



ABOUT THE EPILEPSY FOUNDATION

The Epilepsy Foundation is the national voluntary agency solely dedicated to the welfare of the more than three million people with epilepsy in the U.S. and their families. The organization works to ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through services, education, advocacy and research. In addition to programs conducted at the national level, people with epilepsy are also served by local Epilepsy Foundation affiliates across the country.

If you have any questions about epilepsy and seizure disorders, living with epilepsy, or helping a friend or family member who has epilepsy, please visit us on the Web at www.EpilepsyFoundation.org or call 800-332-1000.

Our Web site has information about the disorder, offers opportunities to network with others touched by epilepsy through our eCommunities forums and Web events. You can also subscribe to our bi-monthly magazine *EpilepsyUSA*. Each issue contains exciting developments for people affected by seizure disorders—new treatments and medicines, ground-breaking research, safety tips, personal stories, advice for parents and much, much more—all delivered right to your door.



ABOUT EPILEPSY

Epilepsy is a disorder of the brain's electrical activity.

It is not a **mental illness**.

It is not an illness that will make a child mentally disabled. Most children who have it are otherwise quite normal and healthy.

Epilepsy is an illness that, for a short time only, changes the way a child's brain works.

Epilepsy may make a child have blackouts.

It may make them fall suddenly to the floor, get stiff, and shake all over.

It could make parts of their body jerk and shake, give them a sudden pain in their stomach or make them feel afraid or angry.

A seizure can make a child act as if they are half asleep. During these times, they may walk around, pick at their clothes or not make sense when talking. These changes in how a child feels and acts are called seizures.

Sometimes seizures are called fits, spells, or falling out, depending on what they look like.

While a seizure is going on, the child has no control over their actions. They may not remember anything about it at all once the seizure is over.

WHY SEIZURES HAPPEN

Epilepsy isn't the only reason for a child to have a seizure. Seizures can be caused by anything that changes the way the brain works.

A high fever can do it,

Or a bad infection that goes to the brain,

Or a blow to the head,

Or a scar on the brain from an old injury,

Or a poison, like lead.

Some of these things can be cured or will go away, then the seizures will go away too.

But if a child has epilepsy, they will go on having seizures of one kind or another until they are treated by a doctor.

HOW EPILEPSY IS TREATED

When a doctor is sure a child has epilepsy, they will pick out the medicine that will work best against the kind of seizure the child has been having.



If the medicine doesn't work well or if the child begins to feel sick, gets rashes, or has other side effects from it, the doctor will try another medicine. It may take time to find the right medicine for the child.

Sometimes, if none of the medicines work, a special diet can be tried instead.

Children do not always react to medicine in the same way. Your doctor will want to know how your child does on the medicine.

Be sure to tell your doctor if your child gets very sleepy, won't eat, feels dizzy, acts drunk, gets a rash, or starts acting mean or different in any way after taking the epilepsy medicine.

Don't stop the medicine yourself if you think your child is getting sick from it. Call your doctor at once and do what he or she says.

If you suddenly stop the medicine on your own or if it runs out, you run the risk of your child having a bad seizure that could go on and on and could even be a risk to their life.

Any time a child has a seizure that won't stop, you should take the child to the hospital at once.

Most seizures last only a minute or two and end by themselves.

A long seizure or one seizure right after another means your child needs medical attention quickly.

HELPING THE TREATMENT WORK

Some children who have epilepsy do very well on the medicine. They have no seizures as long as they keep taking it. Other children still have some seizures even though they take the medicine.

There is no way to tell how well a child is going to do, but here are things parents can do to help the medicine work.

- Make sure your child takes the medicine at the same time every day as the doctor prescribed.
- Tell your child why they are taking the pills. Taking them ensures they will stay well and makes it harder for a seizure to start.
- You can help your child understand that epilepsy medicine only works when it is in the body. The body uses up medicine like a car uses up gas. If your child doesn't put medicine into his or her body every few hours, there won't be enough medicine to stop the seizures and they will start again.



- If your child is old enough, have he or she help you each morning count out the pills that need to be taken each day.
- Put the medicines in a special place so you or the child can check if you think one might have been missed.
- Some children mark a calendar so they can keep track of when they take their pills. You can get pill boxes that have sections for each day's pills to help your child keep track.
- If you are giving the medicine out of a bottle, be sure to shake it before you pour the dose so it's always the same strength.
- Sometimes children think they get sick because they did something bad. You can help your child know this is not true. Having epilepsy is not your child's fault or anyone else's fault.

If your child goes on having seizures, he may think more medicine is needed and try to take more than he or she should. Make sure your child knows that the best dose is what the doctor has said to take, and that taking more will not do a better job. It could possibly make them feel sick.

HANDLING SEIZURES

If your child has tonic-clonic seizures, where he or she gets stiff and shakes, make sure that everyone in your family knows what to do.

Assure them the child is not going to die.

Tell them your child can't swallow his or her tongue.

That's an old idea that lots of people still talk about, but it is not true. You can't swallow your tongue.

Tell your family that all they have to do if your child has this kind of seizure is to:

- Keep calm.
- Put something flat and soft under your child's head so it won't bang on the floor when his or her body shakes.
- Turn your child gently on his or her side.
- Don't put anything hard in your child's mouth or they could hurt their teeth or jaw.
- Don't try to hold him or her down to stop the shaking.
- Don't try to give your child a drink or throw water on your child to bring him or her around.

- Stay with your child until the seizure stops and he or she is awake again.

Most children do NOT have to go to the hospital every time they have a seizure. Most seizures end by themselves without any harm to the child. If you are unsure, talk to your child's doctor about whether or not you should go to the hospital as part of your child's treatment.

If a seizure looks different from the others your child has had, if it lasts longer, if another one starts right away, or if the child is having trouble breathing or can't be woken up afterwards, take them to the hospital immediately.

UNDERSTANDING HELPS

When a child has epilepsy it helps a lot if everyone in the family thinks the same way about it, and knows what it means.

- Your child should know that they have an illness that only happens sometimes.
- Your child should know what medicines they take to help keep the seizures away.
- Your child should feel that in every other way they are just like any other kid.



BROTHERS AND SISTERS

Other children in the family should know that their brother or sister has epilepsy and what to do if he or she has a seizure.

Brothers and sisters should have a chance to talk about it and ask about things that might be scaring them.

They may be afraid the child with epilepsy will die during a seizure. You can tell them that this is very unlikely to happen.

They may be afraid they'll get epilepsy and start having seizures. You can tell them that's not likely to happen either.

They may be getting teased at school and not know what to say. You can help them work out what is the best way to handle the situation.

They may think their brother or sister with epilepsy gets away with a lot of things they get in trouble for. You may want to think about whether that's true and how you can change it if it is.

OLD IDEAS

Some people in your family may have ideas about epilepsy that are way out of date.

They may feel very bad that your child has it, and see it as a mark of shame on the family.

They may not want you to tell anyone about it.

They may say you should keep your child quiet and not let him or her play rough or get too warm for fear of having a seizure.

They mean well, of course, but if your child is kept away from other children, they won't learn how to get along with others. Your child won't know how to be independent, and may always have to depend on others.

The fact is, most children with epilepsy will not have more seizures just by being active, playing sports or getting hot and sweaty. If you think there's special risk, ask your doctor about it.

A normal, active life with other children is just as good for the child with epilepsy as it is for others.



THINGS TO REMEMBER

- Seizures are not the work of any evil spirit and can't be cured by magic spells or charms. (It is a physical problem just like a broken leg.) They are signs of an illness that doctors know about and can treat.
- There is always hope when a child has epilepsy. Lots of children who are now free of seizures had bad times when their seizures were hard to control.
- Don't give your child less medicine when they have gone a long time without a seizure. Not having seizures is a sign that the medicine is working.
- If you think your child would be okay on less medicine, talk to your doctor about it first.
- Help your child learn how to talk about epilepsy to other people without feeling bad about it. Help your child see it as just a part of life.
- Don't give in to a child or fail to make him or her behave because you think getting the child upset will cause a seizure. Like any other child, they can act up and be hard to handle if you give in.

- Try not to make your other children look after the child who has epilepsy all the time.
- Do everything you can to help your child with epilepsy feel good about him or herself and what they can do in life.





Epilepsy Foundations Offices throughout the country have additional materials and offer a variety of programs to help people understand this common disorder.

*For further information about epilepsy and the name of the Epilepsy Foundation nearest you, log on to **www.epilepsyfoundation.org** or call **800-332-1000**.*

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This pamphlet is intended to provide basic information about epilepsy to the general public. It is not intended to, nor does it, constitute medical advice. Readers are warned against changing medical schedules or life activities based on the information it contains without first consulting a physician.