

Growing up with a Sibling with Severe Epilepsy, YOU ARE NOT ALONE.

Severe epilepsies, such as Dravet and Lennox-Gastaut syndromes, are rare and difficult to treat - affecting not only the individual with severe epilepsy, but also their entire family in many ways.^{1,2}

The Sibling Voices Survey

The **Siblings Voices Survey** – which included young siblings (**ages 9-12**), teenage siblings (**ages 13-17**), and adult siblings (**ages 18 and over**) was created to help families understand more about what it is like to have a brother or sister with severe epilepsy.^{3,4} The results showed that siblings of children with severe epilepsy may be at risk for having anxiety or depression at some time in their lives, and many expressed fear that their sibling might die.^{5,6}

Are there times when you feel unhappy?

Feeling unhappy is something many siblings feel.



More than
50%

of all siblings reported experiencing **feelings of unhappiness** ranging from sometimes to a lot.⁵

Do you ever feel grumpy?

It's ok to feel grumpy or angry.



54%

of siblings aged 9-12 report experiencing **feelings of irritability or grumpiness** sometimes or a lot. Most of these kids also report they are easily startled and unhappy. Some (29%) reported having bad dreams.⁶

Have you ever worried that something might happen to your sibling with severe epilepsy?

Being worried about your sibling is understandable.



79%

of young siblings aged 9-12 expressed **fear that their sibling might die**.⁷

Other Concerns from Siblings⁶

The top concerns reported by young siblings (under 13) are:

- feeling worried/scared
- getting less parental attention
- worrying about their parents being stressed
- having their activities disrupted
- having more responsibilities at home
- at times experiencing feelings of embarrassment about their brother's or sister's epilepsy



5

THINGS YOU CAN DO

- 1 **Talk with your pediatrician, counselor or other trusted adult** about what you are feeling
- 2 **Connect** with other severe epilepsy siblings & families
- 3 **Ask to be part** of your sibling's treatment and care
- 4 **Focus** on your special talents & interests
- 5 It is okay to **have fun & do things you enjoy!**

And something really important to know is that:

42% of siblings aged 9-12 reported **high scores of sadness.**



20% of parents reported recognizing **signs of a high degree of sadness in siblings.**⁴

The Bottom Line

It's tough for kids who have a brother or sister with severe epilepsy. That's why it's important that you reach out to talk to someone when you have these feelings.



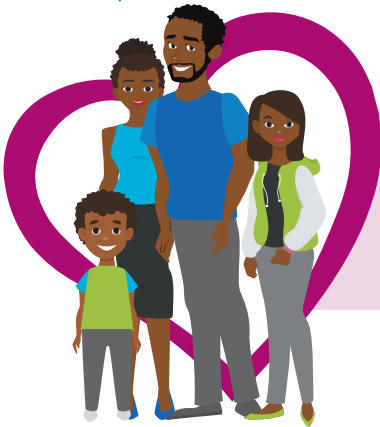
- Talk to **your family, grandparent, aunt, uncle, teacher**—whoever you are comfortable talking with. And it's also okay to ask for help from your doctor or healthcare provider.



- A **licensed therapist or counselor** can be super helpful when you may be feeling overwhelmed or stressed.



- Talk to your **mom or dad** about it.



Find Out More

Did you know that siblings who felt more knowledgeable about their sibling's severe epilepsy and/or being informed of ways to help seemed to feel less depressed or anxious about their brother's or sister's epilepsy?⁸ **KNOWLEDGE CAN BE POWER!**

Here are some ways to find out more about your brother or sister's severe epilepsy:

- Talk to your parents about how to help during a seizure
- Talk to your sibling's doctor
- Talk to other siblings who have a brother or sister with severe epilepsy
- Find out if the patient organization in your community offers a sibling support group



Your parents love you and want to support you, but sometimes when caring for a child with severe epilepsy, it's easy for the other kids in the family to get lost in the shuffle. Not on purpose, but sometimes it just happens.

Probably the most important thing you can do is to **talk to your parents**. Share how you feel, good or bad. Even though they love you and want the best for you, your parents may not be able to see what you are feeling inside about all the stresses and challenges of life with rare epilepsy. It's up to you to let them know. **Don't be afraid to speak up and ask for help.**

YOU ARE NOT ALONE.

References:

1. Villas N, Meskis MA, Goodliffe S. Dravet syndrome: Characteristics, comorbidities, and caregiver concerns. *Epilepsy Behav.* 2017 Sep; 74:81-86.
2. Jensen MP, et al. Life impact of caregiving for severe childhood epilepsy: Results of expert panels and caregiver focus groups. *Epilepsy & Behavior.* 2017; 74:135-143.
3. L. Bailey, A. Gammaitoni, B. Galer, L. Schwartz, C. Schad. Psychosocial Concerns of Growing Up With a Sibling With a Severe Epileptic Encephalopathy: Results From the Sibling Voices Survey Identify Potential Targets for Psychosocial Assessment. Presented: 72nd American Epilepsy Society Annual Meeting, New Orleans, LA, December 2018.
4. L. Bailey, A. Gammaitoni, B. Galer, L. Schwartz, C. Schad. Assessing Quality of Life in Siblings of Children With Severe Epileptic Encephalopathies: A Comparative Analysis of Sibling Self-Reports and Parental Perception of Sibling Experiences. Presented: 72nd American Epilepsy Society Annual Meeting, New Orleans, LA, December 2018.
5. L. Bailey, A. Gammaitoni, B. Galer, L. Schwartz, C. Schad. Siblings of Epileptic Encephalopathy Patients Are at Risk for Depression and Anxiety: Results From the Sibling Voices Survey. Presented: 13th European Congress on Epileptology (ECE) Annual Meeting, Vienna, Austria, August 2018.
6. L. Bailey, A. Gammaitoni, B. Galer, L. Schwartz, C. Schad. Impact of Severe Rare Childhood Epilepsy on Siblings Under 18 Years of Age. Presented: 13th European Congress on Epileptology (ECE) Annual Meeting, Vienna, Austria, August 2018.
7. L. Bailey, A. Gammaitoni, B. Galer, L. Schwartz, C. Schad. Impact of Severe Rare Childhood Epilepsy on Siblings: Fear of Death in Siblings of Children With Severe Epilepsy. Presented: 2018 Partners Against Mortality in Epilepsy (PAME) Conference, Alexandria, VA, June 14-16, 2018.
8. L. Bailey, A. Gammaitoni, B. Galer, L. Schwartz, C. Schad. Constructive vs Destructive Coping Methods in Siblings of Patients With Epileptic Encephalopathies: Presented at the National Organization for Rare Disorders (NORD) Rare Diseases & Orphan Products Breakthrough Summit, October 15-16, 2018, Washington, D.C.

ZOGENIX

©2019 Zogenix, Inc. All rights reserved. US-NP-1900001 July 2020