

Epilepsy (Parents)



Epilepsy: What is it and who has it?

Epilepsy is condition where a person has repeated seizures. A seizure happens when the brain does not work as it should. If your child has more than one seizure, a doctor may do more tests and tell you that your child has epilepsy.

Millions of people in the world have epilepsy. There are different reasons why people may have it. Sometimes, more than one person in the same family can have it. It can also start after a head injury or an illness. The doctor may not be able to tell you why your child has it because many times the reason is not known.

What happens during a seizure?

Not all seizures are like what you may have seen or heard about. The brain tells the body how to move, feel, and see. When your child has a seizure in a part of the brain, they may lose control of their body. Seizures can happen the same way each time or can also change. A seizure may cause your child to:

- Shake or jerk the body
- Blink or move eyes
- Laugh, cry, or scream
- Stare like daydreaming
- Have a hard time breathing
- Smell, hear, or see things
- Pass out
- Smack their lips, drool, bite their tongue
- Make their body stiff, run, walk, or move (without wanting to)
- Throw up or have a stomachache
- Mix up words

What should I do if my child has a seizure?

1. Please stay with your child when they are having a seizure and try to time how long it lasts.
2. Do not put things in your child's mouth.
3. Do not try to hold your child down, but it is okay to turn them on their side. Please teach this to friends and family.

Please call 911 if your child:

- Has a seizure that lasts more than five minutes.
- Has more than 2 or 3 seizures in a short time.
- Can't breathe or turns blue.
- Has a seizure in water (inside a pool, bathtub, etc.)
- Your child gets hurt

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What happens after your child has a seizure?

After your child has a seizure, they may show many types of behaviors. They may:

- Not respond right away, feel confused, or get very sleepy.
- Feel fuzzy, dizzy, or lightheaded.
- Experience many emotions like sadness, fear, frustration, anxiety, embarrassment, or shame.
- Have difficulty talking or writing

Your child could also be hurt if they fell during the seizure. Please get medical attention right away if your child says that their body or head hurts.

Why should I talk about epilepsy?

When you talk about your child's epilepsy diagnosis, you can teach others that epilepsy is a part of your child but does not make them who they are. You may feel mad that your child cannot do everything that you wish they could do. Your friends may know others with epilepsy or other conditions and may be able to relate to you and help talk you through your feelings.

It is also important to share information about epilepsy for your child's safety. You may feel scared about your child having a seizure in front of people, but when your friends and family know this, they may help you. Being open with school staff helps them understand why your child takes medicine and allows them to help your child follow their medicine plan. They can also help with resources your child needs to help them succeed in school.

You can teach others that epilepsy is not a curse and that judging your child is not okay.

How do I talk about my child's epilepsy with friends and family?

- Explain that your child may have seizures sometimes.
- Tell them about the type of epilepsy and seizures that your child has. This will help them know when they need to get help.
- Explain that it is a medical condition that they cannot "catch" from your child.
- Help them understand that having epilepsy does not mean that your child cannot play! Your child should still be able to go on school trips and the school has to treat your child the same as other children.

Bullying

Children with special medical needs sometimes have a higher risk of being bullied at school. Bullying is when someone makes fun of your child or is mean to them because of their medical issue. This can sometimes cause emotional problems such as depression and anxiety. In serious cases, it can lead to suicide. If someone is bullying your child, talk to someone to find the help to stop it. There are many programs to stop bullying in school.

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If you want to learn more about epilepsy and issues related to epilepsy, you can look at these websites:

- <http://talkaboutit.org/>
- <https://www.epilepsy.com/>
- <https://www.stopbullying.gov/>

You can also call a toll-free line to answer questions to help support your child and learn more: **U.S. Toll-Free Helpline 24 hours a day: 1-800-332-1000**

Who do I contact at CHLA if I need more information?

Please call the Neurology Clinic at 323-361-2471