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# EPILEPSY

A PRIMER FOR PARENTS



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*This publication is brought to you by Epilepsy Alliance Florida's Project IMPACT-Transforming Health Care for Children & Youth with Epilepsy*

### EPILEPSY ALLIANCE FLORIDA

Epilepsy Alliance Florida (EAFLA) is dedicated to supporting those impacted by epilepsy by confronting the spectrum of challenges created by seizures. The organization was established in 1971 as a not-for-profit 501(c)(3) and serves as the principal agency for epilepsy programs and services sponsored by the State of Florida. There are an estimated 500,000 Floridians who suffer from the condition. EAFLA is a proud member of the national Epilepsy Alliance America and serves as the lead advocate for the rights and needs of people with epilepsy and seizures at the local, county, state and national level.

1 in 26 people live with epilepsy. There is no cure. We are here to help. By supporting Epilepsy Alliance Florida, you are helping us further our mission: supporting those affected by epilepsy in local Florida communities. Will you join us in our fight against epilepsy? Services include ongoing medical care, social services, case management, psychological services, support groups, summer camp for children with epilepsy, prevention and education for individuals, groups or the community at large as well as advocacy for persons with epilepsy.



## What is Epilepsy?

Epilepsy is a neurological disease, which causes your child to have recurring unprovoked seizures.

## What Are Seizures?

Seizures are strong bursts of electrical activity in the neurons (nerve cells) of the brain. During normal brain activity, nerve cells fire as different parts of the brain are activated. Those different nerve cells alternate their firing patterns as they send their messages throughout the brain. However, during a seizure, large groups of nerve cells fire all at the same time. A seizure is like an electrical storm in your brain.

A child's brain has billions of nerve cells that "talk" or communicate with each other through tiny electrical charges. If too many of these cells suddenly fire together, a wave of electrical energy sweeps through the brain and causes a seizure.

There are many different kinds of seizures which typically fall under two categories; either generalized seizures affecting the whole brain or focal seizures affecting only part of the brain

## What are the signs of childhood epilepsy?

Seizures take many different forms. A seizure may last for a few seconds and involve a blank stare or a sudden fall. It may last for a few minutes and involve a convulsion or random purposeless movements such as chewing motions or pulling at clothing. Sometimes it is difficult to distinguish between a seizure and unusual behavior in a child. What is important to watch for is a pattern of behavior that happens too often to be by chance.

**Signs that may indicate that a child is having a seizure include:**

### Babies

- Clusters of bowing or bending movements while a baby is sitting
- Clusters of grabbing movements with both arms while a baby is lying down

### Children and Adolescents

- a sudden loss of awareness that may appear like daydreaming
- repeated jerking movements of the body, arms, or legs
- a brief lack of response
- memory gaps
- sudden fear, panic, or anger without an apparent reason
- rhythmic head nodding
- rapid blinking
- repeated movements that seem unnatural
- unusual irritability and sleepiness when awakened from a sleep
- sudden falls without an apparent reason
- sudden stomach pain followed by sleepiness and confusion
- frequent complaints that things taste, sound, smell, look, or feel strange

## What causes epilepsy & seizures?

Epilepsy is caused by a number of factors that affect the brain. The cause of epilepsy is sometimes genetic and sometimes acquired but often the cause includes both genetic and acquired factors. The causes vary according to the age of the onset of epilepsy. Seizures are classified as symptomatic in which the defined cause is known or idiopathic in which the cause is unknown. In approximately 60 to 75 percent of epilepsy cases, no specific cause of the seizures can be identified. In the remaining 25 to 40 percent, some of the identifiable causes include:

- Genetic
- Birth injury (e.g. lack of oxygen to the baby's brain at birth)
- Developmental disorder
- Brain trauma (e.g. from car accidents, sports injuries)
- Infection (e.g. meningitis, encephalitis, AIDS)
- Brain tumor

## What are the different types of seizures?

Seizure type	What It Looks Like
<b>Generalized Tonic Clonic</b> (also called Grand Mal)	Sudden cry, fall, rigidity, followed by muscle jerks, shallow breathing or temporarily suspended breathing, blush skin, possible loss of bladder or bowel control, usually lasts a couple of minutes. Normal breathing then starts again. There may be some confusion and/or fatigue followed by return to full consciousness.
<b>Absence</b> (also called Petit Mal)	A blank stare beginning and ending abruptly lasting only a few seconds, most common in children. May be accompanied by rapid blinking or some chewing movements of the mouth. The child or adult is unaware of what is going on during the seizure but quickly returns to full awareness once it has stopped. May result in learning difficulties if not recognized and treated.
<b>Focal Onset Aware Seizures</b> (simple partial seizures)	Jerking may begin in one area of the body such as in the arm, leg, or face. Can't be stopped but the patient stays awake and alert. Jerking may proceed from one area of the body to another; seizure sometimes spreads to become a convulsive episode. Partial sensory seizures may not be obvious to an onlooker. Patient experiences a distorted environment and may hear or see things that are not there or may feel unexplained fear, sadness, anger, or joy, may have nausea, experience odd smells, and have a generally "funny" feeling in the stomach.

<p><b>Focal Onset Impaired Awareness Seizures</b> (complex partial seizures)</p>	<p>Usually starts with a blank stare, followed by chewing, followed by random activity. Person appears unaware of surroundings, may seem dazed, may mumble, and may be unresponsive. Actions appear clumsy, not directed. May pick at clothing, pick at objects, and try to take clothes off. May run, appear afraid, struggle, or flail at restraint. Once a pattern is established, same set of actions usually occur with each seizure. Lasts a few minutes but post- seizure confusion can last substantially longer. No memory of what happened during the seizure period.</p>
<p><b>Atonic Seizures</b> (also called drop attacks)</p>	<p>A child or adult suddenly collapses and falls. After 10 seconds or a minute he/she recovers, regains consciousness, and can stand and walk again.</p>
<p><b>Myclonic Seizures</b></p>	<p>Sudden, brief, massive muscle jerks that may involve the whole body or parts of the body. May cause a person to spill what they were holding or to fall off a chair.</p>
<p><b>Infantile Spasms</b></p>	<p>These are quick, sudden movements that start between three months and two years of age. If a child is sitting up, the head will fall forward and the arms will flex forward. If lying down, the knees will be drawn up with the arms and head flexed forward as if the baby is reaching for support.</p>

## What are Epilepsies and Epilepsy Syndromes?

In addition to different types of seizures, there are also different types of epilepsy. Types of epilepsy are classified as epilepsies and epilepsy syndromes. This classification system is based on patterns of features common to a type of epilepsy.

**Some of the childhood epilepsy syndromes and epilepsies include:**

<p><b>Benign Rolandic Epilepsy</b></p>	<p>Seizures can occur when the child is awake or during sleep. Seizures that begin during wakefulness involve twitching, numbness, or tingling of one side of the face or tongue. These symptoms can interfere with speech and may cause drooling. The child remains fully aware. These seizures are typically brief, lasting no more than 2 minutes in most cases, and are usually infrequent. Seizures that come on when the child is sleeping may start with twitching of one side of the face, but often progress to a generalized tonic-clonic seizure. They typically are seen shortly after the child goes to sleep or just before they wake up. They can also be seen during daytime naps. Other than seizures, most children are otherwise developing normally.</p>
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<p><b>Juvenile Myoclonic Epilepsy (JME)</b></p>	<p>The seizures usually involve the neck, shoulders, and upper arms. In many patients the seizures most often occur soon after waking up. They usually begin around puberty or sometimes in early adulthood in people with a normal range of intelligence. In most cases, these seizures can be well controlled with medication but it must be continued throughout life.</p>
<p><b>Landau-Kleffner Syndrome</b></p>	<p>This epilepsy syndrome is rare and generally begins in young children under the age of six. The syndrome is characterized by a language disorder that affects the child's ability to understand language and to speak. The syndrome is characterized by a relapse in speech development. Convulsive and non-convulsive seizures may occur although epilepsy-related seizures are often infrequent and are not always experienced with the condition. Seizures may be controlled with hormonal therapy and may be outgrown. In some cases, speech may be recovered by adulthood.</p>
<p><b>Lennox-Gastaut Syndrome</b></p>	<p>Children with this syndrome generally have several different types of seizures including atonic seizures. Its onset is typically in early childhood before the age of six. The syndrome is most common in children who have acquired brain damage or a developmental problem of the brain. Lennox-Gastaut syndrome can be difficult to treat and often involves mental impairment. The prognosis is poor for seizure remission.</p>
<p><b>Dravet Syndrome</b></p>	<p>One of the most severe of a group of conditions known as SCN1A- related seizure disorders. Symptoms include seizures which first occur in infancy that are often triggered by high temperatures (febrile seizures). In childhood, many types of seizures may occur and they may increase in frequency. Seizures may be difficult to treat. Other symptoms include loss of motor skills, intellectual disability, speech impairment, and difficulty with movement. Most cases of Dravet syndrome occur when the SCN1A gene is not working correctly.</p>
<p><b>Rasmussen's Syndrome</b></p>	<p>This rare syndrome is associated with uncontrolled partial seizures, intellectual deterioration, and progressive weakness on one side of the body. Typically, the epilepsy begins before the age of 14 years. Medication does not appear to be effective but hemispherectomy surgery may stabilize the condition.</p>
<p><b>Reflex Epilepsy</b></p>	<p>In this type of epilepsy, seizures are triggered by a specific stimulus or event. In photosensitive epilepsy, the most common type of reflex epilepsy, lights flickering at a certain speed and brightness (e.g. from televisions, computer screens, strobe lights, video games, movies) can trigger a seizure. Sometimes natural light patterns such as sunlight reflecting off of water can trigger seizures. Seizures are most often tonic clonic.</p>

## Infantile Spasms (West Syndrome Epilepsy)

Infantile spasms are myoclonic jerks that usually occur in clusters in babies before the age of one. Spasms last only a few seconds but often repeat in a cluster or a series of five to fifty or more. The clusters may occur numerous times a day. When the seizure occurs, the baby appears startled or in pain. If lying down, the baby will suddenly draw up the knees and raise both arms. If sitting, the baby's head and arms may suddenly flex forward and the body flexes at the waist. Typically, the spasms occur when the baby is awakening, is sleepy, or is going to sleep. Often the child experiences developmental delay and cognitive problems. A child with infantile spasms may later develop Lennox-Gastaut syndrome.

## Does Epilepsy Affect Cognitive Function & Development?

The association between epilepsy and cognitive function is a complex one. Cognitive function involves mental processes such as remembering, perceiving, and thinking. Although many people with epilepsy do not experience significant impairment in cognitive function, some do experience changes. Factors that may have a negative impact on cognition and development are:

- Pre-existing cognitive impairment as a result of birth trauma or previous illnesses (e.g. meningitis).
- Severity and frequency of seizures including a history of status epilepticus, a life-threatening neurologic condition defined as 5 or more minutes of either continuous seizure activity or repetitive seizures without regaining consciousness.
- The use of high doses of one or more seizure medications.

Certain epilepsies and epilepsy syndromes are associated with impairment of cognitive development. Some epilepsy syndromes such as Benign Rolandic Epilepsy are referred to as benign. This means that impairment of development or cognitive function is not associated with these types of epilepsy. Other syndromes such as West Syndrome and Lennox-Gastaut are known as progressive because seizures and/or the individuals motor or cognitive abilities can worsen over time. Developmental delay means that the process of physical growth and the development of intelligence and the ability to problem solve are interrupted. If both seizures and developmental delay occur, there is an underlying problem in the brain contributing to both. Although epilepsy is associated with other disorders such as cerebral palsy, epilepsy is just one of a set of symptoms commonly found in people with this disorder.

## How is Epilepsy Diagnosed?

An epilepsy diagnosis is generally made when seizures occur more than once without identifiable reasons. Doctors will try to determine what caused the seizure during the diagnostic process and will begin to check for signs of epilepsy along with other treatable conditions.

Although the diagnostic process may vary, the major steps should include:

- Family History and Medical History
- Detailed Account of the Seizure
- Physical and Neurological Examination
- Genetic Testing
- CAT (Computerized Axial Tomography) or CT Scan
- EEG (Electroencephalogram)
- EEG video telemetry
- MRI (Magnetic Resonance Image)
- PET (Positron emission tomography)
- fMRI (Functional MRI)
- Ictal SPECT (single-photon emission computed tomography)
- MEG (Magnetoencephalography)

The doctor will use exams, tests and a period of observation to determine whether your child's seizures are unprovoked or due to a treatable condition. If your child does receive a diagnosis of epilepsy from the doctor request they classify what types of seizures your child is having and discuss different treatment options that are available. Seizures often do not happen in the doctor's office, so it is important that parents and caregivers observe any unusual behavior and report these to their doctors.





## **First Aid for Seizures**

**What to do if someone has a non-convulsive seizure (staring blankly, confused, not responding, movements are purposeless)**

1. Stay with the person. Let the seizure take its course.  
Speak calmly and explain to others what is happening.
2. Move dangerous objects out of the way.
3. DO NOT restrain the person.
4. Gently guide the person away from danger or block access to hazards.
5. After the seizure, talk reassuringly to the person.  
Stay with the person until complete awareness returns.

**What to do if someone has a convulsive seizure (characterized by stiffening, falling, jerking)**

1. Stay calm. Let the seizure take its course.
2. Time the seizure.
3. Protect from injury. If necessary, ease the person to the floor. Move hard or sharp objects out of the way. Place something soft under the head.
4. Loosen anything tight around the neck. Check for medical identification.
5. DO NOT restrain the person.
6. DO NOT put anything in the mouth. The person will not swallow his or her tongue.
7. Gently roll the person onto their side as the convulsive seizure subsides to allow saliva or other fluids to drain away and keep the airway clear.
8. After the seizure, talk to the person reassuringly. Do not leave until the person is re-oriented. The person may need to rest or sleep.

## **When to call 911**

- If it is a first-time seizure, or the person is injured, pregnant, or has diabetes.
- If a convulsive seizure lasts longer than 5 minutes.
- If consciousness or regular breathing does not return after the seizure has ended.
- If seizure repeats without full recovery between seizures.
- If confusion after a seizure persists for more than one hour.
- If a seizure occurs in water and there is any chance that the person has inhaled water.

## Stages of a seizure:

Certain medical terms are used to refer to the stages of a seizure.

An **aura** results in an unusual sensation, feeling, or movement. An aura is a Focal Onset Aware (simple partial) seizure that may occur alone or may progress to a Focal Onset Impaired Awareness Seizure (complex partial seizure) or a generalized seizure. If the aura indicates the onset of a complex partial or generalized seizure, it can sometimes be used as a warning signal to allow a person to take the necessary precautions to avoid injury. The **ictus** refers to the seizure itself. The **postictal period** follows the seizure. A child may temporarily experience confusion (postictal confusion), weakness (postictal paralysis), or sleepiness (postictal state).

**Seizure Record:** Carefully observing your child's seizures is important. As your doctor may not view one of your child's seizures personally, providing detailed descriptions of the seizures will assist the doctor. Asking others who were with your child during a seizure (e.g. teachers or caregivers) for detailed descriptions is useful. Often a person who has had a seizure does not remember the seizure. Seizure record charts are available from most epilepsy organizations or you could use a notebook or create your own chart. In addition to detailing the characteristics of the seizures, a record will also provide information regarding the frequency and duration of the seizures. It may also help to identify any consistent seizure trigger.

In the seizure record, it is important to record information such as:

- the time the seizure occurred
- the date the seizure occurred
- how long the seizure lasted.

Include any information that describes your child's behavior before, during, or after the seizure such as:

## Before the seizure:

- What was your child doing before the seizure?
- Were there any provoking factors (e.g. lack of sleep, exposure to flickering lights from television, strobe lights, etc., recent illness, drug or alcohol abuse, missed medication, missed meals)?
- Did your child experience symptoms that preceded the seizure by many hours or days (known as prodrome) such as mood changes, dizziness, anxiety, restlessness?

### **During the seizure:**

- How did the seizure begin?
- Did your child experience an aura?
- Was there unusual or involuntary body movement? What part of the body moved first? Next?
- Was your child responsive during the seizure?
- Did your child experience automatisms (e.g. lip smacking, chewing movements, rapid blinking, head turning, pulling at clothing, random walking)?
- Did your child appear to be daydreaming?
- Did your child stare blankly?
- Did your child's eyelids flutter or eyes roll?
- Did your child's body become rigid?
- Did your child cry out or yell?
- Was there jerking and if so, did it occur on one side of your child's body more than on the other?
- Did your child's skin change color?
- Did your child's breathing change?
- Did your child fall?
- Did your child bite his or her tongue or lip?
- Did your child lose bowel or bladder control?

### **After the seizure:**

- Did your child experience temporary weakness in any part of the body, fatigue, confusion, and/or headache?
- How long did this period last?
- Was there injury as a result of the seizure?



## What should I tell teachers and friends?

Even though over 3 million Americans are affected by epilepsy, most people still know little about it. Help others in your child's life understand what epilepsy is and make sure they know what to do if your child has a seizure. This will not only help keep your child safe, but it will help your child feel more comfortable and do better at school. By talking openly and honestly about epilepsy, you can help decrease some of the stigma and fear about it. Ask your child's doctor about a Seizure Action Plan to share with your child's school. A blank Seizure Action Plan is available to download on the Epilepsy Alliance Florida website: [www.epilepsyalliancefl.org](http://www.epilepsyalliancefl.org)

## Life Stages with Epilepsy

Epilepsy is the type of disorder that is not restricted to a certain age or stage of life. It can affect anyone at any time—more than 470,000 children experience it. It is never too early to start the conversation about epilepsy with your child but assessing what is appropriate for their age and comprehension is key in initiating these conversations. First, seek to learn all that you can about epilepsy then encourage conversation with them and be ready to answer their questions as well. Your local Epilepsy Alliance America member can assist you with locating a doctor or resources to aid in the education of your children surrounding this topic. In addition, please see the Resources section for educational material on our website: [www.epilepsyalliancefl.org](http://www.epilepsyalliancefl.org)

Professionals may be needed in this process including your child's teacher or caregiver as well as professional counselors and psychologists. It is important to remember that factors such as the type of epilepsy your child has, seizure triggers and more will determine how it affects their life. Epilepsy can feel very isolating so consider ways to keep your child engaged in social activities including Epilepsy Alliance America summer camps held each year.





## **Infants and Toddlers**

While seizures can occur at any stage of life, it happens most frequently in infants and toddlers. This may be attributed to the fact that this stage is characterized by the most changes and growth in the brain. Observing any irregular behavior or events and informing your health care provider is essential in early diagnosis and getting seizures under control. This is especially essential for younger children who cannot communicate what happened and how they are feeling as yet.

Childcare centers and schools can often be a challenge for parents of children with epilepsy whether due to refusing to accept these children or refusing to be responsible for the administration of rescue medication. These centers or schools may not be allowed to make such restrictions under the Americans with Disabilities Act. Contact Epilepsy Alliance Florida for further information on local laws and resources.



## Children

The impact of epilepsy may not just be physical especially for children as they get older. It is not uncommon for epilepsy to affect their academic performance, social relationships and the types of activities they may or may not be allowed to participate in. Addressing concerns with your child's teacher or a psychologist may be needed. In addition, keeping your child active and socially engaged especially among peers who understand epilepsy and will not treat them differently is important for your child's development. Having routines and boundaries is also essential as with any child. For assistance in disciplining your child if there is concern of triggering a seizure speak with your child's doctor.



## Adolescents

The adolescent stage early teen years is also a stage typically characterized by many new changes and experiences. Social relationships are especially important to them at this age and they want to be treated like everyone else. Encourage open and honest conversation with your adolescent child about epilepsy and what that means for them. Contact Epilepsy Alliance Florida for resources on online discussion groups they can join to meet peers also living with epilepsy.

## Keeping your child safe

You want your child to have a fulfilling childhood, but you also want to protect him/her from any seizure related accidents. When your child has epilepsy, everyday things, such as climbing steps, riding a bike and swimming in the local pool can be dangerous. Each family has to make their own decisions about what is safe for their child. This will vary depending on your child's age, interests, and type of seizures and how well the seizures are being controlled. If there is any doubt, talk to your doctor.

In general, the more active and involved your child is the better. However, for the child with epilepsy there are some extra safety precautions you should take. This is especially true around water. You should always:

- Supervise young children during baths and have older children take showers. Adjust the water temperature in your house to low in order to avoid serious injury if a child has a seizure when hot water is running. Make sure the drain works well and won't clog. Never let your child swim without an adult watching.
- As with all children, those with epilepsy should wear helmets when bicycling, skateboarding, etc. If your child has seizures that cause sudden falls, your doctor might also recommend wearing a helmet when playing outdoors around steps, and/or other areas that may impact the severity of a fall. Children with epilepsy can participate in many organized sports. Your physician or allied health professional should be consulted regarding any questions you may have. For the older child, be aware of the potential risks related to cooking such as injuries from hot water and stove tops.
- Two of the most important things you can do to protect your child are to make sure that:
  1. Your child takes medication as directed.
  2. There is always someone with your child who knows what to do if your child has a seizure.

It is only natural for a parent to worry about their child with epilepsy. The risk of injury and even death are possible if your child has seizures but there must be a balance between keeping your child safe and overprotecting your child at the expense of valuable life experiences such as your child's need to explore and master his environment, which is crucial for healthy development. Children with epilepsy need to play and take responsible risks.

# LIVING WITH EPILEPSY?

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### **Camp for Kids with Epilepsy**

Campamento para niños con epilepsia



**And More!**

¡Y Mas!

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