

By Nichole Stangel, MA, MS, LPC, NCC, CT
Illustrations by Xenia Voronicheva

My sibling is special



Tips for children who have a sibling
with a rare epilepsy

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This is a book for siblings who have a brother or sister with a rare epilepsy. It can be read alone or with a parent or caregiver.

This book is designed to help young children explore their feelings and think about coping tools they can use to help them manage those feelings.

Note to Parents and Caregivers from a rare epilepsy sibling — "When I was younger, it really bothered me; I didn't understand that my brother NEEDED my mom's attention, and that I didn't need medical care and he did. Your parents love you the same, but your sibling has special needs. If I were to write a book for parents, I would ask them to set aside time for each child, and agree on times with mom and dad."

My Rare Epilepsy Sibling Is Special...and So Am I!

Learning about rare epilepsy isn't easy for anyone in your family. The first time your brother or sister has a seizure, it might feel a little scary. Sometimes, it can take doctors a long time to figure out why your sibling is having seizures. That can make everyone feel upset. It can make you feel sad and mad all at the same time. You may not know what to do or how to feel. It can be confusing.

Rare epilepsy siblings actually helped write this book. They thought it would be a good idea to share their experiences by telling you a story about a little boy with a rare epilepsy and his family. They want to help you learn about having a sibling who has a rare epilepsy and help you find positive ways to share your feelings. They think the best way to help you feel better is by helping you learn when and how to express your feelings to your family and the other people in your life who love and support you. There are different ways to do that. The siblings also wanted to let you know that you are not alone. They know that some things will be really hard, but you will also have lots of happy times and if you don't already know this, your brother or sister can be very funny, so you will spend lots of time goofing around and laughing together.

If you are a little kid, it's best to have your mom, dad or someone older read this book with you.

If you have a question about your sibling's rare epilepsy while you read the story, it's okay to ask. The siblings who shared their stories and ideas to help with this book say that it helps them feel better when they understand more about their sibling affected by a rare epilepsy. If you have a question about your sibling's rare epilepsy, or about the feelings you may have, it's a good idea to ask your mom or dad. And as you read this book together, you can also share how the story makes you feel.





My name is Lisa and I am 7 years old. I have a brother named Joey and he is very special. He has a rare epilepsy. I also have a mom, dad and a dog named Al.



Because Joey has a rare epilepsy, he can have a hard time walking or talking or playing the same ways you do. He also has seizures and can get very, very, very sick. Sometimes he even has to go to the hospital.

He has seizures that can last a long time. Every day Joey takes medicine to help him. He needs to go to special classes in school.

Do you have a brother or sister who has a rare epilepsy? Can you draw a picture of your brother or sister?



It can be hard to have a brother who gets sick a lot. Because my brother has a rare epilepsy, I can have a lot of different feelings. Sometimes I am mad or sad or worried. My mom and dad tell me my feelings are normal and okay.

I feel scared when Joey has a seizure, or gets so sick, he goes to the hospital. I also get scared when he yells or acts out.



When I am scared, I have a special teddy bear that I like to hold, or I breathe deeply five times. It also helps me feel less scared if I talk to my mom or dad.

What makes you feel scared? When you are scared, what can you do to help you feel better?

I worry that Joey won't get better. I worry that I might do something to cause a seizure.

When I am worried, I like to blow bubbles. It makes me feel better. I focus on the nice things in my life by making a list of five good things in my life. This helps me worry less.

What worries do you have? When you are worried, what can you do to help you feel better?



Sometimes I get so mad at Joey. Like the times I have to miss something or we have to leave a fun party early because Joey is sick or has a seizure. It makes me mad when I see other kids not being nice to Joey, too.

When I am mad, running or doing jumping jacks helps me calm down. Reading a book also helps me feel less mad.

What makes you feel mad?
When you are mad, what can you do to help you feel better?





When I get mad at Joey for things he doesn't understand or for being different, I feel guilty. Sometimes I feel jealous when Joey is sick and my mom and dad spend a lot of time with him and not me. Then I feel guilty for being jealous that Joey is sick.

I write a nice note or draw a picture for Joey when I feel guilty and this makes me feel better. Doing something nice for my mom and dad or Joey is another thing I can do that helps me when I feel guilty.

What makes you feel guilty? When you are feeling guilty, what can you do to help you feel better?





I want my brother to be able to do all the things I can do and it makes me sad that he can't. I'm sad when I try to make Joey happy or feel better and nothing I do works.

I like to go outside and play when I feel sad. I also feel better when I listen to music or watch a funny video.

What makes you feel sad? When you are sad, what can you do to help you feel better?





Having a brother with a rare epilepsy may make life hard sometimes but I am happy a lot too. My whole family has a lot of laughs and fun together. We find different ways to talk and play together. It's okay to feel happy even when things are tough.

What makes you feel happy? What can you do to feel happy?





**FOR PARENTS
&
CAREGIVERS**

Dear Parents,

As a parent or caregiver, it can be difficult to navigate both the complex medical needs of a child who has a rare epilepsy and the complex experiences of the other children in the family. The following sections offer guidance to help the parent or caregiver better support the experience of the rare epilepsy sibling. We hope you find this helpful.

—Nichole Stangel, MA, MS, LPC, NCC, CT

Normalize the child's experience by creating an atmosphere where questions and emotions are allowed and welcomed.

- Talk about rare epilepsy and what that means physically, cognitively, etc.
 - Give them the correct words.
- Children will ask questions repeatedly. This is how they process—let them know it's okay to ask the same question over and over.
- Answer all questions openly, honestly and lovingly.
 - Don't leave out details about rare epilepsy to "protect" the child.
- Let the child know that all emotions are normal—it is okay to be sad, mad, glad, and more.
- Adults should be aware that they model emotions and ways to cope to children.
- Tell them what to expect during their brother's or sister's hospital stay or during other scary times.
 - Explain to the child that they may feel sad, mad or even guilty.
 - They may not want to do things that they used to like doing, they may have a hard time concentrating at home and school, and it may be harder for them to connect with friends and family.

- All of these feelings are normal and natural during a difficult time.

Build and strengthen a caring relationship with the child.

- Respect the child's thoughts, feelings, wishes and expectations.
- Never say that what they are thinking or feeling is wrong or that they shouldn't think or feel that way.
- Be sensitive to the child's perceptions and circumstances.
- Be nonjudgmental of the child's thoughts, feelings and behaviors—even when they are upsetting or disruptive.
 - This does not mean that these behaviors are approved, just understood.
- Reassure the child about their place within the family and that all their efforts are appreciated.
- Adults need to be aware of their nonverbal behaviors and what those may express to the child.

Help the child feel involved.

- Allow them to participate in tasks, according to their maturity and developmental level. Here are some examples of what they might do when their brother or sister has a seizure:
 - Call 9-1-1.

- Get a stopwatch and time the seizure.
- Get an icepack from the freezer.
- Call a relative or neighbor to have them come over in case the parents need coverage in order to go to the hospital.

Help the child develop healthy coping strategies.

- Everyone is different; discover how each child processes their feelings.
 - Talking, writing, poetry, art, building, exercise, etc.
- Find appropriate avenues for the child to express feelings in a healthy way.
 - If angry and physically acting out, have the child do something physical, smash ice on the driveway or draw out their feelings.



A LIST OF HEALTHY COPING SKILLS

1. Exercise.
2. Spend time in nature; play outside or go for a hike.
3. Read a book.
4. Be silly.
5. Garden; take care of a plant.
6. Play with your pet; take your dog for a walk.
7. Wiggle your body; dance around your room.
8. Write in a journal.
9. Draw a picture.
10. Make something; use paint and other art supplies or build something with wood or Legos.
11. Use your senses; look around and make a list of five things you hear, smell, taste, see and feel.
12. Play a game with someone or by yourself.
13. Watch a calming jar; make a DIY calming jar first.
14. Write an encouraging note to yourself.
15. Write about what you are good at or something hard you succeeded at.
16. Listen to music you like.
17. Stretch or do yoga.

18. Meditate.
19. Do breathing exercises.
20. Hug yourself or hug someone else.
21. Remember a fun or happy time.
22. Cuddle with a stuffed animal or a pet.
23. Talk to a friend or a trusted adult.
24. Blow bubbles.
25. Scream into a pillow or rip up newspaper/magazine if angry.
26. Write a poem or song.
27. Laugh; read a joke or watch a funny video
28. Do a mindfulness exercise.
29. Imagine a peaceful, safe place in your mind.
30. Do something nice for someone else.



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