

The Psychosocial Impact of Growing Up With a Sibling With Severe Childhood Epilepsy

Severe childhood developmental epileptic encephalopathies (DEEs), such as Dravet and Lennox-Gastaut syndromes, are rare, intractable (treatment-resistant) types of epilepsy in which seizures typically contribute to brain dysfunction.^{1,2} These syndromes occur in a small number of people but can affect the individual and their family in numerous and significant ways.^{3,4}

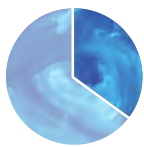
SIBLINGS OF CHILDREN WITH DEES MAY BE AT RISK FOR ANXIETY OR DEPRESSION, AND MANY EXPRESSED FEAR THAT THEIR SIBLING MIGHT DIE.



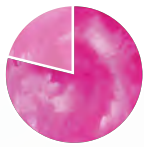
≥47% of young and adult siblings reported experiencing **feelings of unhappiness** sometimes or a lot⁷



≥53% of young siblings reported experiencing **feelings of irritability or grumpiness** sometimes or a lot⁹



35% of adult siblings reported a history of treatment for **clinical depression**⁸



79% of young siblings aged 9-12 expressed **fear that their sibling might die**¹⁰

The Siblings Voices Study, which was developed to assess the emotional impact of growing up with a sibling with an DEE, revealed that siblings often suffer from negative psychosocial effects that can impact their quality of life.⁵ Parents of these siblings may underestimate the effect growing up with a sibling with severe epilepsy has on them.⁶

The study included 3 subgroups of siblings:

The young siblings group included cohorts of siblings aged 9-12 and 13-17, and the adult siblings group included siblings aged 18 and over. Parents were also invited to participate in the study.

MOST FREQUENTLY REPORTED EMOTIONAL CHALLENGES CITED BY YOUNG SIBLINGS⁹

- Easily startled
- Unhappiness
- Irritability
- Bad dreams



TOP CONCERNS CITED BY YOUNG SIBLINGS⁹

- Worried/scared
- Less parental attention
- Parental stress
- Activities being disrupted
- More responsibilities at home
- Embarrassment



GREATER KNOWLEDGE ABOUT A SIBLING'S DEE HAD A BENEFIT (LESS PSYCHOSOCIAL IMPACT) FOR UNAFFECTED SIBLINGS

52-76% OF YOUNG AND ADULT SIBLINGS

who felt knowledgeable about DEEs and/or helped during a seizure had **lower depressed/anxiety mood symptom scores**⁸

38-86% OF YOUNG AND ADULT SIBLINGS

who felt knowledgeable about a sibling's DEE reported feeling more **comfortable talking with others about their sibling's diagnosis**⁸

ADULT SIBLINGS ARE WORRIED ABOUT TAKING ON THEIR SIBLING'S CARE

65% expressed concern over the **psychological/emotional toll** of caring for their affected sibling⁵

70% fear that **something bad would happen** to their sibling in their care⁵

67% expressed concern over being able to **provide a fulfilling life** for their sibling⁵



SIBLING SELF-REPORTING OF PSYCHOSOCIAL IMPACT DOES NOT ALIGN WITH PARENTAL REPORTS

24-58% of siblings' responses indicated potential **anxiety symptoms**,⁶ yet only

14-38% of parents perceived that the siblings experienced anxiety symptoms⁶

42% of siblings aged 9-12 reported high scores of **sadness**,⁶ while only

20% of parents reported recognizing signs of this degree of sadness in siblings⁶



Siblings of children with severe DEEs grow up in an environment permeated by stress, anxiety, and fear. The significant strains on the family's emotional and financial resources have the potential to significantly negatively impact the sibling's psychological health and may lead to feelings of depressed mood, anxiety, or other psychological comorbidities.

FAMILIES ARE ENCOURAGED TO SPEAK TO A HEALTHCARE PROFESSIONAL about ways to support the challenges siblings face when having a brother or sister with a DEE.



ZOGENIX
Rare Disease Therapies

References:

1. Khan S, Al Baradie R. Epileptic encephalopathies: an overview. *Epilepsy Res Treat.* 2012;2012:403592.
2. Dravet C. The core Dravet syndrome phenotype. *Epilepsia.* 2011;52(suppl 2):3-9.
3. Villas N, Meskis MA, Goodliffe S. Dravet syndrome: characteristics, comorbidities, and caregiver concerns. *Epilepsy Behav.* 2017;74:81-86.
4. Jensen MP, Lijtenquist KS, Bocell F, et al. Life impact of caregiving for severe childhood epilepsy: results of expert panels and caregiver focus groups. *Epilepsy Behav.* 2017;74:135-143.
5. Bailey LD, Gammaitoni AR, Galer BS, Schwartz L, Schad C. 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. Poster presented at: 72nd American Epilepsy Society (AES) Annual Meeting; November 30-December 4, 2018; New Orleans, LA.
6. Bailey LD, Gammaitoni AR, Galer BS, Schwartz L, Schad C. 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. Poster presented at: 72nd American Epilepsy Society (AES) Annual Meeting; November 30-December 4, 2018; New Orleans, LA.
7. Bailey LD, Gammaitoni AR, Galer BS, Schwartz L, Schad C. Siblings of epileptic encephalopathy patients are at risk for depression and anxiety: results from the Sibling Voices Survey. Presented at: 13th European Congress on Epileptology (ECE); August 29, 2018; Vienna, Austria.
8. Bailey LD, Gammaitoni AR, Galer BS, Schwartz L, Schad C. Constructive vs destructive coping methods in siblings of patients with epileptic encephalopathies: targets for intervention. Poster presented at: National Organization for Rare Disorders (NORD) Rare Diseases & Orphan Products Breakthrough Summit; October 15-16, 2018; Washington, DC.
9. Bailey LD, Gammaitoni AR, Galer BS, Schwartz L, Schad C. Impact of severe rare childhood epilepsy on siblings under 18 years of age. Poster presented at: 13th European Congress on Epileptology (ECE); August 26-30, 2018; Vienna, Austria.
10. Bailey LD, Gammaitoni AR, Galer BS, Schwartz L, Schad C. Impact of severe rare childhood epilepsy on siblings: fear of death in siblings of children with severe epilepsy. Poster presented at: 2018 Partners Against Mortality in Epilepsy (PAME) Conference; June 14-16, 2018; Alexandria, VA.