For Kids By Kids

a guide to epilepsy

Compiled by Elizabeth Grand
Designed by Jillian Daidone

epilepsy SERVICES NEW JERSEY

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about this book

Hi there!

The children in this book are all real kids with epilepsy living across the state of New Jersey. They are boys, girls, brothers, sisters, sons, and daughters who have epilepsy and are doing amazing things! They explain what epilepsy is, how it makes them feel, and give advice to other kids who have epilepsy. You can also see some of their own signatures and drawings throughout the pages. I hope this book will help you learn a little more about epilepsy and realize that you are not alone!

Sincerely,
Elizabeth Grand

Q & A

(adapted from "A Child's Guide to Seizure Disorders" by ESNJ, 2006)

what is epilepsy?

Epilepsy is a disorder when a person has seizures.

How does a seizure happen?

There are millions of cells (like little batteries) in your brain, and they send messages to each other to make everything in your brain and body work. Sometimes when the cells are talking to each other, the messages get mixed up for a few seconds or minutes. These mixed signals may make your body shake, get stiff, fall down, or they may make the things around you smell, look, or sound different, or they make you stare off. All of these things that happen because of the mixed up messages are called seizures.

Is there only one kind of seizure?

No. There are many different kinds of seizures.

Can a person swallow their tongue during a seizure?

No, because your tongue is attached to your mouth.

why do I have to take so much medicine?

The medicine you take helps stop the seizure before it happens. You have to keep taking it every day because you want to stop seizures from happening every day, not just some days. After you take your medicine, your body uses it up, just like a car uses up gas. After a while, you have to take another pill to refill your "medicine tank."

Can I give epilepsy to other people?

No. You cannot get it from someone else, and other people cannot catch it from you. Some doctors might ask you to go for certain tests, like an EEG or MRI.

...continued on back

Q & A

What is an EEG?

An EEG is a machine that records what is going on in your brain. It can see how active your brain is, but it can't tell what you are thinking.

What is an MRI?

An MRI is a machine that takes a picture of your brain. It can't tell what you're thinking either.

Am I the only person who gets seizures?

No. There are lots of other children all around the world who have seizures too. And there are lots of adults who had seizures when they were kids (some may still have seizures) and now they are all grown up, work at a job, and have children of their own!

What should I do if my friend has a seizure?

Just remember the word TRUST:

T- Turn the person on his or her side
R- Remove all objects from the area
U- Use something soft under his or her head
S- Stay calm and Stay with the person
T- keep track of the Timing of the seizure (how long it lasts)

Who can answer my questions about seizures?

If you have any questions about seizures and epilepsy, you can always ask your doctor when you go for a check-up!

CORTNEY age 4

and her Big Brother age 9

(Cortney has epilepsy, and her brother does not. Cortney and her family call her seizures "clumsies".)

Can you tell me what happens when you have a clumsy?

When I'm mad I do. I have a clumsy.

When you're mad? And then what happens when you have a clumsy?

Freeze.

You freeze. What does it feel like?

Nothing.

Do you want to tell me what happens when your sister has a clumsy?

(Brother) You just know 'cause she automatically freezes. Well it happens for like at least 5 seconds and when it happens, you like black out.

What's it like?

*She goes like *blinking and rolling eye movements**

What happens with her eyes?

She twitches.

How do you feel when you see your sister?

When I see her having a clumsy, I just make sure nothing bad happens to her... if she's leaning she might like fall down and hurt herself.

So you take care of her?

Yeah. Once Cortney had a clumsy in our pool and I didn't want her to drown so I held her so she didn't get hurt.

Can you tell me about what happened in the pool?

(Cortney) I was swimming and I had floaties on and I froze.

You froze. Was it scary?

No.

Did your brother help you?

Yeah.

What did your brother do?

(Brother) I don't think she felt me hugging her to keep her safe.

Well, I heard about how soon Cortney might be twitching all over when she gets a seizure and was wondering if that means that it's getting worse?

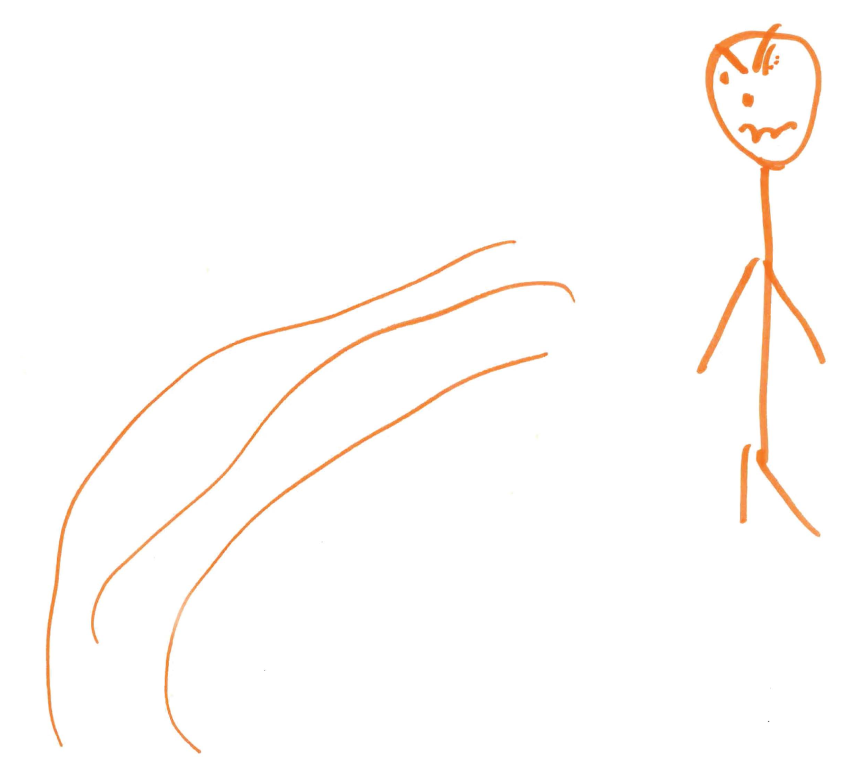
I actually don't know the answer to that but next time you can always ask the doctor if you're worried about Cortney. If you have any questions, you can always speak up and ask the doctor.

A drawing by

CORTNEY

Self-portrait of Cortney with a "stop sign" and all of her toy pets. She was playing with her pets the first time her father saw her have a seizure.

Drawings by CORTNEY'S Big Brother



"This is Cortney and these little things here (the yellow rounded lines on the sides) are her twitching and that's me making sure she doesn't fall."

"And this one is what happens if no one makes sure she doesn't fall. She slips and falls in her seizure. But as soon as she bumps something on the ground she gets out of it."

olivia

age 8

I don't have epilepsy, I don't know what it's like. Can you tell me about what it's like?

What do you have to do in the morning?

Take pills.

And what do you have to do at night?

Take pills.

Is it hard to take the pills?

No. I need something to take it with.

What do you usually take it with?

Any chocolate.

What would you tell a child to pack in their suitcase if they have to go sit in a hospital bed for five days?

Pajamas that have buttons.

How come you need pajamas that have buttons?

So it does not get connected to the wires (on your chest).

Anything else you would bring?

Anything that you sleep with.

(Debbie, Olivia's Mom): You would bring your hot pink sleep mask because you have to sleep with the lights on for an EEG. And you bring lots of snacks.

What's an EEG like?

They wrap your head with wires. They put a machine in your room and it spies on you.

What's that like?

It's like you're sitting in front of a big camera and there's wires on your head.

Is it scary?

No. You get used to it.

you get used to it.

What about your friends at school, do they know you have epilepsy?

A couple of them but most of them no.

Did you tell them?

I did.

What did you tell them?

Just that I have epilepsy, that's all. Some of them did not even believe me.

(Debbie) They had done a big thing at Olivia's school this year. We worked with Andrea and Jenna (from ESNJ) and we did Epilepsy Awareness Month, we did a coin drive, we raised almost $6000. It was very exciting. And they also did the helmet safety program and the gym teachers during health read one of the (epilepsy) books to the class. So I think some of them knew, they had kind of touched on it at an elementary level.

In March, Olivia's family went to Washington D.C. to participate in the National Walk for Epilepsy.

What was that like?

Just walking. I got really tired.

What color shirt do you wear?

Purple.

What's purple?

Someone that has epilepsy. And the people that don't wear white.

Did you like doing the walk?

Yeah. A couple of days before the walk we were just hanging out in D.C.

What was your favorite part about the walk?

Going to D.C. and looking around.

If one of your friends went to the doctor and the doctor told her that she had epilepsy, what would you want to say to make her feel better?

That I have epilepsy too. That's all I really would say.

(Debbie) What did the boys (Olivia's brothers) tell you not too long ago? Does epilepsy make you different, or does it make you special?

Special.

You're very special Olivia.

MARK

How would you explain what a seizure is?

I don't know.

It's a tough question. Can you tell me what happens?

I get dizzy.

How does it make you feel?

Like, the earth is moving fast.

What do you talk about with your friend (who also has epilepsy)?

We actually don't talk about it.

Do you ever get scared when you go to the doctor?

No.

No? Never?

Sometimes.

What about in the beginning?

Yeah. It's scary sometimes... not always.

If you had to explain epilepsy to a person who had never heard of it before, what would you tell them?

At first it's a scary thing when you're in the hospital. You feel different and dizzy. You black out.

Did you have to get certain tests done at the hospital?

Yeah. They hook you up to these electric cords and they glued it on my head and the nurses wrap it up and they hooked it up to a backpack and there's a TV so the nurses can see if I'm having a seizure or not.

How did you feel when you were doing that?

It hurt and the glue smelled bad.

Is there anything you would tell someone to bring that was going to the hospital the first time?

Books. puzzles. You only have a TV in your room. that's pretty much it. and your bed. You can bring arts and crafts and coloring.

If one of your friends went to the doctor and the doctor told her that she had epilepsy, what advice would you give her?

I would say it's a scary feeling in the first place but then once you find everybody. all the people who have it. you don't really feel alone. If you sleep and take your medicine and eat you won't really have any seizures.

raina

age 9

How do you feel about epilepsy?

At first I didn't really like it but then there was a walk in Washington D.C. that I saw so many people had epilepsy and it didn't really make me feel alone with it.

What was your favorite part about it?

When some people made some speeches before we started the walk. The people that had epilepsy got to wear purple shirts and their families and whoever else came to the walk got to wear white shirts. So you got to see everyone else who had epilepsy in purple. MmHmm. There were lots of purple shirts.

Was there anything you learned from going to the walk?

I didn't feel alone. And the walk helps for research.

once you find everybody...
all the people who have it...
you don't really feel alone.

WE USUALLY TALK MORE ABOUT WHAT'S IN THE MYSTERY MEAT AT LUNCH!

samantha

How would you define epilepsy to a person who does not know what it is?

When I was younger my mom told me to explain it like my brain was doing a jig or something, and after a while my friends were like "Huh?" so I stopped using that and I started saying that everything besides my heart shuts down basically.

Can you tell me about how you feel about epilepsy?

I think epilepsy isn't that bad compared to some of the other diseases... I think it would be easier to have epilepsy than some of the other diseases people have, like cancer.

Do some of your friends know you have epilepsy?

All of them do. I have a friend who has epilepsy so we tell each other all about what we do. And she was on a TV show and I'm gonna be in a book so we're both gonna be famous!

How did your friends who don't have epilepsy react when you told them?

It was a long time ago. They were probably like "What? What is epilepsy?" and then I explained to them and they were like, "Okay, now what's in the nachos?". They really didn't care... I don't think anyone really cares. Except for the boys because they were like, "Woah! That's interesting!" It was so weird, I was like, why are the boys so interested?! It's just epilepsy, people!

Is this something you talked about with your friends?

Yeah but that was only when Andrea (from ESNJ) came and talked to us (at school). We usually don't talk about that. We usually talk more about what's in the mystery meat at lunch.

call me “SAM”

If one of your friends went to the doctor and the doctor told her that she had epilepsy,

what advice would you give her?

What I would want to say to people who just got epilepsy is that one, the medicine tastes really gross; two, if you can swallow pills and you have enough money, take them; and three, epilepsy is pretty easy unless you have to get an EEG or an IV or something, that's kind of hard. Other than that, there's nothing really sad about it.

Don't get hyper because nothing really interesting happens besides the fact that you have seizures and you can go to more cool places. Other than that, you just do normal things like swim, eat, dance, listen to music. You do whatever you want to basically. But sometimes you're not allowed to do things like ride horses or maybe ride a motorcycle.

Sam

Do what you want to because epilepsy doesn't really stop you from doing that much... You can do really almost anything you want to... except for things that are illegal!

Rachel

"Sometimes I feel different because nobody I know has epilepsy. But other times it doesn't even bother me because I have my singing and my sports and when I have that and when I'm with my family it doesn't bother me because it's not as big as it used to be. Now I'm okay with it because I know my parents and family are on my side, and I know that I can still play the sports and I can still participate in activities, so I don't feel as left out as I used to when I was younger."

Don't sweat it.

If one of your friends went to the doctor and the doctor told her that she had epilepsy what advice would you give her?

I'd say, "If you need me, I can come over and help you, and that it's okay because I have it too. And that you can still do things as long as you put your heart to it. You should never give up because you have one thing that's bad. And I always got your side so it's going to be okay."

Can you describe what it was like to have a seizure?

I was a baby... I don't remember. Just from what I heard it was just that I got really tired and after I would just want to go to sleep, and I guess I could have sometimes gotten sick. It really depended... depended on which type.

How would you define epilepsy to a person who doesn't know what it is?

It's when you have seizures and it depends what case you have... but I wouldn't worry about it because, based on my experience, it doesn't really bother me because I still do the things that I do so, and I don't have seizures anymore so that's a definition.

There are other people in the world who... well this is what my mom always told me... there are people who are worse than my case. I have it easy. I don't have it that bad. I'm sure that other cases are worse than epilepsy. So don't let epilepsy knock you down because you can always get back up if you put your heart to it.

YOU SHOULD TELL YOUR CLOSEST FRIENDS FIRST.

If you had to define epilepsy to a person who had never heard of it before how would you define it?

I would say it's a disorder that goes to your brain and it makes you have really bad stuff happen in your brain.

Epilepsy is a brain disorder... you have to go on medication in order to control it, and like get brain surgery. Or if you're a kid you could grow out of it. You're gonna have to.. if you run tests they'll find a cure.

If one of your friends went to the doctor and the doctor told him that he had epilepsy, what advice would you want to give him?

I've actually had that experience before. My friend has epilepsy. At first my mom told me and so at first I kind of felt bad for him and the advice I gave to him is always tell someone if you ever have a seizure. Before you tell everybody you have epilepsy in school you should tell your closest friends first or someone that has it and then if they accept it, just tell your friends and then start to tell other people about it. When you go to the hospital, don't be nervous when you get your wires done.

Could you tell me what it's like when you have a seizure?

It's when everything freezes and what just happened I forget, like I was doing something and right after I had it I forgot what I did. The second one is an absence seizure where I just stand there and do nothing and I see nothing but black. And my dizzy spells.

Do you talk to your friends about it?

Yeah I do. I told my whole class in third grade that I had epilepsy. Sometimes I tell my friends that I have it.

How do they react?

Well they don't make fun of me at all. I thought they would but they don't. They don't laugh. One time in third grade they made a banner for me when I told my whole class when I was in the hospital. At first I thought it was gonna be a total disaster but then I felt really good and ever since then I told the people what I have and they've been fine with it.

JACK

age 11

> “I thought that a lot of people didn't have epilepsy
> *so I thought I was the only one at my school that had it.*
> *But actually, there were a couple people in my school.”*

CLAIRE

age 11

How would you explain epilepsy to a person who had never heard of it before?

Well it's really scary because I really don't know what's happening. People don't know what's happening. They don't know what you have and what's wrong so they're trying to help but they don't know how.

What does it feel like when you have a seizure?

Sometimes a part of your body hurts, it tingles. You get dizzy sometimes. Sometimes you fall.

If one of your friends went to the doctor and the doctor told her that she had epilepsy, what advice would you give her?

I would tell her that it's not scary.

If you don't eat a lot then you'll feel bad and then you'll get tired and then you'll have a lot of seizures.

Do you have to take a lot of medicine?

Yeah, but if you're doing well then the doctor can get rid of some medicines.

Any advice for a kid who doesn't like to take medicine?

At first I had to take liquid and then I practiced swallowing some things, small things like candies, and then I could take the pills. So I would say practice swallowing things.

How is your doctor?

He's nice. He gives good advice.

How do you deal with everything so well?

I just do what the doctor said to do so then I would feel better. He said just write everything down whenever I get a seizure... what time, how big it was.

Do you think that helps?

Yeah.

Do you talk about epilepsy with your friends?

With my close friends.

How did you tell them?

I told them "Promise not to tell anyone else?" and then I just told them.

How did they react?

They were kind of nervous for me.

Claire

CLAIRE

A drawing by Claire

KATIE

How would you explain epilepsy to someone who has never heard of it before?

How can I explain? You have to stay calm after a seizure and think positive thoughts.

I was confused because I didnt know what epilepsy was and I didnt know what seizures meant. I was going through a lot and thats it.

What about just general feelings about epilepsy? When the doctor first told you, what did you think? Were you confused?

Kind of but I thought I needed to think positive thoughts and I know that I'm going to get over it eventually.

If one of your friends went to the doctor and the doctor told her that she had epilepsy, what would you say to help make her feel better?

I have epilepsy and I'm being strong about it. I'm thinking positive thoughts because I know that I'm going to get over it.

"If your child starts to have seizures you should do research about it... you can get information and find out more information for what seizures are. Know about seizures and that can help your child."

Katie

age 17

Don't be negative because you'll probably get over it some day.

Just after a seizure, stay calm and think positive thoughts.

ROSIE

How would you define epilepsy to a person who does not know what it is?

You are just a normal kid that has seizures. You're just like any other kid.

Can you tell me a little bit about how you feel about epilepsy?

Kind of embarrassed. Kind of special because you can get whatever you want sometimes! But not all the time.

Can you tell me how your friends reacted when you told them (you had epilepsy)?

They said, "Really? I don't care!".

So it wasn't a big deal? No.

What did you tell them?

I said you can't tell anyone because I don't want anyone to know. I said I have seizures and we went on to our normal, playful selves.

If one of your friends went to the doctor and the doctor told her that she had epilepsy?

You'll be fine. You're a normal kid but just with seizures.

Rosie
age 13

KELLY

age 15

How would you define epilepsy to a person who doesn't know what it is?

As if there was a thunderstorm going on inside your head where different things are being set off that are causing your body to do something you don't want your body to do. That's how I would basically explain what's going on for a seizure. Let's say somebody came up to you and said "What is epilepsy?" My explanation is probably more when somebody has seizures.

Can you tell me a little bit about how you feel about epilepsy?

In the beginning I felt very unsure and very confused and didn't understand what it was exactly... But now I've made it where I really try to teach other people to understand what it's about and understand that it's not scary and you shouldn't be afraid of somebody who has it. I made it more of a positive thing , so it's almost me being a walking experience of how you could make it a good outcome of more of a negative part of your life.

It's definitely NOT something to be afraid of.

Nobody knew what epilepsy was and so I wanted to make it my goal to try and get people to understand what it was and that it's actually out there and it's very common. It was weird how some people would keep it a secret. I even kept it a secret at a time but finally told my best friend who completely didn't change what she thought about me which made me feel a lot better, which made me feel very weird to think that other people don't get to feel that because they keep it to themselves.

What did you tell your friend?

She was into just talking about anything at the moment but then I told her, "I need to let you know something about me, that I've been sick for quite a while," and she was very confused but then I said, "I have epilepsy," and she paused for a moment and she didn't know what it was so she asked me and I tried to explain it as best as possible. But her exact words were, "Well you're still you!" and she just kept on going with the conversation from before. So she was the first one I told and I felt very relieved.

If one of your friends went to the doctor and the doctor told her that she had epilepsy, what advice would you give her?

My advice would probably be to not be afraid and I would always be there for the friend and for anybody else who had a problem and that it's not something that you have to fight on your own or feel like you have to be strong. You have your weak moments and it's okay to have them. It's scary at times but it's not the end of the world for you and you can live through it.

Tips for taking medicine?

Certain medicines I remember not wanting to take it, it tasted terrible. But I knew it was going to make me feel good, and make me be me, and not have any seizures going on. I knew that it was going to help me so that's what keeps you going, to make sure that it's going to be for your health and you'll be all good with it.

> "...you have your weak moments and it's okay to have them."

Kelly

EMILY

"I used to call them daydreams when I was little because I didn't know what to call them"

age 16

Emily

How would you define epilepsy to a person who doesn't know what epilepsy is?

I still quite haven't figured out how to explain it myself to my friends. I usually just say I have just small seizures but they're nothing, you wouldn't notice; it's not like I fall on the floor or start shaking. You would think that I was not listening to you or staring off. It's just little, small things that... it's not really that noticeable I guess. I still don't know how to really describe it.

Anything about your emotions going through all of this?

It was hard when I was younger, and I mean it still is, but it could be worse. I'm grateful that it's not. And, it's just something you have to deal with every day. Like I said, when I was younger in grammar school, middle school I was like "Oh my god, it's so embarrassing!" But I mean, it's becoming less of a big deal to me because I have lived with it for so long so I learned to deal with it. It's getting better, I think. It's not that bad.

If one of your friends went to the doctor and was told that she had epilepsy, what advice would you give her?

I would probably tell her that it is really hard at first, like first learning will be hard. I was too young to really understand. But it's hard to deal with sometimes, and when I run cross country, for example, I have to really listen to my body and make sure nothing happens and even stupid things like strobe lights when we went to a haunted house, I had to kind of stay away from that. So it's hard sometimes. But you're not alone. It's not like you're the only person. Even friends who don't have it, everyone still accepts you and even if they don't then they're stupid.

How did your friends react (after you told them you had epilepsy)?

Well they all were just like, "It doesn't change the way we feel about you. You're still one of our best friends and it doesn't..." I mean, it worries me but it's not something we have to talk about. They're just like, "You're just normal like everyone else. It doesn't make you any different." They were all supportive. It was really, really nice.

"There are a lot of other people like this that you can call and talk to. It's not as bad as it seems. Don't let it freak you out."

thank you !

This book would not have been created without the help of Andrea Racioppi and Liza Gundell of Epilepsy Services of New Jersey. Andrea and Liza gave me both the freedom and the guidance to put this guide together, and I cannot thank you enough for giving me the opportunity to work with both of you at such great organizations. I also owe many thanks to Jillian Daidone, who designed "For Kids By Kids" and "For Parents By Parents" and helped turn my vision into a reality. Additionally, I would like to thank everyone at ESNJ and FRN for welcoming me with open arms and allowing me to work in a positive, motivational environment. I hope that ESNJ and FRN continue to use this book as a useful tool for children with epilepsy and their parents.

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-Elizabeth Grand

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