

# Raising a Child with Epilepsy



Founded in 1954, the Epilepsy Foundation of Minnesota (EFMN) is a non-profit organization that offers programs and services to educate, connect, and empower people affected by seizures.

Together we can...

**EDUCATE** the community about seizures to reduce the stigma surrounding epilepsy.

**CONNECT** people with epilepsy to others, and to resources.

**EMPOWER** people living with epilepsy to reach their full potential.



### **Our mission**

EFMN leads the fight to overcome the challenges of living with epilepsy and to accelerate therapies to stop seizures, find cures and save lives.

### **Our vision**

A world where people with seizures realize their full potential.



## INTRODUCTION

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

In the United States, more than 470,000 children under age 18 live with epilepsy and seizures. Living with seizures is different for every person. For most kids, seizures can be easily controlled with medication — and some kids will actually 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 constantly improving, 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 help control the seizures.

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 occurs
- Determine who to inform 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:

- Loss of consciousness
- Convulsions (whole body shaking)
- Confusion
- Brief periods of staring
- A sudden feeling of fear or panic
- Uncontrolled shaking of an arm or leg

### Are there different types of seizures?

Yes, there are over 40 different 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. There are three major groups of seizures:

- **Generalized onset seizures** happen in the entire brain
- **Focal onset seizures** begin in one specific part of the brain
- **Unknown onset seizures** are when the beginning location is unknown



### What is epilepsy?

Epilepsy, sometimes called a "seizure disorder," is a medical condition. Doctors will usually diagnose epilepsy if:

- A person has one or more seizures;
- The doctor thinks the child is likely to have a seizure again;
- And the seizure was not directly caused by another medical condition, like a severe infection or diabetes.

Epilepsy is a general term that includes people who have any of the different types of seizures. Some people with epilepsy have just one type of seizure, while others have more than one.

### What is the most common treatment for epilepsy?

Medication is the most common treatment for epilepsy. Seizure medications will successfully control seizures for about seven out of ten people with epilepsy. These are sometimes called "anti-epilepsy drugs" (AEDs) or "anti-seizure medications."

Your child may need to try different medications before finding the one that works best. Sometimes, a combination of medications is the best treatment. To choose the best medication for your child, the doctor will look at their type(s) of seizure, age and sex, possible side effects from the medication, and any other medical problems they may have.



# Epilepsy

If your child starts taking seizure medication, be sure to ask the doctor or nurse about:

- Common side effects
- Any side effects that are considered more serious or dangerous
- How long it will take to know if the medication is working
- What to do if you forget to give your child the medication on time
- If there is other medication your child shouldn't take (such as aspirin or cold medicine)
- Whether it is okay to switch between different versions of your child's medication, like going from brand name to generic

## **What if medication doesn't work for my child?**

If medication isn't working for your child, talk with their medical provider about other options, such as special diets, medical devices, or 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").

## **Epilepsy over time, teens with epilepsy.**

Teens and their parents share the highs and lows of the often-stormy period when children become adults.

- As their body changes so can their seizures and seizure triggers
- Late nights, emotional stress, and trying alcohol or recreational drugs can be typical parts of teenage life, however, these can make seizures more likely to happen
- Children without additional developmental challenges and whose epilepsy is well controlled can achieve independence during adolescence and adulthood
- Families with children who have more severe physical and mental challenges must begin to explore the options for their future living arrangements, employment possibilities, security, and more





## TALKING TO YOUR CHILD

Your child will need help understanding what's happening. Kids can be frightened by seizures, and may think they have epilepsy because they did something wrong. Tell your child what they need to know, but don't overwhelm them. Offer comfort and make it clear that seizures are nobody's fault and it's something you can talk about.

- Make sure your child understands that epilepsy is a medical condition, like asthma or diabetes
- Let your child ask questions and talk about their fear or confusion
- Remember that conversations can happen over time and you don't need to cover everything at once

### **Involve your child in treatment.**

Help your child stay involved in the treatment of their seizures. Depending on their age, they may be able to count out pills into a weekly pillbox or take medication on their own. As they get older, help them learn it's their responsibility to take good care of themselves. Make sure your child knows that seizure medication will help them stay well, and not taking it enough or on time might lead to more seizures.

Help your child interact with their health care team. Your child may be able to describe how the seizures feel and think of questions to ask the doctor or nurse at appointments. Let your child know they can talk to their team about any problems at school or with friends.

## **Help your child learn how to talk about epilepsy.**

Help your child learn how to talk about epilepsy as a part of life, and not something to hide. People may ask your child about their seizures. Your child may also want to share 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 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

## **SAFETY, INJURY PREVENTION, AND HEALTH**

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 occurs. Here are some simple things you can do to make your home a safer place for a child who has seizures.

### **To prevent injuries from falling during a seizure:**

- Install thick, soft carpets instead of hard flooring
- Pad sharp corners of tables and other furniture
- Make sure that staircases 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 and consider installing a guardrail on their bed
- Consider using a baby monitor or a seizure alert monitor that can alert you if your child has a seizure during the night

### **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



### **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 occurs. Make sure that kids always wear helmets while riding bikes.

### **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 or use a life jacket. Others may be able to go swimming as long as they're carefully supervised. If you go to a pool or the beach, let the lifeguards know that your child may have a seizure. Supervise your child at all times while swimming, boating, and even wading.

### **Encourage your child to eat a healthy, balanced diet.**

As much as possible, eat meals and snacks at regular times as missing a meal can make a seizure more likely. Additionally, if your child is on a special doctor-recommended diet, be sure to follow their instructions and explain to your child why it's important for them to do so.

### **Importance of sleep.**

Make sure your child gets plenty of sleep. Getting enough sleep lowers the risk of seizures. It can help create a calm mood in the hour before bed. You might try having bath time and then reading a story together. For an older child or teenager, encourage them to get to bed early. Help them understand that getting enough sleep is part of keeping themselves healthy.



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

SUDEP (sudden unexpected death in epilepsy) is when a person with epilepsy dies unexpectedly and without a clear cause of death. Each year, about 1 in 4,500 children with epilepsy die from SUDEP.

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

- Making sure your child always takes their seizure medication and follows their treatment plan
- Identifying and avoiding seizure triggers as much as possible
- Telling the doctor if you think your child needs more or different treatment to control seizures
- Working with your doctor to create a seizure response plan
- Asking your doctor how to improve your child's safety at night

## **CREATING A SEIZURE ACTION PLAN**

### **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 right before a seizure. 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 medication
- Menstrual cycles (periods)

Learning to identify seizure triggers can help you take steps to prevent seizures. If the trigger is something you can't change, like the time of day, being aware of it can still help you be prepared. Make sure that babysitters, family members, and teachers know about your child's seizure triggers too.

## Watch your child carefully after a seizure.

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

Warning signs to look for:

- Vomiting
- Trouble seeing
- Trouble breathing
- Being unusually sleepy

Call 911 right away if your child:

- Has another seizure after the first one
- Has a seizure that lasts more than five minutes
- Has a seizure in water

## Make a seizure action plan.

A seizure action 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 action 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 lie down
- A list of seizure medications your child takes, including rescue medication
- 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

Have your child's doctor review and approve any seizure action plan you create.

<b>SEIZURE INFORMATION:</b>			
Seizure Type	Length	Frequency	Description

Seizure triggers or warning signs: \_\_\_\_\_

Response after a seizure: \_\_\_\_\_

\_\_\_\_\_

<b>TREATMENT PROTOCOL: (include daily and emergency medications)</b>				
Medication	Emergency Med?	Dosage & Time of Day Given	Route of Administration	Common Side Effects & Special Instructions
	<input type="checkbox"/>			
	<input type="checkbox"/>			
	<input type="checkbox"/>			

Full Seizure Action Plan form available at [efmn.org](http://efmn.org).



## 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.

### **Give your child responsibilities.**

Doing chores like setting the table, cleaning up, and doing yard work 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.

### **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 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 your 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.

### **Spend time with your other children.**

If you have other children who don't have 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.

## 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 medication at school.**

If your child needs to take seizure medication during the day, talk to the school nurse or another school official. Most schools won't let kids give themselves medication, but you can arrange for an adult at the school to do so.

### **Talk to your child's teachers.**

Reach out to your child's teachers and school officials before the school year starts 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
- If you have a seizure response plan for your child, give a copy to the teachers and the school nurse

### **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 EFMN to learn more about these 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.

### **Seizure Smart Schools**

EFMN's Seizure Smart Schools program brings training and resources into schools, helping school communities understand seizures and reduce the stigma that surrounds epilepsy. Teachers, school nurses, staff, and families can work together to reduce bullying in schools, teach seizure first aid, and help foster a better understanding of epilepsy.

If your child's teacher isn't familiar with epilepsy or seizures, you may want to provide some educational materials. EFMN can assist — just go to our website at [efmn.org](http://efmn.org) to find Seizure Smart Schools 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.

Encourage your child to make friends and play with other children. Remind them that besides having seizures, they are 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.

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

### **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 abnormal electrical activity in the brain that leads to seizures, or it can be a side effect of seizure medication.

If your child isn't doing well in school, it's important to find out why. Talk to your doctor or 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 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 EFMN 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 behavioral challenges that your doctor isn't able to address. For older children, talking with a counselor is a good way to work out difficult feelings or problems — about seizures or anything else.

### **Get support for your family.**

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.

### **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 are able to 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.

## EFMN PROGRAMS FOR YOUTH

We believe it's important for youth with epilepsy to connect with each other and ease the feeling of isolation that often comes with this diagnosis. For information on all youth and adult programming visit [efmn.org](http://efmn.org).

### Camps

Camp Oz transforms the lives of youth with epilepsy by providing a safe week-long camping experience, with the security of 24/7 medical staff. Our single-day camps include Day Camp, Family Camp, and Regional Camps. Day Camp is designed to help prepare eligible campers ages 6-10 for future attendance at Camp Oz. Family Camp is for youth with seizures ages 6-17 with additional medical, developmental, social, or emotional needs and their family. Regional Camps are located across the region and open to all campers ages 7-17 and their family.

### Shining Stars

EFMN's Shining Star program connects youth from across Minnesota and eastern North Dakota with other families living with epilepsy. It's a way for youth to meet others with seizures and try new activities while families are able to gain valuable resources related to living with epilepsy.

### Family Fun Events

From picnics to baseball games to movie viewings, these year-round events help connect local families impacted by epilepsy so they can support and learn from others in similar situations.



## **Additional Resources**

For information on seizure first aid, seizure types, treatment options, driving, SUDEP, safety tips, additional resources, and more, please visit the following:

- [efmn.org](http://efmn.org)
- [epilepsy.com](http://epilepsy.com)

## **24/7 Support**

Call 800.779.0777 or [info@efmn.org](mailto:info@efmn.org) during business hours or 800.332.1000 (en Espanol: 866.748.8008) after hours with any questions or concerns.