

## **SEIZURES AND EPILEPSY**

### ***What is Epilepsy?***

Epilepsy is a condition involving the brain that makes people more likely to have seizures. It is one of the most common problems of the nervous system and affects people of all ages, races and ethnic background.

When your child has two or more seizures, he or she is considered to have epilepsy. There are many possible causes of epilepsy including tumors, strokes and brain damage from illness or injury. It can also be caused if the brain did not develop normally. This is called cortical dysplasia. Many times there seems to be no likely cause for epilepsy—in this case, the cause may be genetic. This means it runs in the family.

### ***What is a Seizure?***

The brain is the center that controls all responses in the body. The brain is made of nerve cells that talk with each other through electrical activity. A seizure occurs when there is abnormal activity in the brain and causes a sudden change in awareness, movement or behavior.

When you think of a seizure, you may think of a person lying on the ground and shaking. Sometimes shaking may not happen. Seizures look different for each child. The reason is that there are many types of seizures in children:

- Recurring shaking of all or part of the body
- Blank stare
- Falling to the ground
- Brief and sudden muscle spasms
- Repeating movements such as blinking of the eyes, pulling at clothes or lip smacking

### ***What Causes a Seizure?***

**Provoked seizures** are caused by something that affects the brain for only a short time. Some examples are:

- Fever
- Low blood sugar
- Brain infection or injury
- Taking a poison or other toxin

**Unprovoked seizures** are caused by a change in the electrical activity of the brain. The cause may be genetic (runs in the family). It may also be in the way the brain was formed early in your child's life. Sometimes the cause is not known.

### ***What are the Different Types of Seizures?***

Seizures are put into two basic groups: partial and generalized. Generalized seizures involve both sides of the brain and partial seizures are limited to one side of the brain but can spread to other portions of the brain and cause generalized seizures.

#### **PARTIAL SEIZURE**

**Simple Partial Seizures:** During this type of seizure:

- Your child is awake and alert and does not lose consciousness. Your child may experience an aura, or strange feeling, consisting of changes in smell, vision or hearing. Not all children experience an aura.
  - The seizures typically last less than one minute. Your child may do different things depending upon which area of the brain is involved:
    - Back of brain-visual changes
    - Muscles-small groups such as fingers or large groups in arms or legs

**Complex Partial Seizures:** This is the most common type of partial seizure.

- The seizure starts in one small part of the brain and then spreads to involve more parts of the brain. Your child may be awake but not alert. This means that your child cannot answer questions or may not make sense when talking.
  - The seizures typically last one to two minutes.
- Characterized by repeating activities such as lip smacking, running, screaming, crying, laughing, swallowing or talking without making sense.
- After regaining consciousness, you or your child may complain of being tired or sleepy.

#### **GENERALIZED SEIZURE**

**Tonic-Clonic Seizures:** This type of seizure used to be called a grand mal or convulsive seizure. You or your child will be unconscious and fall to the ground. All of the body's muscles are involved.

- Tonic Phase: You or your child will lose consciousness with generalized stiffening of the arms and legs. Straightening of the back, neck, arms and legs for a long period of time often occurs. The eyes remain open and a cry or yell is common.
  - The seizures typically last 10-30 seconds.
  - The tonic phase is followed by the clonic phase.
- Clonic Phase: You or your child will have a rapid tremor that continues to large jerks/movements of the arms, legs, and body. You or your child may turn blue around the mouth or face, have increased drooling, sweating, big pupils, and may pee or poop without control (This is also known as incontinence).

- Once the seizure is over, you or your child will be sleepy, confused or upset. There may also be short term weakness of one side of the body—this is called Todd's Paralysis.
  - Some children with generalized tonic-clonic seizures or their parents are aware of the seizure, hours or days before it occurs. This is because you or your child may experience a prodrome (something they feel or see) such as a headache, insomnia, irritability, or a change in appetite to alert you to an oncoming seizure.

**Absence Seizures:** This type of seizure used to be called a petit mal seizure. Hyperventilation (breathing in and out very fast) is a common trigger for absence seizures. Your child will:

- Stop their activity and stare blankly. Typically they stay in the same position during the seizure. The mouth or face may move or the eyes may blink.
- The seizure usually lasts less than 30 seconds and occurs many times on a daily basis.
  - When the seizure is over, you or your child may not remember what happened and will return to previous activities.

**Myoclonic Seizures:** This type of seizure involves sudden jerks of the head, arms and/or legs. The jerk may be strong enough that you or your child falls to the ground. Myoclonic seizures may come in clusters. This means that several seizures happen one after the other.

**Tonic Seizures:** This type of seizure involves a sudden stiffening of the body and can cause a child to suddenly drop to the ground.

**Atonic Seizures:** These seizures are also called drop attacks. This type of seizure involves a sudden loss of muscle tone causing you or your child to fall to the ground. During the seizure, you or your child is limp and unresponsive.

**Infantile Spasms:** This type of seizure occurs in infants from 2-12 months of age.

- The neck and upper body will jerk forward and the arms and legs will become stiff or flex. Sometimes, the head will drop. The movements occur in clusters and usually last 10 to 20 minutes.
  - Each movement lasts seconds. There is a high occurrence rate of this seizure when the child is awakening, or when he/she is trying to go to sleep. Infants may have hundreds of these seizures a day.
  - Early treatment is critical.

**Febrile Seizures:** This is a generalized tonic-clonic seizure and happens with fever. These seizures are more commonly seen in children between 6 months and 5 years of age. There may be a family history of this type of seizure. Epilepsy will develop in a small minority of children who have had febrile seizures.

## **UNDERSTANDING CHILDHOOD EPILEPSY**

Epilepsy means seizures that happen over and over again therefore this diagnosis is restricted to those with two or more seizures (with no cause).

### ***Recurrence after a First Seizure***

Very few children with one seizure will develop severe epilepsy; less than half will have a second seizure. Children that do have a second seizure (especially if no medication was started) are more likely to have a third seizure.

### ***Starting Medication Treatment***

Giving medication every day after one seizure without cause is not needed. It has become common for doctors to prescribe medication after a second seizure.

### ***Long-Term Remission***

For some children, epilepsy is not permanent and with age the epilepsy disappears. These children usually have at least one of the following:

- Normal intelligence
- Normal neurological exam
- Few seizures when diagnosed
- Age of first seizure below 12 years of age

### ***Stopping Medication***

Over half of the children with epilepsy who have no seizures for 2 years can stop medication treatment. If the antiepileptic medication (AED) is stopped and seizures start again, then medication is usually restarted. If again the child is seizure free for 2 years, then the medication is stopped for a second time with good success. NEVER stop taking AED medication without talking to your doctor.

### ***Intractability***

Intractable epilepsy means that seizures are difficult to control even though the child is on two or more seizure medications.

### ***Survival Rate with Epilepsy***

Even though seizures are scary, normal children with epilepsy have the same survival rate as the general population.

## **COGNITIVE AND BEHAVIORAL DISORDERS**

### ***Cognitive Disabilities in Children with Epilepsy***

Not all children with epilepsy have developmental delays. Nonetheless, children with severe mental retardation and cerebral palsy are more likely to have epilepsy.

### ***Cognitive Function in Benign Childhood Epilepsy Syndromes***

Children with epilepsy with good medical management can still have issues with thinking due to problems with attention, memory, saying words, reading, writing and math abilities.

### ***Learning Disabilities and Special Education Services***

Learning disabilities are reported more often in children with epilepsy. Children with epilepsy are more likely to repeat a year in school and over half require special education services. They have more problems in reading, writing and math. Therefore, children diagnosed with epilepsy, even when seizures are mild and controlled, should be screened for learning disabilities and how they do in school should be monitored.

### ***Psychiatric Disorders in Childhood Epilepsy***

Depression has been reported to happen more in children and adolescents with epilepsy. Children with epilepsy may also suffer from anxiety disorders. The way epilepsy affects children and adolescents emotionally is complex—part of the problem may be if they encounter people who look at them differently, are given less job opportunities, or lack friends.

### ***Behavioral Problems, Conduct Disorders, and Delinquency***

Parental anxiety about epilepsy and other family problems may cause problems with behavior in children and adolescents with epilepsy. Feeling bad about themselves occurs more often in children and adolescents with epilepsy when compared to other children and adolescents with or without chronic illnesses. Children with epilepsy have higher rates of oppositional-defiant disorder and conduct disorder when compared to the general population.

## HOW ARE SEIZURES DIAGNOSED?

Sometimes doctors may not know why a seizure happens. There are tests that can be done to help provide more information.

### *What tests may be done?*

- EEG (Electroencephalogram)—This test records the brain's continuous electrical activity by using electrodes (wires placed on your child's head). Your doctor will order a specific EEG that will tell you more about you or your child's seizures or condition.
- MRI (Magnetic Resonance Imaging)—The MRI is a machine that uses large magnets and a special computer to take very clear pictures of you or your child's brain. It can sometimes help with finding very small problems in the brain.
- Blood tests—These tests check for infections or other problems.
- Lumbar puncture (spinal tap)—A special needle is placed into the lower back into the spinal canal. A small amount of cerebral spinal fluid (CSF) can be removed with the needle and sent for testing to look for infection or other problems. CSF is the fluid that bathes your child's brain and spinal cord.

## HOW ARE SEIZURES TREATED?

Knowing what to do and how to make it safe for your child during a seizure is very important. Many children do not need medicine after only one seizure as they may not have any more seizures. Most of the time, doctors will not start medicine until there are 2 or more seizures. Your child will be treated by your child's doctor based on age, overall health, medical history, type of seizure and you or your child's opinion or preference.

### *Medications*

The goal of epilepsy management is to completely control the seizures while allowing you/your child to grow and develop normally. The major goals of seizure management include:

- Knowing the seizure type
- Using the right medicine for that type of seizure
- Using the smallest amount of medicine needed
- Keeping the right amount of that medicine in your child's blood (checked by blood tests)
  - The Doctor may increase or decrease the dose based on test results.
  - The Dose may also be changed if tests show that medicine is affecting the kidney, liver, or your child's weight changes.

The medications used for epilepsy are called "AED" (Anti-Epileptic Drug). AED's are used to help the brain fight off seizure activity. Your child will start taking one AED at a time. The amount of medicine will be increased slowly until the seizures are controlled. Most of the time only one AED is needed and few side effects occur. If the amount of medicine is too high, it can cause

side effects. If one AED is not enough to control the seizures, the doctor can add another AED. The first AED may be continued or may be slowly decreased and then stopped.

### ***Vagal Nerve Stimulation***

Some children with seizures that cannot be controlled with AED's may find vagal nerve stimulation (VNS) helpful. The vagal nerve stimulator device is surgically inserted under the child's skin on the left of the chest, usually above the left nipple. The small wires attached to the device are wrapped around the vagus nerve. The VNS is an electrical pacemaker used to help control seizures.

### ***Ketogenic Diet***

The ketogenic diet is sometimes offered to those children who continue to have seizures while on AED's. This is a special way of eating that is helpful for some children who have uncontrolled seizures. Starting the ketogenic diet means your child will have to stay in the hospital for at least 3-4 days. The diet involves eating very high fat and low carbohydrate foods. Protein is given in amounts to help your child grow. The diet requires close supervision by the child's medical team, including the dietitian, pharmacist and physician specializing in ketogenic diets.

### ***Epilepsy Surgery***

Some types of seizures respond well to surgery. Surgery should be considered if your child's seizures are not well controlled using AED's, even after trying many types and combinations. Usually surgery is an option in a child who has seizures that always start in one area of the brain and that part of the brain can be removed without affecting behaviors such as speech, memory, or vision. Surgery is not an option for everyone with seizures. Your child's doctor will talk to you about this type of treatment if it is needed.

## SEIZURE PREPAREDNESS PLAN

### What To Do When Your Child Has a Seizure

- Stay calm.
- Do not try to stop the movements.
- Clear the area around your child of any hard, sharp or hot objects. If walking around, gently lead your child away from hard, sharp or hot objects, doors or stairways.
- If your child is lying down, pillows or blankets may be used to pad items that cannot be removed. An item that is flat and soft should be put beneath the head.
- Do not try to put anything between your child's teeth.
- For a tonic-clonic seizure, gently roll your child onto one side until he/ she is fully awake.
- Stay with your child until the seizure is over and your child can answer questions such as "Who am I?" or "Where are you?"
- Allow your child to rest if he or she is sleepy. Check on your child frequently.

**Helpful Hints and Tips:** Your child's doctor may recommend a rectal form of medication called *Diastat Acudial*. This can be used at home to stop a seizure that lasts longer than five minutes or three seizures in one hour. If you do not have this prescription, ask your doctor if this would be helpful for your child.

### When To Go To The Emergency Department or Call 911

- The seizure lasts longer than 5 to 7 minutes.
- Seizures are followed by more seizures and your child does not wake up in between seizures.
- Your child has trouble breathing, seems hurt or in pain.
- Your child's color appears bluish or gray after the seizure is over.
- Your child also has diabetes or may be pregnant.
- The seizure occurred in the water.

**Helpful Hints and Tips:** Please bring your child's medication bottle and have the name of your child's neurologist and clinic phone (714-509-7601) available for the emergency providers.

### When To Call Your Child's Neurologist/Doctor

- Your child's seizures have increased in frequency.
- Your child has experienced a new type of seizure.
- Your child has side effects from the AED's.
- Your child developed a rash after starting new AED's.

**Helpful Hints and Tips:** Use the following list of questions to help record the seizure and share this information with your child's neurologist.

1. How did your child act before and after the seizure?
2. Were there any warning signs that the seizure was starting?
3. What happened during the seizure?
4. Was one side or part of the body more affected?
5. Did it start on one side of the body and affect the other side?
6. Did the head or eyes turn to one side during the seizure?
7. How long did the seizure last?
8. How long did it take you or your child to return to normal?
9. Was one side of the body weaker after the seizure?
10. Did your child pee or poop during the seizure?

**Helpful Hints and Tips:** Illness in your child may cause your child to have a breakthrough seizure easier. A breakthrough seizure is a seizure that occurs in a child whose seizures had previously been well- controlled. If your child is sick, please share this information with your neurologist because it will influence his or her decision to adjust your child's AED's.

## LIVING WITH EPILEPSY

You may wonder how seizures are going to affect everyday life.

Certain things may make seizures occur more easily. These are called seizure triggers. Some triggers **can be avoided**, such as:

- Lack of sleep
- Forgetting to take medicine
- Drinking alcohol

Some triggers that **cannot be avoided**:

- Getting sick
- Menstrual period

Taking good care of your body can help to avoid some of these seizure triggers, such as:

- Eating 3 well-balanced meals every day.
- Getting regular exercise to keep the body healthy.
- Getting a full night's sleep. Children should get at least 10-12 hours of sleep each night. Teenagers should get at least 8-10 hours of sleep.
- Avoiding caffeine close to bedtime.

As your child gets older, help him or her to learn to take part in their own health care, by doing the following:

- When your child is 8 year old, begin talking to them about the changes that will happen in their clinic visits. Tell your child that doctors and nurses will start to ask them questions directly. This will let your child get comfortable answering questions while they have the "safety net" of a parent in the room.
- Gently encourage independence, but know that it will take time.
- When your child is 14 years old, encourage them to see the team without you for most of the visit. You can join your child and care providers at the end of the visit to review information. This will also give you a chance to ask any questions or address concerns you may have.

## FREQUENTLY ASKED QUESTIONS

While we strive to allow our children with epilepsy to live as normal lives as possible, there are a few activities that should be avoided and other activities that require closer supervision and attention to safety. The following are frequently asked questions by our parents regarding certain activities.

**Question:** “Are there things my child can’t do now?”

**Response:** When your child’s seizures are under good control, regular physical activity is good for your child. However, your child should avoid sports that involve climbing to a high location or those contact sports that may result in head injury until your doctor has approved of these activities. Your child may swim once the doctor determines the seizures are under control, but he or she needs to ***always*** have adult supervision. ***Your child should never engage in any type of water sports without adult supervision and that includes wading in a small pool.*** The adult should be able to swim and have the strength to carry your child if the need arises. If there is a lifeguard on duty, inform the lifeguard that your child has epilepsy.

**Question:** “Can my child play video games?”

**Response:** For most children with epilepsy, playing a video game is not a problem. However, some children have seizures that are triggered by light. These are called photosensitive seizures. These seizures may be triggered by flashing lights such as when playing a video game, watching television or simply driving past trees on a sunny day.

**Question:** Can my child ride a bicycle, skateboard or roller blades?

**Response:** Once your child’s seizures are under control, your child should wear a helmet when riding a bike or scooter, rollerblading, roller skating, and skateboarding. The helmet will prevent serious head injury.

## TRAVELING WITH YOUR CHILD WHO HAS EPILEPSY

Enjoyable, safe travel starts with planning before you leave home. Suggestions for easier travel include:

### Advance planning

- Call the airlines and explain your needs. Ask what they provide. Ask about the rules for carry on medicines.
- If you are traveling to theme parks or other locations, call and ask what help they can provide.
- Pick out snacks, books or toys with your child to help them enjoy the trip.
- Put together a packet that has phone numbers you may need including your child's:
  - Primary care provider
  - Neurology provider
  - Pharmacist
  - Emergency family contact who knows your child's medical history
  - Pharmacy and hospital where you will be traveling

### Medicine

- Be sure to have prescriptions filled and picked up before you leave home.
- Pick up your medications 2-3 weeks before the start of your vacation to be sure you have enough to take with you.
- If needed, call your insurance company to see if they will give you advance doses so you will not run out.
- For air travel, carry two supplies of medicines with you. Put one in your carry-on and the other in your checked baggage. **If your child uses Diastat, keep this in your carry-on bag.**
- Carry a written list of medicines and doses. This is called a Home Medication List.
- Bring your pharmacy phone number from home. If needed, they can help you with possible insurance issues at a new pharmacy.
- If your child is not using a rescue medicine now, such as Diastat, call your nurse or doctor to see if it is needed for the trip.

## Emergency Care

- Ask for and carry a current emergency care plan signed by your care provider.
- Your child should wear a medical bracelet or necklace stating that they have epilepsy. Also include any allergies on the bracelet/necklace.
- Everyone traveling with your child should know first aid. Know what to do and what not to do during a seizure and know how to describe the seizure.

## Vagal Nerve Stimulator

- Carry the registration card with you in case it is needed at the airport.
- If airline or tourist attraction screening is needed, ask to have your child manually searched. This will avoid setting off the security screening device.

## Ketogenic Diet

- Ask to have a refrigerator put in your hotel room to store special diet foods.
- Make enough meals to have on hand during the time that you are traveling. Plan extra meals in case you are delayed by weather. Be sure to take an insulated carrier and enough cooling packs to keep food that you are carrying safe.
- For travel out of the country, you will probably need a letter from the doctor to take foods/liquids for the diet in and out of the country.

## At Your Destination

- Check for the location and phone number of a pharmacy and hospital near you.
- Call ahead for advance seating at restaurants and local attractions.
- Have a hospital bag put together ahead of time so that you will have everything that you need if an emergency happens. Include a change of clothes, money, the emergency care plan and your care notebook or notes about your child's care.
- If you need to visit the Emergency Room while on vacation, the following tips may help make it a smooth visit:
  - Carry an emergency care plan from your care provider. The plan should include the doses of emergency medicines already calculated for your child's weight. This care plan should be signed by your care provider.
  - Bring notes on what has been done in the past to control your child's seizures. Include information on what has not worked for your child.
  - Speak up for your child. You know your child's care best.
  - Bring your care provider's contact information with you.