Seizures and Autism

Research studies suggest that 15-30% of people with Autism experience seizures. Besides headaches, seizures are the most common neurological disorder in children in general. In fact, 1 in 26 Americans will experience a seizure at some point in his/her life and about 1% of the population has a diagnosis of epilepsy.

What are seizures?
A seizure is a temporary, abnormal firing of the cells in the brain. There are many types of seizures that appear in a wide variety of ways. Different types of seizures may affect a child’s life differently and may have different treatments. 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.

What forms can seizures take?
People may typically think of violent shaking on the ground when they hear the word seizure. But seizures can take many forms. Features can include:
- Staring off “glassy expression,” usually such that no one can get the child’s attention, even through tickling or light pinching
- Sustained limb or body tensing, stretching or bending
- Rhythmal, repeated muscle movements
- Quick twitches
- Eyeball twitching

There are, however, causes of these spells other than seizures, so it is important to discuss the symptoms and your child’s condition with a neurologist to determine whether or not your child is actually having seizures. A very important thing you can do is **take videos of your child’s events.** This is often the most helpful piece in the puzzle for the doctor to figure out whether the spells are seizures or not.

What is epilepsy?
Sometimes also referred to as “Seizure Disorder,” a diagnosis of epilepsy means that an individual has an increased risk of having future seizures. It is usually diagnosed after an individual has experienced two or more seizures, though there are instances in which having only one seizure would prompt a diagnosis of epilepsy and the treatment for seizures. Epilepsy is a neurological disorder. It is not contagious, and it can be managed.

What causes epilepsy?
Epilepsy can occur for a variety of reasons, including known or presumed genetic mutations that may also contribute to the autism symptoms. Some of these include well-known genetic syndromes, such as Rett syndrome and tuberous sclerosis. In other cases, there may or may not be genetic tests. In some cases, the epilepsy may result from brain malformations, blood vessel malformations on the brain, strokes or abnormal brain development that affects the structure of the brain.

What tests do doctors use to evaluate epilepsy?
When your child has his/her first possible seizure, you need to take him/her to the emergency room to be evaluated. At this point, the doctor is trying to figure out whether or not the spell was a seizure; if so, what type of seizure it was; what the cause of the seizure was and what the risk of another seizure is. Some medical tests can help answer these questions:

- An EEG (electroencephalogram) is a test that records the electrical activity in the brain. EEGs can be useful in helping doctors diagnose epilepsy, determining what type of epilepsy your child has, 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. EEGs are only rarely able to say that a child definitely does or does not have seizures—it is one piece of the puzzle. The helpfulness of the EEG is increased greatly when a child has a seizure while the EEG is being recorded, but this may be very difficult to do if the child is having seizures only occasionally, which is the most common case. In some cases, usually later in treatment, the doctor will admit a patient to a special hospital room in which an EEG is recorded continuously for one or several days, in hopes of capturing a seizure during the EEG.
- A CT Scan (computed tomography) or MRI (magnetic resonance imaging) which looks for structural abnormalities in the brain, in case a tumor or brain malformation is suspected.
- A Blood Test or Lumbar Puncture (spinal tap) to determine if an electrolyte abnormality or infection is the reason for your child’s seizures. This is usually done in cases in which the child is ill. A lumbar puncture is almost always done in an emergency room.
- Genetic Testing may be helpful in some cases to find a gene mutation or genetic syndrome that helps explain both the autism and epilepsy.

What is the link between epilepsy and autism?
The link between these two disorders is complex. Researchers are currently dedicating a lot of effort to uncover the links, as they may help us better understand the causes and potential treatments of both epilepsy and autism. The lifetime risk for epilepsy in a child with autism is around 20%--about 20 times greater than people not on the spectrum. Additionally, the risk of autism in children with epilepsy is also increased. Certain gene mutations have been found both in types of epilepsy and cases of autism. An extremely rare form of epilepsy, Landau-Kleffner syndrome, in which there is continuous abnormal electrical brain activity at night, is known to cause symptoms similar to autism. Aggressive and complex treatments may be able to reverse the epilepsy and autistic symptoms in a small number of cases. In general, however, the treatments for epilepsy in individuals with autism are identical to those for individuals who have epilepsy but no autism. Autistic symptoms generally do not change when the seizures are treated.
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Additionally, children with autism are known to have abnormalities on EEGs that suggest epilepsy—despite the fact that the child has never had a seizure. The importance of these findings is a matter of debate. Some doctors have been known to prescribe seizure medications for these EEG abnormalities, but it is not known that this treatment—which has potential side effects—can produce benefits to the autistic symptoms.

What type of doctor treats 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 should parents do if their 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. 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.** Seizures usually seem to last much longer than they actually do.

**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.**

What are the precautions parents can take to keep their child safe during a seizure?
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:

• **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.
• **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.

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.

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**Additional Resources**

- The Epilepsy Foundation
  [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)
- Abilities Network
  [www.abilitiesnetwork.org](http://www.abilitiesnetwork.org)
- The Carson Harris Foundation
  [www.carsonharrisfoundation.org](http://www.carsonharrisfoundation.org)
- Kennedy Krieger Institute
- KKI EEG Information Packets for Parents
- Johns Hopkins Medicine Pediatric Neurology
  [http://m.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/pediatric-neurology/](http://m.hopkinsmedicine.org/neurology_neurosurgery/centers_clinics/pediatric-neurology/)
- The Charlie Foundation
  [www.charliefoundation.org](http://www.charliefoundation.org)
- The Chelsea Hutchinson Foundation
  [www.chelseahutchisonfoundation.org](http://www.chelseahutchisonfoundation.org)
- The Danny Did Foundation
  [www.dannydid.org](http://www.dannydid.org)
- CURE Epilepsy
  [www.cureepilepsy.org](http://www.cureepilepsy.org)
- The Danny Did Foundation
  [www.dannydid.org](http://www.dannydid.org)
- Stroup Kids for Kids Foundation
  [www.tritohelp.org](http://www.tritohelp.org)
- Talk About It!
  [www.talkaboutit.org](http://www.talkaboutit.org)