Epilepsy & Seizures: **Raising a Child Living with Epilepsy**

Raising a Child

Living with Epilepsy and Seizures

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Disclaimer:

This publication is designed to provide general information about epilepsy and seizures to the public. It is not intended as medical advice. People with epilepsy should not make changes to their treatment or activities based on this information without first consulting their healthcare provider.

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Table of Contents

Raising a child is always a big job — and if your child has epilepsy and seizures, you probably have special concerns.

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In the United States, more than 470,000 children under age 18 live with epilepsy and seizures. Living with seizures affects people differently. For most kids, seizures can be easily controlled with medicine — and some kids will grow out of their seizures and be seizure free as adults. For other people, seizures are a lifelong challenge.

The good news is that medical treatment of seizures in children is getting better, and there's a lot you can do to help your child live a happy, healthy life.

My child has epilepsy. Now what?

The first step is getting medical help for your child and finding a treatment to control the seizures. But there's a lot more to raising a child who has epilepsy. That's where this booklet can help.

As a parent of a child with epilepsy, you will need to know how to:

- Talk to your child about epilepsy and seizures.
- Keep your child safe when a seizure happens.
- Figure out what to tell people about your child's seizures.
- Help your child get the most out of school and playtime.
- Do what you can to keep everyone in the family healthy — including yourself.

Epilepsy and Seizure Basics

What is a seizure?

Our brains use tiny electrical signals to control everything we think, feel, and do. A seizure happens when a person's brain is overloaded by an abnormal amount of electrical activity.

Some doctors describe a seizure as a "storm in the brain." While a seizure is happening, it causes temporary changes in how a person thinks, feels, or moves. These changes might cause:

- Short attention blackouts, dazed behavior, memory gaps, mumbling, or no response
- Sudden falls, frequent stumbling, or unusual clumsiness
- Repeated, unusual movements such as head nodding or rapid blinking
- Sudden stomach pain followed by confusion and sleepiness
- Unusual sleepiness and irritability when woken up
- Frequent complaints that things look, sound, taste, smell, or feel "funny"
- Sudden, repeated fear or anger
- Clusters of (repeated) "jackknife" movements by babies who are sitting down
- Clusters of grabbing movements with both arms in babies lying on their backs.

> "We started recording videos of my son's seizures so he could see what we saw. Before that, he didn't know why we were scared or upset because he couldn't tell what was happening during a seizure. Showing him the video helped him understand."

Are there different types of seizures?

Yes. There are many types of seizures. The type of seizure your child has depends on where the abnormal activity happens in the brain — and how much of the brain is involved.

- General Onset Seizures - these happen on both sides of the brain at once.
- Focal (partial) Onset Seizures - begin in one area or on one side of the brain.
- Unknown Onset Seizures - The beginning of these seizures is not known. The seizure may happen at night or when the person is alone. As more information is learned, these seizures may be renamed depending on where they begin.

Learn more about the different types of seizures at epilepsy.com.

What is epilepsy?

Epilepsy, also called a seizure disorder, is a medical condition. Healthcare providers diagnose epilepsy when:

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- A person has had two or more unprovoked seizures 24 hours apart and not caused by another medical condition.
- A person has had one seizure and has a high risk for more.
- A person is diagnosed with an epilepsy syndrome, like childhood absence epilepsy, temporal lobe epilepsy, or Lennox-Gastaut syndrome.

Some people with epilepsy have just one seizure type, while others can have more than one type.

What is the most common treatment for epilepsy?

Medicine is the most common treatment for epilepsy. Seizure medicines will successfully control seizures for about 7 out of 10 people with epilepsy.

Many different medicines can be used to prevent seizures. These are sometimes called "anti-epilepsy drugs" (AEDs) or "anti-seizure medications (ASMs)."

Your child may need to try different medicines before finding the one that works best. Sometimes, a combination of medicines is the best treatment.

To choose the best medicine for your child, the healthcare provider will look at:

- The type of seizure your child has
- Your child's age and sex
- Possible side effects of the medicine
- Any other medical problems your child has

If your child starts taking a seizure medicine, be sure to ask the healthcare team about:

- Common side effects
- Serious side effects to watch out for
- How long it will take to know if the medicine is working
- What to do if you forget to give your child the medicine on time
- If there are other medicines your child shouldn't take such as aspirin, cold medicine, herbal or other supplements

What if medicines don’t work for my child?

If medicines are not working for your child, talk with the doctor or nurse about other options like:

- Special diets
- Medical devices
- Surgery

If your child continues to have seizures, you may want to ask for a referral to a doctor who specializes in epilepsy (called an “epileptologist”). And remember, if you aren’t happy with your child’s doctor, it’s always okay to ask for a second opinion.

To learn more about treatment options, visit www.epilepsy.com/treatment.

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Talking to Your Child

Your child will need help understanding what's happening. Kids can be frightened by seizures, or they may think they get seizures because they did something wrong. Offer comfort to your child and make it clear that seizures are nobody's fault.

Start a conversation.

There may be many things you want to say about epilepsy and seizures. Tell your child what they need to know, but don't overwhelm them with information. As they get older, you can tell them more.

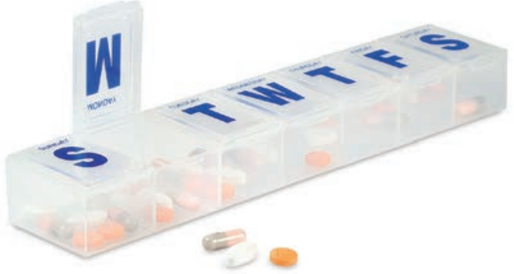
- Make sure your child knows that epilepsy is a medical condition, like asthma or diabetes.
- Let your child ask you questions and talk about their fears or confusion.
- If you don't know the answer to a question your child asks, write it down to ask the doctor or nurse later.
- Remember that you can have conversations over time. You don't need to get through everything all at once.

Make it “normal” to talk about epilepsy and seizures with your child. Try not to complain about challenges or anxiety caused by seizures or the cost of medical care in front of your child.

Involve your child in treatment.

Help your child stay involved in the treatment of seizures. Depending on their age, they may be able to count out pills into a weekly pillbox or take medicine on their own. As they get older, help them learn that it’s their responsibility to take good care of themselves.

Make sure your child knows that seizure medicine will help them stay well, and not taking it enough or on time might lead to more seizures.



> “My son has a reminder set on his phone to take his medicine every morning at breakfast. This way, he’s responsible for taking them, but I’m there to make sure he does. The peace of mind this gives me is priceless — and it helps him feel more in control of his health, too.”

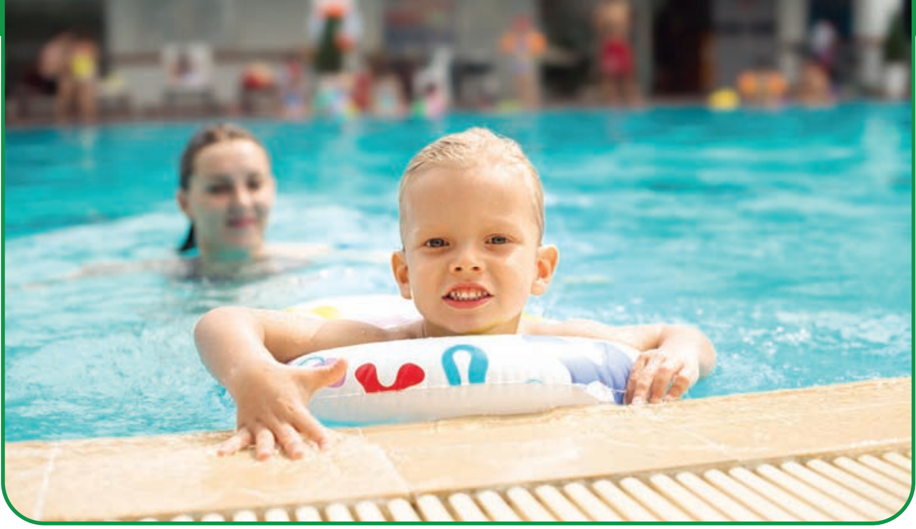
Help your child interact with their healthcare team. Your child may be able to:

- Think of questions to ask the doctor or nurse at appointments.
- Describe how the seizures feel.
- Say if they've had any problems at school or with friends.

Help your child learn how to talk about epilepsy.

At some point, people may ask your child about their seizures. Your child may also want to volunteer information so that people will know what to do if a seizure happens. There's no right or wrong way to do this, but it can help to be prepared.

- Try a brief role-playing exercise where you ask your child questions and they reply. Then talk afterward about what happened, and give feedback.
- Have a conversation about what certain people need to know and why they need to know it (like teachers or the school nurse).
- Let your child know they don't have to share more information with friends than they want to.
- Help your child learn how to talk about epilepsy as just a part of life, and not something to feel bad about.



Safety and Injury Prevention

There are many things you can do to help your child have a full childhood while lowering their risk of getting hurt when a seizure happens.

Take steps to keep your child safe at home.

Here are some simple things you can do to make your home a safer place for a child who has seizures. Remember, it's especially important to be careful when your child is in or near water.

To prevent drowning at home:

- Never leave your child alone in the bathtub or near water.
- Keep the water level in the bathtub low.
- When your child is old enough to wash themselves, have them take showers instead of baths.
- Consider using a shower seat with a safety strap.

To prevent injuries from falling during a seizure:

- Install thick, soft carpets instead of hard flooring.
- Pad sharp corners of tables and other furniture — or look for rounded corners when you shop for furniture.
- Make sure that steps have handrails.
- To prevent burns, put gates around radiators and fireplaces.
- Get chairs with arms so your child can't easily fall out.
- Use plastic or non-breakable dishes and cups.

To keep your child safe while sleeping:

- Make sure your child's bed is close to the floor. You may want to install a guardrail on the bed.
- Consider using a baby monitor or a seizure alert monitor that can alert you if your child has a seizure during the night.

Ask your child's doctor or nurse about swimming.

Having a seizure in water can be very dangerous, so ask your child's doctor or nurse for advice about swimming. Children who are having lots of seizures may be told not to swim at all. Others may be able to go swimming if they're carefully supervised and follow precautions.

If you go to a pool or the beach, let the lifeguards know that your child may have a seizure. Supervise your child while swimming, boating, and even wading. Consider a bright colored bathing suit so your child is easy to see in the water.

Help your child play safely.

Getting plenty of physical activity is important for everyone. Most kids who have seizures can be active and playful just like other children. Check with your child's doctor about any special concerns.

For certain sports, your child may need to wear a helmet, use a safety harness, or play on safety mats. If your child plays on a team, let coaches know that your child has seizures — and what to do if one happens. Make sure that kids always wear helmets when riding bikes.

Learn what can trigger your child's seizures.

Keep a seizure diary and write down as much as you can about your child's seizures, including what happens days, hours, or right before a seizure. This can help you figure out if certain things seem to make a seizure more likely. There are also online tools you can use to keep track of seizure information.

Seizure triggers can include:

- A specific time of day or night
- Not getting enough sleep
- Feeling stressed
- Missing meals
- Eating certain foods
- Being sick or having a fever
- Flashing lights
- Missing a dose of seizure medicine
- Menstrual cycles (periods) — for girls

Learning to identify seizure triggers can help you take steps to prevent seizures — like making sure your child gets to bed on time or doesn't eat certain foods. If the trigger is something you can't change, like the time of day, being aware of it can help you be prepared.

Make sure that babysitters, family members, and teachers know about your child's seizure triggers, too.

Make a seizure response plan.

A seizure response plan is a document that lets people know what to do when your child has a seizure. Share copies of the plan with babysitters, teachers, and relatives.

A seizure response plan usually includes:

- Notes about the types of seizures your child has, how often seizures happen, and how long they usually last
- First aid instructions, like gently helping the child to lie down
- A list of seizure medicines your child takes, including rescue medicine
- Information about what to do if a seizure doesn't stop (called "status epilepticus") and instructions about when to call 911
- Notes about where the nearest hospital is
- Emergency contact information for you, other family members, and your child's doctor

Download a free seizure action plan from **epilepsy.com/toolbox**. Have your child's health care provider review and approve any seizure response plan you create.

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Watch your child carefully after a seizure.

Let your child rest if they feel tired after a seizure, but make sure they recover normally. This is even more important if they fall and hit their head during the seizure.

Warning signs to look for:

- Vomiting (throwing up)
- Trouble seeing
- Trouble breathing
- Being unusually sleepy

Call 911 right away if your child:

- Has one seizure after another within a brief period of time
- Has a seizure that lasts more than 5 minutes
- Has a seizure in water
- Is injured

Document your child's behavior after the seizure. This can help you learn what to expect after your child has a seizure and identify any changes.

Ask the doctor about your child's risk for SUDEP.

SUDEP (sudden unexpected death in epilepsy) means death in a person with epilepsy that happens without warning and without a clear cause of death. SUDEP can happen in anyone, but the risk is low in children with seizures. It happens in 1 out of 4,500 children each year. The risk is higher in people with tonic-clonic seizures, seizures at night, developmental disabilities, or with poorly controlled seizures.

The best way to lower your child's risk of SUDEP is to help your child have as few seizures as possible. You can do this by:

- Making sure your child always takes their seizure medicine and follows the treatment plan
- Identifying and avoiding seizure triggers as much as possible
- Attend all doctor appointments and talk with your child's doctor about different treatments to control seizures. Don't settle for continued seizures. If the medicines are not working, see an epilepsy specialist.

> "It's important to talk to all families about SUDEP. Most parents are surprised to hear how low their child's risk is. Everyone who may be at increased risk needs to know how to get the best seizure control."
>
> — Epilepsy specialist

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Family and Home Life

When a child has epilepsy, it helps for everyone in the family to be able to talk about it. Do your best to help your child take part in everyday activities with the family whenever possible.

Create healthy routines at home.

Family routines — like regular mealtimes or nightly bedtime stories — can give your child a sense of security and organization. Some of these routines are also helpful for controlling seizures.

Make sure your child gets plenty of sleep. Getting enough sleep lowers the risk of seizures.

- It can help to create a calm mood in the hour before bed. You might try having bath time and then read a story together.
- For an older child or teenager, encourage them to get to bed early. Setting a regular bedtime routine also helps. Help them understand that getting enough sleep is part of keeping themselves healthy.

Give your child chores — like setting the table, cleaning up, or doing yard work.

- Doing chores encourages responsibility and gives kids an opportunity to feel good about what they can do.
- Help your child build self-esteem by letting them know when they do something well.

> “One of our favorite routines is getting active as a family. We make a point of going for a walk after dinner or going to the park at least once a week.”

Encourage your child to eat a healthy, balanced diet.

- If your child is on a special diet for seizure control, be sure to follow the instructions for that diet.
- As much as possible, eat meals and snacks at regular times. For some children, missing a meal may make a seizure more likely.

Set limits with your child when you need to.

Just like other children, your child needs love — and they need you to set limits on the behavior you don't like.

If you are nervous about disciplining your child or worried that upsetting your child could cause a seizure, talk to the doctor or nurse. Say that you're concerned about your child's seizure risk, and ask for suggestions about safe ways to set limits and correct your child's behavior.

> "When I'm frustrated with my daughter, I try to choose my words carefully and be loving toward her. It's important for our kids to know we always love them, even when we don't love their behavior."

Spend time with your other children.

If you have children who don't have epilepsy and seizures, help them understand what's happening with their sister or brother.

- Make time for them to ask you questions about epilepsy and seizures.
- Tell your children that epilepsy can't spread from person to person, so they don't need to worry about catching it.
- Reassure them by saying that a seizure isn't usually dangerous, even though it may look scary.
- Help them learn what to do when their brother or sister has a seizure.

It's normal for your other kids to be jealous if you spend a lot of time taking care of your child who has epilepsy. Let them know it's okay to talk about these feelings.

Do your best to spend some time alone with each of your children. Doing something special like reading a book, taking a walk, or watching a movie together can help you stay connected.

School and Friends

Having seizures at school can be hard for your child and scary for classmates — but it doesn't have to be. Talk with your child's teacher, the school nurse, and school administrators about what they can do to support your child.

Make sure your child can take medicine at school.

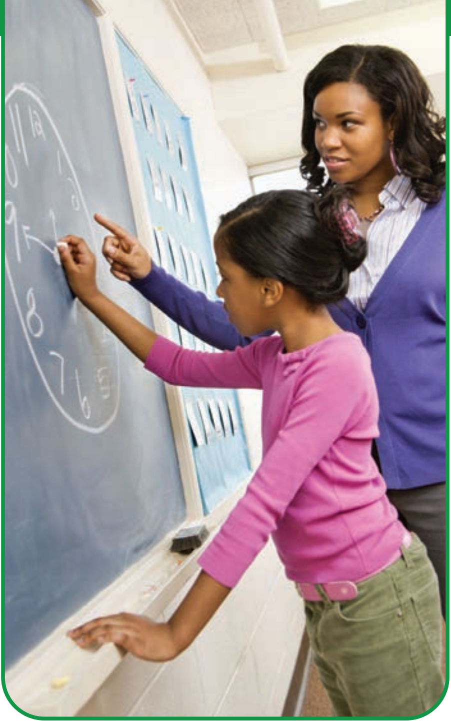
If your child needs to take seizure medicine during the day, talk to the school nurse or another school official. Most schools won't let kids take medicine on their own. Work with the school nurse to make sure your child gets their seizure medicine on time.

Talk to your child's teachers.

Reach out to your child's teachers and school officials before the school year to talk about:

- How epilepsy affects your child
- What happens when your child has a seizure
- What the teacher needs to do if your child has a seizure
- Anything else you think the teacher needs to know

If you have a seizure response plan for your child, give a copy to the teachers and the school nurse. See page 13 for more information on creating a seizure response plan.



Get involved in your child’s education.

Know your child’s legal rights. Most schools must follow the Americans with Disabilities Act (ADA) and provide “reasonable accommodations” if your child has special needs. Other laws, like Section 504 of the Rehabilitation Act of 1973 and the Individuals with Disabilities in Education Act (IDEA), might also apply if your child has special physical or learning challenges. Call the Epilepsy Foundation at 1-800-332-1000 to learn more about the laws and your child’s right to be in school.

You can help your child be safer and happier at school by educating the community about epilepsy and seizures. Ask if you can give a presentation to staff or students. The Epilepsy Foundation has a curriculum you can use — or there may be a volunteer who can visit your school.

Encourage your child to make friends and play with other children. Remind them that besides having seizures, they’re just like any other kid. You might want to take a few minutes at the end of each school day to ask your child how the day went, including both fun times and challenges.

If your child's teacher isn't familiar with epilepsy or seizures, you may want to provide some educational materials. The Epilepsy Foundation can help — just go to our website at www.epilepsy.com to find resources you can share.

Watch out for signs of bullying.

Bullying is when a person tries to hurt someone on purpose, either physically or emotionally. Different types of bullying include hitting and pushing, teasing and name-calling, and leaving someone out on purpose. Bullying can happen to any child, but kids who have a medical condition may be more at risk.

If your child has unexplained cuts or bruises, seems unhappy or depressed, or doesn't want to go to school, try to find out why. If bullying is happening, talk to your child's teacher or principal.

Tell your child that it's not their fault if people are mean or exclude them. Listen to their feelings and let them know that you will figure out what to do together.

> “In our school, the whole class knows what to do if my daughter has a seizure. I've tried to involve all of her classmates as much as possible.”

Be alert for signs of learning challenges.

It's possible your child may have attention problems or another learning challenge related to epilepsy. This can be due to the same cause in the brain that leads to seizures, or it can be a side effect of seizure medicine.

If your child isn't doing well in school, it's important to find out why. Talk to your doctor and school officials about which tests your child might need. As a parent, you have the right to request an assessment of your child's learning challenges and needs. You may also want to ask about whether an individualized education plan (IEP) is right for your child.

Getting Support

Caring for a child with epilepsy can be hard — but you aren't alone. You can get support from counselors, friends, and the Epilepsy Foundation community.

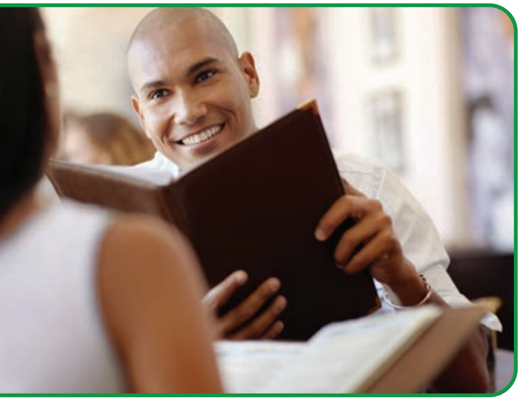
Get help for your child.

Seeing a counselor (like a social worker or psychologist) can be helpful if your child has social issues or behavior challenges that your doctor isn't able to address. For older children, talking with a counselor is a helpful way to work out difficult feelings or problems — about seizures or anything else.

Another source of support for many kids are the Epilepsy Foundation summer camps. These overnight camps let children with epilepsy play, explore, and learn together. Go to www.epilepsy.com for complete camp information.

Take care of yourself.

Make time to relax and de-stress without feeling guilty about it. Ask a family member or friend to watch your child so you can do something you enjoy — whether it's going for a walk, reading a book, or calling someone.



Remember, taking time for yourself isn't selfish — it's healthy for you and your family. Most parents say they feel happier when they can make time for things they enjoy, and happier parents are more able to be there for their children.

Talking with friends, family, or religious leaders may help — or you might want to see a professional counselor. Counseling sessions can help you learn to cope with the challenges of raising a child with epilepsy. To find a counselor, ask your doctor or nurse — or your child's school counselor — for a recommendation.

> "I've learned to face the fact that I'm not a perfect parent. I try to focus on the important stuff instead of tackling everything at once. When I feel overwhelmed, I stop and take a few deep breaths before reacting. It really helps."

Get support for your family.

If your child has severe epilepsy, people like social workers or counselors can help you figure out what your child needs, and help you make plans for your child's future.

As your child becomes a teenager, new challenges will probably come up. Making choices about dating, driving, and drinking or drugs are things that all teens and parents deal with. But living with epilepsy can make these things more complicated. Talk to a doctor or counselor if you or your child have questions or need extra support.

Learn more, connect, and get involved.

Visit **www.epilepsy.com** or call 1-800-332-1000 to:

- Learn more about the Americans with Disabilities Act and what it means for your child.
- Find resources about epilepsy to share with teachers, schools, and day care providers.
- Find support groups of other parents and caregivers.
- Locate the Epilepsy Foundation office nearest to you.

Notes

About the Epilepsy Foundation

With a network of partners throughout the United States, the Epilepsy Foundation is leading the fight to overcome the challenges of living with epilepsy. The Foundation connects people to treatment, support, and resources; leads advocacy efforts; funds innovative research and the training of specialists; and educates the public about epilepsy and seizure first aid. For more than five decades, the Epilepsy Foundation has shone a light on epilepsy to promote awareness and understanding and to advocate for laws that matter to people with epilepsy while also funding epilepsy research and supporting epilepsy investigators and specialists in their early careers. In partnership with the CDC, the Epilepsy Foundation has helped to improve access to care for people with epilepsy, expanded its digital reach and online resources in homes across the country, and trained people in seizure recognition and first aid. The Epilepsy Foundation continues to focus on serving the epilepsy community through advocacy, education, direct services, and research for new therapies. To learn more visit epilepsy.com or call 1.800.332.1000.

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