates supporting your family as you proceed from your child's initial diagnosis to ongoing support throughout his or her lifetime.

What is Epilepsy?

Having a seizure does not necessarily mean that a person has epilepsy. A person who has one or multiple seizures while suffering from a fever, trauma, or infection is *not* considered to have epilepsy. In fact, epilepsy is defined as a neurological disorder (a disorder of the brain) manifested by two or more *unprovoked* seizures. Epilepsy may be caused by:

- genetic conditions,
- head injury,
- stroke,
- brain tumor,
- toxic poisoning or severe infections like meningitis and encephalitis.

These causes may occur during the prenatal (during pregnancy), peri-natal (during birth) or postnatal (after birth) period. However, in approximately 70% of cases, no etiology or cause for epilepsy can be identified.

It is important to know that epilepsy is usually classified into three categories. The three major types of epilepsy are:

1. **Partial Epilepsy:** Seizure originates in one area of the brain (although it may generalize or expand to other parts of the brain), typically lasts for a short time (2-5 minutes), and is the most common form of epilepsy among adults. Doctors will often further describe this type of seizure based on whether the person is conscious or unconscious during the seizure. Some examples include:
 - Simple partial (without loss of consciousness) is characterized by uncontrollable jerky motions of a body part (such as a leg or arm), sudden sweating or flushing, nausea, or changes to the person's ability to see, hear, or smell
 - Complex partial (with loss of consciousness) can include a trance-like state lasting from a few moments to several minutes, uncontrollable body movements (such as lip smacking or chewing motions), automatisms

(when a person moves about aimlessly), and motor seizures preceded by an aura (feelings of fear, abdominal discomfort, dizziness, or strange odors and sensations). After this type of seizure, the individual will have no memory of it afterwards.

2. **Generalized Epilepsy** affects both cerebral hemispheres (sides of the brain) from the beginning of the seizure. They produce a loss of consciousness, either briefly or for a longer period of time, and are sub-categorized into several major types:
 - Typical Childhood Absence (petit mal) epilepsy involves non-convulsive seizures that are common in childhood and usually diminish or disappear in adulthood. It may simply be a brief lack of awareness (5-30 seconds) evidenced by a long hard stare, eye blinking or facial twitching followed by a period of confusion. This type of seizure is easily missed because there is no preceding aura and the child will usually not remember having the seizure.
 - Tonic-clonic (grand mal) epilepsy involves convulsive seizures that usually last under 5 minutes and involve the entire body (there is an initial stiffening of muscles – tonic phase – followed by a period of alternating relaxation and contraction – clonic phase). They can happen at any age and the individual has a complete loss of consciousness during the seizure, as well as no memory after it occurs. The physical manifestations of this type of seizure can include back arching, the reddening of the face, momentarily cessation of breathing, clenched jaws and hands, eyes wide-open, fixed and dilated pupils, tongue/cheek biting, and loss of the bladder or stool control. The person may need to sleep or rest immediately after the seizure and he/she will usually have sore muscles, nausea, and suffer through some confusion.
 - Myoclonic epilepsy are sudden, brief, massive muscle jerks involving all or only some muscles. You usually see repetitive muscle contractions and they may occur in clusters.
 - Atonic (astatic) epilepsy begins between ages 2 and 5 and is uncommon in adults. They can last 10 to 60 seconds and includes a sudden, brief loss of muscle tone (for example, the child may fall to the ground if standing or head may drop suddenly if he/she is seated). The child will usually make sudden jerky movements during the seizure (similar to myoclonic epilepsy). Also while the child will lose consciousness during the seizures, he/she will make a quick recovery afterwards.
3. **Status Epilepticus** is a life-threatening condition in which the brain is in a state of persistent seizure. This is usually characterized by successive seizures with no intervening periods of consciousness or seizures lasting 20-30 minutes or more. It can be convulsive or non-convulsive seizures.

How did my child receive this diagnosis?

A doctor determines a diagnosis of epilepsy through a series of steps:

- **Carefully looking over the parents' and child's medical history.** This is an important first step – it allows the doctor to understand your own parental concerns, as well as review the results of your child's previous tests and medical history. It also helps the doctor to avoid repetitious testing, which can be very stressful to your child.

- **Administering blood tests.** Doctors often take blood samples for testing, particularly when they are examining a child. These blood samples are often screened for metabolic or genetic disorders that may be associated with the seizures. They also may be used to check for underlying problems such as infections, lead poisoning, anemia, and diabetes that may be causing or triggering the seizures.
- **Administering developmental, neurological, and behavioral Tests.** Doctors often use tests devised to measure motor abilities, behavior, and intellectual capacity as a way to determine how the epilepsy is affecting that person. These tests also can provide clues about what kind of epilepsy the person has.
- **Administering EEGs and brain scans.** An EEG records brain waves detected by placing electrodes on the scalp. This is the most common diagnostic test for epilepsy and can detect abnormalities in the brain's electrical activity. People with epilepsy frequently have changes in their normal pattern of brain waves, even when they are not experiencing a seizure. Brain scans, like MRIs or CT scans, reveal the structure of the brain, which can be useful for identifying brain tumors, or cysts. Brain scans can also be used to monitor the brain's activity and detect abnormalities in how it works.

Evaluating Treatments

Before you explore the various treatments for epilepsy, here are some suggestions to help you evaluate your options for your child's therapy.

Find a team of trusted professionals. You will need to make important decisions about your child's treatment and education. Your child should have a primary care doctor who is able to communicate with specialists, coordinate care and provide you with a medical home. Your child should also have a neurologist, preferably one who specializes in child neurology, to evaluate and manage the epilepsy. Find a team of doctors, teachers and therapists that you trust. These professionals can help evaluate the resources in your area and help maximize your child's potential.

Seek out other families who are dealing with the same issues. Most communities have support groups for parents of children with epilepsy, as well as the option for online forums on the Internet. This can be a great outlet for emotional support, as well as a place to discuss treatment experiences with other parents.

Understand how much time and commitment the treatment will require. It is important to know that your family will play an important role in supporting your child through out his or her treatments. Therefore, many treatments may be stressful, not only for your child, but for your entire family. Some treatments may not have great benefit for your child in his or her situation. When considering possible treatments, you should consider both the financial and emotional costs. *Does the benefit outweigh the costs for your child and family?* Also, if you decide to pursue a specific treatment, it is important that you know how to decide if the treatment is working. This allows you to monitor the progress of your child, so that you can decide whether or not you should continue or stop the treatment after a period of time.

Management and Treatment of Epilepsy

Once epilepsy is diagnosed, it is important to begin treatment as soon as possible. For about 70% of those diagnosed with epilepsy, seizures can be controlled with modern medicines and surgical techniques when needed.

Medication. Epilepsy is generally treated with antiepileptic medications. The most important step is to select an antiepileptic drug that is appropriate for your child's particular type of epilepsy because specific medications are used for different types of seizures. The main objective of drug therapy is to maintain maximum control of the seizures with the least side effects. It is important to take the medicines regularly and as directed. The effectiveness of anti epileptic drugs depends on the amount of medicine in the body. It is for this reason that your doctor may order frequent laboratory tests in the beginning and at regular intervals during the course of treatment.

All noted side effects should be reported to your doctor. Most side effects of antiepileptic drugs are relatively minor, such as fatigue, dizziness, or weight gain. However, severe and life-threatening side effects such as allergic reactions can occur. Epilepsy medication also may predispose people to developing psychiatric issues, such as depression or psychoses. You should consult a doctor immediately if your child develops any kind of rash while on medication, or if your child becomes depressed or otherwise unable to think in a rational manner. Other danger signs that you should seek medical attention immediately are extreme fatigue, staggering or other movement problems, slurring of words and thoughts of suicide. You should be aware that epilepsy medication can interact with many other drugs in potentially harmful ways. For this reason, you should always tell your doctors which medications your child is taking. Women also should know that some antiepileptic drugs can interfere with the effectiveness of oral contraceptives and they can cause birth defects, so they should discuss this with their doctors.

Some doctors will advise people with epilepsy to discontinue their antiepileptic drugs after two years have passed without a seizure. Others feel it is better to wait for four to five years. Discontinuing medication should only be done with a doctor's advice and supervision. It is very important to continue taking epilepsy medication for as long as the doctor prescribes it. People also should ask the doctor or pharmacist ahead of time what they should do if they miss a dose. Discontinuing medication without a doctor's advice is one of the major reasons people who have been seizure-free begin having new seizures. Seizures that result from suddenly stopping medication can be very serious.

Surgical Treatment. Seizure surgery can be considered for patients in whom antiepileptic drugs fail to completely control seizures. However, it is very important to determine whether or not your child is a viable candidate and you should consult your doctor about surgical treatment. To decide if a person may benefit from surgery, doctors consider the type or types of seizures he or she has. They also take into account the brain region involved and how important that region is for everyday behavior. Surgeons usually avoid operating in areas of the brain that are necessary for speech, language, hearing, or other

important abilities. Surgery should always be performed with support from rehabilitation specialists and counselors who can help your child deal with the many psychological, social, and employment issues he or she may face.

While surgery can significantly reduce or even halt seizures for some people, it is important to remember that any kind of surgery carries some amount of risk. Surgery for epilepsy does not always successfully reduce seizures and it can result in cognitive or personality changes, even in people who are excellent candidates for surgery. Patients should ask their surgeon about his or her experience, success rates, and complication rates with the procedure they are considering.

Even when surgery completely ends a person's seizures, it is important to continue taking seizure medication for some time to give the brain time to re-adapt. Doctors generally recommend medication for 2 years after a successful operation to avoid new seizures.

Specialized Diet. The ketogenic diet is another approach to the treatment of epileptic seizures. It is generally tried in children younger than 10 years of age (although it has also had some success with adults). Studies have shown that, in some cases, children may experience fewer seizures if they maintain a strict diet rich in fats and low in carbohydrates. This ketogenic diet is not easy to maintain, as it requires strict adherence to an unusual and limited range of foods. Possible side effects include slow growth due to nutritional deficiency and a buildup of uric acid in the blood, which can lead to kidney stones. People who try the ketogenic diet should seek the guidance of a dietician to ensure that it does not lead to serious nutritional deficiency.

Ongoing. During any treatment it is important for you to keep track of your child's sleep behavior, appetite, weight gain or loss, and menses. Sleep is important in the treatment of epilepsy. Your toddler should be getting 11-14 hours of sleep; your child should be getting 9-10 hours of sleep. Keep track of tests, the frequency and nature of seizures and medications and report all the information to your physician.

Most people with epilepsy lead outwardly normal lives. While epilepsy cannot currently be cured, for some people it does eventually go away. Most seizures do not cause brain damage. It is common for people with epilepsy, especially children, to develop behavioral and emotional problems, sometimes the consequence of embarrassment and frustration or bullying, teasing, or avoidance in school and other social setting. For many people with epilepsy, the risk of seizures restricts their independence (some states refuse drivers licenses to people with epilepsy) and recreational activities.

What to expect medically

Your child should have a primary care doctor in addition to a neurologist. The primary doctor should continue to provide your child with regularly-scheduled medical care and preventive health screenings. Individuals with epilepsy have the same basic healthcare needs as typically developed people, including vaccine schedules (including flu shots), as well as screenings for high blood pressure, heart disease, cancer and dental disease.

Resources at WRC

- Health and Medical Department (310-258-4254)
- Equipment Clinic
- Family Resource Center (310-258-4063)
- Service Coordination
- Support Groups – Birth to Five Parent, Teen Social Group, Networking and Social Group
- Trainings & Events – self advocacy, consumer discussion, and behavior management

Resources in the Community

For general information websites, you may log on to:

<http://www.epilepsyfoundation.org>, reliable information on legal affairs and community services.

<http://www.naec-epilepsy.org>, to find a comprehensive epilepsy center near you.

<http://specialchildren.about.com/cs/epilepsy> lists websites for parents of children with epilepsy

References

<http://www.ddhealthinfo.org/>

<http://www.fbhc.org/Patients/Modules/epilepsy.cfm>

[National Institute of Neurological Disorders and Stroke](http://www.ninds.nih.gov)