

Always talk to your doctor first for information and answers to questions, but it can also be good to get in touch with organizations created to support and advocate for individuals with epilepsy.

HERE ARE JUST A FEW OF THE MANY HELPFUL RESOURCES AVAILABLE:

- Ask your physician if there is a **Resource Center** where you are currently receiving medical services.
- Contact your regional chapter of the **Epilepsy Foundation** www.epilepsyfoundation.org
- The **Epilepsy Therapy Project** website has physician-curated information www.epilepsy.com
- Private and non-profit organizations that work to provide epilepsy information and advocacy, such as:
 - The Carson Harris Foundation** www.carsonharrisfoundation.org
 - CURE Epilepsy** www.cureepilepsy.org
 - The Charlie Foundation** www.charliefoundation.org
 - The Chelsea Hutchinson Foundation** www.chelseahutchinsonfoundation.org
 - The Danny Did Foundation** www.dannydid.org
 - Stroup Kids for Kids Foundation** www.tritohelp.org
 - Talk About It!** www.talkaboutit.org



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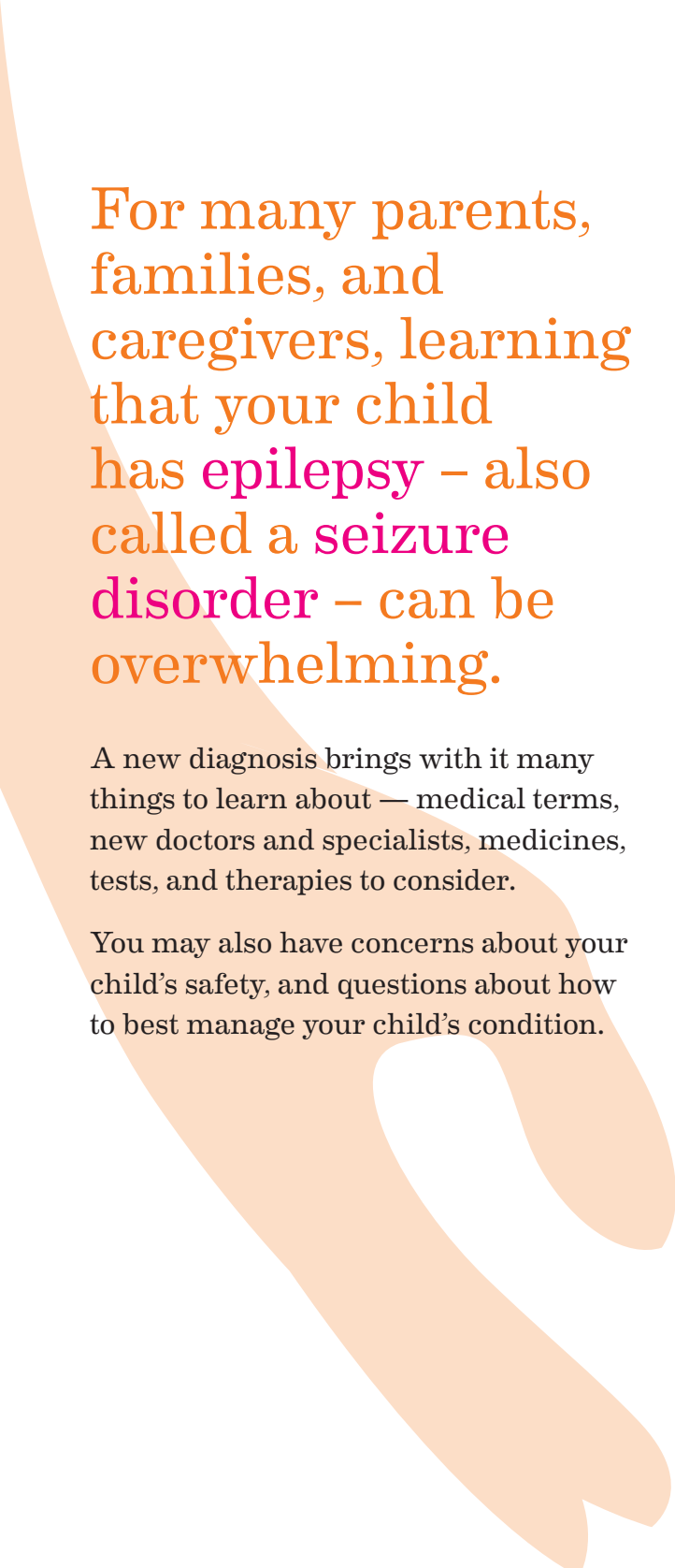
Kennedy Krieger Institute: Joshua Ewen, M.D., Janet Lam, M.D., M.H.S.
Johns Hopkins Medicine, The John M. Freeman Pediatric Epilepsy Center:
Sarah Doerrer, C.P.N.P.
Parent Consultant: Laura LeBrun Hatcher © 2014 Hatcher Design Office, LLC

IF YOUR CHILD HAS SEIZURES

A GUIDE FOR THE PARENTS, FAMILIES, AND
CAREGIVERS OF NEWLY DIAGNOSED CHILDREN
WITH **EPILEPSY** OR A SEIZURE DISORDER



*Brought to you by Johns Hopkins Medicine
and Kennedy Krieger Institute*



For many parents, families, and caregivers, learning that your child has epilepsy – also called a seizure disorder – can be overwhelming.

A new diagnosis brings with it many things to learn about — medical terms, new doctors and specialists, medicines, tests, and therapies to consider.

You may also have concerns about your child's safety, and questions about how to best manage your child's condition.

Fortunately, you are not alone.

Besides headaches, seizures are the most common neurological disorder in children. In fact, 1 in 26 Americans will experience a seizure at some point in their lives and about 1% of the population has a diagnosis of epilepsy. This brochure has been created by parents and doctors who understand how overwhelming it can be in the beginning of your journey with epilepsy.

The information here is intended to introduce you to some important facts and terms, and to answer common questions many people have when their child has seizures. It is not intended to replace the advice and expertise of your child's physician.

We hope that this brochure will help you better communicate with your doctor and increase *your* confidence as the primary expert on YOUR child.

What is epilepsy?

Sometimes also referred to as “Seizure Disorder,” epilepsy is diagnosed after an individual has experienced two or more unprovoked seizures, meaning that the seizure did not occur as a result of a brain infection or, in children under the age of 7, a fever. Epilepsy can sometimes be diagnosed after a single seizure if a person’s EEG shows a high likelihood of seizure recurrence. Epilepsy is a neurological disorder. It is not contagious, and it is manageable.

EPILEPSY CAN OCCUR FOR A VARIETY OF REASONS:

- Structural Epilepsy results from a brain trauma, tumors, strokes, or congenital conditions that affect the structure of the brain.
- Inability of the brain to make certain chemicals or break down certain wastes.
- Genetic abnormalities; sometimes genetic testing is performed to identify certain genes known to cause epilepsy.
- Idiopathic Epilepsy or Epilepsy of Unknown Cause; for many children, it is not yet possible to determine the cause of their epilepsy. As science learns more about the causes of epilepsy it is hoped that we will be able to identify the cause for all children in order to better be able to treat them.

How will I know if my child has epilepsy?

When your child has his/her first seizure, you need to take them to the emergency room to be evaluated. If the cause of the seizure is not apparent, a doctor will request tests to better understand your child’s seizure.

THESE TESTS MAY INCLUDE:

- An **EEG** (electroencephalogram) is a test that records the electrical activity in the brain. EEGs can be useful in helping doctors diagnose epilepsy, determining where in the brain a seizure is coming from, and helping to predict the likelihood of seizure recurrence. During an EEG, the technician may have your child hyperventilate (by blowing on a pinwheel, for example) and flash a strobe light into your child’s face to provoke seizure activity on the EEG. This is safe and will NOT harm your child. The test will also attempt to capture your child’s brain waves when he/she is asleep so it is best to bring your child to the test when he/she is more tired than usual.
- A **CT Scan** (computed tomography) or **MRI** (magnetic resonance imaging) which looks for structural abnormalities in the brain.
- A **Blood Test** or **Lumbar Puncture** (spinal tap) to determine if an electrolyte abnormality or infection is the reason for your child’s seizures.

If your child is diagnosed with or suspected to have epilepsy, you will be referred to a **neurologist** (a doctor specializing in brain function) or an **epileptologist** (a neurologist that sub-specializes in epilepsy) for further treatment.

What are seizures?

A seizure is a temporary abnormal firing of the cells in the brain. There are two type of seizures: focal seizures, or seizures that occur in *part* of the brain, and generalized seizures, or seizures that affect the *entire* brain. A single seizure does not usually require treatment because it is not uncommon for a person to experience one seizure and never have another one. *Having one seizure does NOT mean that a person has epilepsy.*

There are many different kinds of seizures. Your child may have just one kind or a combination of types. Different medicines are used to treat different types of seizures. Knowing about the variety of seizures can help you accurately communicate with your doctor to help determine the best course of treatment.

TYPES OF SEIZURES:

FOCAL SEIZURES: start in PART of the brain.

This is the most common type of seizure. Formerly called “partial seizures,” these usually last less than 5 minutes. Since the seizures originate in different parts of the brain the outward signs of the seizure can vary greatly from person to person.

FOCAL SEIZURE WITHOUT ALTERATION

IN AWARENESS: A person remains awake and alert but may have symptoms that affect their senses, such as seeing or hearing things that are not there. Unusual feelings, like déjà vu, sudden fear or anger can also occur. Sometimes simple partial seizures precede other types of seizures and are called “auras.”

FOCAL SEIZURE WITH ALTERATION IN

AWARENESS: An individual may be unresponsive to touch or sound or exhibit unusual movements such as picking at clothing or lip smacking called automatisms. Sometimes the seizure will *generalize* (spread from part of the brain to all of the brain).

GENERALIZED SEIZURES: Seizure activity occurring in the entire brain at once.

TONIC-CLONIC: Formerly called “grand mal,” this seizure involves the entire brain. A person may experience stiffening and rhythmic jerking of the arms, legs, and torso. Shallow breathing and bluish discoloration of the skin and lips may occur. S/he may bite their tongue and/or become incontinent. Afterwards a person is often confused or tired and may go into a deep sleep. This recovery time after a seizure is referred to as the “post-ictal” state.

TONIC: The body, arms, and/or legs make sudden stiffening movements and the face may grimace. A person may lose balance and fall if they were standing when the seizure started.

ABSENCE: Formerly referred to as “petit mal” seizures, absence seizures generally last less than 10-15 seconds. During an absence seizure, the person seems temporarily “blank” and then returns back to themselves right away. Sometimes they will demonstrate chewing or eye movements while appearing otherwise unresponsive. Typically, children having this type of seizure will experience dozens per day and it can be misinterpreted as behavior associated with ADHD.

DROP or ASTATIC: A sudden loss of consciousness and muscle tone, a child may drop just their head, or their entire body might fall to the ground. These are often brief with a quick recovery.

MYOCLONIC: Myoclonic seizures involve sudden, “lightening fast” involuntary muscle movements or jerks. They can appear singly or in clusters.

INFANTILE SPASMS: Occurring in clusters, a baby’s trunk suddenly bends over while the arms extend outward. This severe form of epilepsy must be treated quickly to reduce the risk of developmental problems.

EPILEPTIC ENCEPHALOPATHIES: In rare cases, seizure activity in the brain (as shown on an EEG) may lead to problems with language, attention, social function and other cognitive abilities. This activity does not present with outward “physical” symptoms as in other seizure types.

Can seizures hurt my child?

Though they may look scary and can be disruptive, most seizures do not have adverse effects. Most people with seizures enjoy very normal lives. However, to keep your child as safe as possible, there are some safety precautions to be aware of.

SEIZURE PRECAUTIONS:

- **Water safety:** Never leave your child unattended in or around water deeper than a few inches. Children should be fully supervised in the bathtub. Showering is recommended and children may shower alone. Swimming is permitted if the child is fully supervised by an adult able to pull the child from the water in case of a seizure.
- **Sports precautions:** Most sports and recreational activities are safe for children with epilepsy. Exceptions include: activities involving guns or bows and arrows, scuba diving, sky diving, and boxing. Your child may ride a bike while wearing a helmet. Roller coasters are safe. If you aren't sure about the safety of your child's preferred activities(s), please ask your doctor.
- **Preventing falls:** Avoid activities involving heights unless your child is wearing a harness.
- **Night-time safety:** Your child CAN and SHOULD sleep in his/her own bed. However, children should not sleep on the top bunk. It is a good idea to reduce bedding and toys in the child's bed. If your child suffers from severe, life-threatening seizures while asleep, ask your provider if night time monitoring devices would be appropriate.
- **Medicine:** If your child has been prescribed seizure medication, make sure to use it as directed. Ask your doctor what to do in the case of a missed dose. Do not discontinue or alter your child's medicine, or give your child any over-the-counter medications, vitamins, or herbal supplements, without consulting your doctor first.

What should I do if my child has a seizure?

Taking care of a child with a medical condition can sometimes take extra care and knowledge. Knowing what to do when your child has a seizure is both important and empowering. See the [Seizure First Aid](#) box below, and be sure to talk to your doctor about what to do during your child's seizures.



TIP: KNOW SEIZURE FIRST AID

Following these basic instructions can help to keep a person having a seizure safe.

- **Remain calm**
- Try to **make the person having the seizure as safe as possible**. Move them to the ground, in a clear area away from anything they could injure themselves with or on. If possible, place them on their side to prevent aspiration in case they vomit.
- **Do NOT restrain the person having the seizure or put anything into their mouth.**
- Whenever possible, try to **time the seizure**.
- **A seizure lasting more than 5 minutes is a medical emergency and you should call 911.** If applicable, deliver rescue medicines as directed by the child's doctor.
- After the seizure is over, try to **reassure the person who had the seizure**. They will likely be confused. Stay with them as they recover.
- In addition to the above tips, it can be helpful to take a CPR class and/or brush up on first aid in case of a seizure-related fall or other injury.

Take note!

A new diagnosis can be overwhelming, but being organized can help you stay on top of your child's treatment. Here you can record doctor's information, write down questions, and take notes.

OUR DOCTOR(S):

Office Phone:

Emergency/After Hours Contact:

OUR PHARMACY:

Phone:

Fax Number:

MEDICINE(S):

Name:

Dosage:

Name:

Dosage:

QUESTIONS to ask and additional notes:



TIP: KEEP A SEIZURE LOG

If your child has a seizure, recording all of the details can be helpful to your doctors as they determine the best treatment options for your child. Answering the questions in the sample seizure log below can help you create an accurate report. You can make copies of this page for future use.

SEIZURE LOG – Note the following information:

Date:

Time:

How LONG did the seizure last? Always try to time a seizure. If a seizure lasts more than 5 minutes, call 911 unless otherwise directed by your doctor.

What did your child do DURING the seizure?

What did your child do AFTER the seizure?

What was your child doing BEFORE the seizure happened?

Note the time of day, activities, and behavior.

Was your child sick at the time of the seizure?

When was the last dose of seizure medicine(s)?

Is your child taking any other medications?