

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



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

## The Siblings Voices Study

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

**The study included three sub-groups 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.



## Siblings of children with EEs 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 lot**<sup>7</sup>



**35%** of adult siblings reported a history of treatment for **clinical depression**<sup>8</sup>



**≥53%** of young siblings reported experiencing feelings of irritability or grumpiness **sometimes** or **a lot**<sup>9</sup>



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

## Most frequently reported emotional challenges cited by young siblings<sup>11</sup>



- Easily startled
- Unhappiness
- Irritability
- Bad dreams

## Top concerns cited by young siblings<sup>7</sup>



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

## Greater knowledge about sibling's EE had a benefit (less psychosocial impact) for unaffected siblings



**52-76%**

of young and adult siblings felt knowledgeable about EEs and/or helped during a seizure had **lower depressed/anxiety mood symptom scores**<sup>11</sup>



**38-86%**

of young and adult siblings who felt knowledgeable about sibling's EE reported feeling more comfortable **talking with others about their sibling's diagnosis**<sup>11</sup>

## Adult siblings are worried about taking on their sibling's care



**65%** expressed concern over the **psychological/emotional toll** of caring for their affected sibling<sup>5</sup>

**70%** fear that **something bad would happen** to their sibling in their care<sup>5</sup>

**67%** expressed concern over being able to **provide a fulfilling life**<sup>5</sup>

## Sibling self-reporting of psychosocial impact does not align with parental reports



**24-58%** of siblings' responses indicated potential **anxiety symptoms**<sup>6</sup>

yet only **14-38%** of parents perceived the siblings experienced anxiety symptoms<sup>6</sup>



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

**20%** of parents reported recognizing signs of sadness in siblings<sup>6</sup>

Siblings of children with severe EEs 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 an EE.



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