A Child’s Guide To
SEIZURE DISORDERS
FOR PERSONAL USE ONLY
My name is

A seizure disorder is a kind of illness that only happens sometimes. It’s not the kind of illness that makes you feel sick inside. It’s not the kind of illness that makes you cough and sneeze. It’s not the kind of illness that means you have to stay in bed and have your temperature taken. A child who has a seizure disorder feels just as healthy as everyone else most of the time but sometimes he or she may have a seizure. This booklet is all about seizures.

Another name for this kind of illness is epilepsy.

(ep-i-lep-sy)

If you have epilepsy, it’s good to find out as much as you can about it. You’ll know how your seizures happen. You’ll know how your medicine works and why you have to take it every day. Then you can tell other boys and girls who might want to know.

If there’s something in this booklet that you don’t understand, ask your mom or dad to explain it to you.

If you have a special question about your seizure disorder, ask your doctor about it when you go for your next check up.
How Seizures Happen

Seizures begin in the wonderful network of cells in your brain. These cells are very, very small, but they make everything in your brain and body work. They do it by sending little signals to each other, faster than you can imagine. The signals flash all over your body so you can run and jump and do all the things you do every minute of every day.

Your brain cells are even hard at work while the rest of you is asleep. You don’t have to think about them. They just keep doing what they’re supposed to do.

Most of the time your brain cells work just the way they’re supposed to work. But if you have a seizure disorder it means that sometimes, for a very short time, they don’t work quite the way they should.

For just a few seconds, or a minute or two, some of your brain cells send mixed up signals. They stop the other cells from working properly, and your body gets mixed up messages.

- This could make your arm shake without you wanting it to shake.
- It could make things look, or sound, or feel strange to you – just for a moment.
- It could even make you stop and stare without really seeing or hearing what is happening – for a moment or two.
- Sometimes those mixed up messages from your brain can make your whole body work in a mixed up way.
- They could make you fall down, get stiff, and then shake all over for a minute or two.
- They could make you move around as if you were half asleep.
Your Seizures

There are lots of different kinds of seizures. Not everyone has the same kind. If you’re not sure, ask your mom or dad. Your kind of seizure will have a special name. Ask your doctor the special name for your kind of seizure and write it here:

My kind of seizure is called:

Does your kind of seizure last for just one minute, or two minutes? Or is it the kind that is over in just a few seconds? Write in the answer:

My kind of seizure only lasts for:

When your seizure stops your brain cells go back to working the right way again. Sometimes this happens right away, and sometimes it can take a few minutes.
Your Medicine

When you have epilepsy and you have seizures, your doctor will give you medicine to take.

Your doctor will let you know how many times a day to take it. He or she may say to take it once a day, or twice a day, or three times a day, or four times a day.

How many times a day do you take your seizure medicine?

Your doctor may change your medicine sometimes if he or she thinks another medicine will work better.

He or she will keep trying to find the very best medicine to stop the kind of seizures you have.

Your medicine has a special name. Do you know the name of your medicine?

Ask at the drug store the next time your prescription is filled what your medicine is called, or ask your doctor the next time you go for a check up.

My medicine’s name is:
The medicine you take makes it much harder for a seizure to get started. It may do such a good job that you don’t have any seizures at all.

It is important to take seizure medicine at the same time every day.

You have to keep taking it because you want to stop seizures from happening every day, not just some days.

Your body uses up the medicine you take just like a car uses up gasoline.

When you take your pills you are putting back into your body the medicine that got used up since the last time you took it.

Taking more pills won’t work. Fewer pills won’t work.

What your doctor has said you should take will do the best job for you.

What times do you take your medicine?

Circle the times on the clock face.
A Special Diet

Some children with epilepsy are on a special diet. Being on a diet means there are some things you can eat. And there are some things you can’t eat.

There is an epilepsy diet that can help to stop seizures. It is called a ketogenic diet.

If you have been put on this diet, you know it’s very important not to eat anything that’s not on the diet. Eating only foods allowed on the diet gives you the best chance of stopping your seizures.

Your mom or dad probably weigh every bit of your food very carefully. They also let you drink only small amounts of water or other drinks.

One day your doctor will say that you won’t have to be on the diet any more. One day you will be able to eat other things, too.

Then you’ll be able to eat all your favorite foods again.

Foods I Like Best:

Menu

- Fruit
- Pizza
- Ice Cream

FOR PERSONAL USE ONLY
At the Hospital

Children who have seizures sometimes go to the hospital. Some children go to the hospital to have a special operation to stop their seizures.

But most children with seizures go to the hospital to have tests.

☀ They have blood tests.

☀ They have EEG tests, too. EEG tests make recordings of what’s going on inside your brain. But it can’t tell what you’re thinking.

☀ MRI tests take a picture of the inside of your head. The picture is taken by a big machine. But it can’t tell what you’re thinking, either.

Have you ever been to the hospital?

Did you have tests there?

Tests I Had at the Hospital:

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________

________________________________________________________________________
First Aid

Do you know what to do if you ever see a child have a falling down and shaking seizure?

This is what you should do:

🌟 Move things out of the way.
🌟 Tell the other children not to be scared.
🌟 Send someone to find a grown-up.
🌟 Put something soft under the child’s head if he or she is lying on the floor.
🌟 Help the child turn to the side.
🌟 Be a friend when he or she wakes up.
🌟 That’s all you have to do.

And that’s all your friends have to do if you have this kind of seizure.

My Best Friends Are:

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

_____________________________________________________________________

FOR PERSONAL USE ONLY
Epilepsy is not something you can catch. You cannot possibly get it from someone else. And no one else can get it from you.

Epilepsy did not happen to you because of anything bad that you did, or that anyone in your family did. No one made you have it. It just happened.

You cannot hurt anyone during a seizure.

Seeing something that is not there, or hearing a funny noise that no one else hears or doing something when you seem to be half asleep doesn’t mean you are crazy. These things are caused by little seizures that other people can’t see.

Having seizures doesn’t mean you are any less smart or intelligent than other people. It doesn’t mean you will get less intelligent, either.

You cannot swallow your tongue during any kind of seizure. It is fastened to the bottom of your mouth.

You should not put anything in the mouth of a person having a seizure. It may hurt his or her teeth or jaw.

Living a normal, active life, playing sports and having a good time will not make you have more seizures.

Remember, too, that you are not alone. Lots and lots of other children have epilepsy.

Thousands of grown ups had seizures when they were young and now have children of their own, work at interesting jobs, and live happy lives.

Things to Remember
Note to Parents

This pamphlet is designed to help the average child understand and adjust to seizure disorders. It does not give medical advice and your child’s doctor is always the best guide for your child’s treatment and level of activity.

About the Epilepsy Foundation

The Epilepsy Foundation, a national non-profit with 47 affiliated organizations throughout the United States, has led the fight against seizures since 1968. The Foundation is an unwavering ally for individuals and families impacted by epilepsy and seizures. The mission of the Epilepsy Foundation is to stop seizures and sudden unexpected death in epilepsy (SUDEP), find a cure and overcome the challenges created by epilepsy through efforts including education, advocacy and research to accelerate ideas into therapies. The Foundation works to ensure that people with seizures have the opportunity to live their lives to their fullest potential. For additional information, please visit www.epilepsy.com.

“Like” the Epilepsy Foundation on Facebook at www.facebook.com/epilepsyfoundationofamerica and follow us on Twitter at www.twitter.com/epilepsyfdn.