
Childhood Epilepsy: 12 Things Parents Should Know

1. Seizure Disorder = Epilepsy (but not all seizures are epilepsy)

Epilepsy is a brain condition that causes seizures. Some doctors might use the term “seizure disorder” instead of epilepsy. A seizure is a brief change in how you act, feel, or move. When a seizure happens, you can’t control these changes in your body.

The brain is made up of cells called neurons. Neurons work by sending electrical signals. With epilepsy, sometimes too many neurons fire at once. This causes a seizure.

There are some seizures, though, that are not considered epilepsy. This includes...

- a seizure caused by fever
- a seizure caused by low blood sugar
- a seizure that comes right after a brain injury
- a seizure following alcohol abuse
- a seizure caused by certain drugs

Another type of seizure that’s not epilepsy is a **psychogenic nonepileptic seizure** (PNES). These episodes are not caused by an electrical problem in the brain. Instead, they are caused by stress, often from something bad that happened in the past. Treatment for PNES is very different from treatment for epilepsy.

There are also many things that can look like seizures but aren’t. This includes...

- fainting
- sleep disorders
- panic attacks
- migraines
- breath holding spells

...and many other conditions.

2. There are many types of seizures and many types of epilepsy.

Epilepsy is not a single condition. It is a general term for over 40 different conditions. There are also over 20 different types of seizures. Seizures can involve a wide range of symptoms. Most often, they start suddenly and end after a minute or two. Tell your neurologist about any brief episodes your child has had that involved any of these symptoms:

- loss of consciousness (blacking out)
- not responding to others
- not remembering what just happened
- confusion
- falling for no reason
- staring, chewing, or unusual eye movements
- fumbling with objects, picking at clothes
- wandering around in a daze
- sudden fear for no reason
- déjà vu (feeling where everything seems strangely familiar)
- seeing, hearing, smelling, or tasting something that's not there
- numbness or tingling
- trouble with speaking
- strange feelings that are hard to describe
- movement your child can't control
 - stiffening
 - jerking, shaking, or twitching
 - sudden drop of the head
 - movements that have no purpose

If any of these episodes are seizures, ask your neurologist what type they are. Also be sure to ask your neurologist what type of epilepsy your child has. The more you know about your child's condition, the better you can manage it. Knowing more about your child's specific epilepsy type can help you...

- talk about it with others
- find out more about it at the library, on the Internet, or through Epilepsy Foundation of Michigan
- understand your child's treatment options
- plan for the future

Many tools can be used to help doctors understand your child's epilepsy. Ask your doctor about...

- routine EEG
- ambulatory EEG
- video-EEG monitoring
- keeping a seizure diary and videotaping seizures
- blood tests
- sleep studies
- MRI
- other neuroimaging tests

Sometimes, a neurologist may not know exactly what type of epilepsy your child has. Even so, you have the right to hear everything your doctor *does* know about your child's condition.

3. Most seizures are not emergencies.

Although they can be frightening to watch, most seizures end on their own after a minute or two. There are a few exceptions, however. For example, generalized tonic-clonic (grand mal) seizures that last for more than 5 minutes or take place in water are medical emergencies. Your neurologist should provide you with a plan for how to respond to your child's seizures. The plan should include...

- When and how to provide first aid
- When to call 911
- When and how to give rescue medication (if necessary)*
- How to watch for and respond to seizures during sleep (if necessary)

*Rescue medications can be given by a parent, teacher, or another person who's been trained. They are designed to stop seizures that have already started or prevent another seizure after one has occurred. Different rescue medications are given in different ways.

4. The goal of epilepsy treatment is “No seizures and no side effects.”

You and your neurologist should always be working toward this goal. This includes telling your neurologist about...

- any side effects your child is having
- any seizures your child has had, including...
 - seizures you think of as “minor”
 - other episodes that *might be* seizures (but you’re not sure)
- any other medicines your child is taking (some can affect how epilepsy drugs work)
- any seizure patterns, triggers, or warnings you’ve noticed
- any problems you’ve had getting the medicine or paying for it
- any changes in the medicine your pharmacist gives you

You should talk with your neurologist about other treatment options if...

- you’ve tried 2 – 3 medicines for child’s epilepsy, and he or she is still having seizures
- the seizures are controlled, but your child is having major side effects

Other treatments include...

Epilepsy Surgery

- mostly for people whose seizures start in one part of the brain
- usually, a part of the brain is removed or disconnected
- may offer the best chance of becoming seizure free
- risk of serious problems is low but should be discussed with doctor

Vagus Nerve Stimulator (VNS)

- device implanted under the skin on the chest
- wires connect to the vagus nerve in the neck
- brain gets electrical stimulation every 5 minutes or so
- can make seizures happen less often or make them less severe
- magnet can be used to stop or shorten a seizure that has already begun
- people with the VNS usually don’t become seizure free

Ketogenic Diet

- high-fat, low-carb diet that can sometimes reduce or stop seizures
- must be closely monitored by a doctor and a dietician
- can be hard to follow
- used mostly in young children

There are other treatment options as well, but less is known about how safe they are or how well they work.

5. You and your child have some control over seizures and health.

With epilepsy, seizures are hard to predict. Much of what happens is beyond your control. There are things you and your child can do, however, to have fewer seizures and better health. Here are some examples:

- Keep a seizure diary, and avoid seizure triggers
- Make sure your child has a regular sleep schedule, with at least 9 hours of sleep each night
- Help your child manage stress through relaxation techniques and other strategies
- Make sure medicines are taken as prescribed (don't change without talking with your doctor)
- Promote exercising and healthy eating
- Discourage the use of alcohol and illegal drugs
- Help your child take on more responsibility for managing epilepsy as he or she gets older

If your child is having trouble with any of these behaviors, talk to your healthcare team. They may be able to help.

6. Women and girls with epilepsy face unique issues.

- Female hormones can affect seizure patterns.
 - Seizure patterns may change during or after puberty.
 - Seizures may be more likely at certain times during the menstrual cycle.
- Women with epilepsy are at higher risk for certain reproductive problems.
- Some epilepsy drugs can...
 - interfere with birth control pills
 - increase the risk of birth defects
 - weaken bones
- Women are more likely to have psychogenic seizures than men.
- Women with epilepsy can have healthy babies, but there are some risks.

Your neurologist should be aware of these issues and able to address them.

7. Memory and attention problems are common in people with epilepsy.

In people with epilepsy, memory and attention can be affected by...

- side effects of antiseizure drugs
- seizures
- changes in the structure of the brain
- changes in how the brain works

Seeing a neuropsychologist may help you learn more about your child's memory and attention problems. It can also give you ideas on how to cope with them at home and in school. Be sure to share your concerns with your doctors as well. Medicine changes or further testing may be needed.

8. Depression and anxiety disorders are common, serious, and treatable problems in children with epilepsy.

It's normal to feel sad and anxious once in a while. When these feelings don't go away, though, it could be depression or an anxiety disorder. These are serious medical problems that require treatment. More

children with epilepsy have depression and anxiety disorders than children without epilepsy. These conditions can...

- cause stress
- cause sleep problems
- make it harder to think, concentrate, or remember things
- make it harder to take medicines
- increase the risk of seizures
- lead to risky behaviors
- lead to suicide

If your child has become more sad, irritable, withdrawn, or anxious, tell your doctor. There are medicines for depression and anxiety disorders that can be safely taken by children with epilepsy. Talking with a therapist can also help.

9. Children with epilepsy can succeed in school and beyond.

Epilepsy Foundation of Michigan can help. Here are some things we can do...

- train school staff on how to recognize seizures and provide first aid
- teach other students about epilepsy
- help to develop a seizure response plan
- train parents and teachers on how epilepsy can affect learning
- inform parents of available support services (IEPs, 504 plans, transition planning, etc.)
- make sure the child gets needed services
- make sure the child is not unfairly restricted from activities
- help the child build social skills

10. There are risks that go along with epilepsy, but you can lower these risks.

Epilepsy can cause injury, other health problems, or, in rare cases, death. Here are some things that can happen with epilepsy:

- Chronic health problems
 - depression
 - obesity
 - bone loss
 - reproductive disorders
- Injuries from seizures
 - muscle, bone, and joint injuries
 - burns
 - cuts and bruises
 - brain injury
- Car accidents
- Drowning
- Injury or death from seizures that won't stop (status epilepticus)
- SUDEP (Sudden Unexpected Death in Epilepsy)

Ask your doctor about these risks and how to lower them. Some basic safety precautions, healthy habits, and treatment changes can help. This can allow you and your child to focus on your goals rather than your fears.

11. Children with epilepsy can and should participate in social and recreational activities.

Epilepsy should not stop your child from being a child. In general, recreational activities are safe for children with epilepsy. In most cases, children with epilepsy can...

- play sports – this includes contact sports; extra caution should be used with sports that involve swimming or climbing; rarely, vigorous exercise can be a seizure trigger, but moderate exercise is safe (and healthy) for all children with epilepsy – it may even help with seizure control
- play video games or attend dances and concerts – only about 5% of children with epilepsy have photosensitivity (seizures triggered by flashing or flickering lights); your neurologist can tell you if this is the case for your child; children with photosensitive epilepsy may need to avoid certain video games or events with strobe lights (or they can ask that strobe lights not be used); for 95% of children with epilepsy, though, moderate use of video games is safe, and strobe lights are not a trigger
- enjoy overnight camps and sleepovers – Epilepsy Foundation of Michigan can help you prepare for a sleepover or summer camp; basic education about seizures can reduce the fears of other parents and camp staff; we also offer Camp Discovery, a 5-day/4-night summer camp with 24-hour medical staffing

Children with epilepsy can be physically and socially active, in addition to being safe. Talk with your neurologist about specific activities and precautions for your child.

12. You are not alone.

One out of 26 Americans will have epilepsy at some point in their lives. You don't have to deal with this condition on your own. Epilepsy Foundation of Michigan offers programs where you and your child can...

- learn from experts about epilepsy and other topics
- get one-on-one help with managing epilepsy
- meet others with epilepsy who have ideas and experiences to share

It's ok to ask for help. Please call us or visit our website to learn more.

Main Office:
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