

The Impact of Caring

FOR A LOVED ONE WITH DRAVET SYNDROME

Caregivers and families are unsung heroes who play a vital role in the health and well-being of the children and young adults with Dravet syndrome.

The disease not only affects those with the condition, but also the entire family unit - parents, siblings, caregivers and loved ones. This commitment can often result in a substantial financial, physical, psychosocial and emotional burden.



WHAT IS DRAVET SYNDROME?

Dravet syndrome is a rare form of intractable (treatment-resistant) epilepsy that begins in infancy and is associated with potentially life-threatening frequent and severe seizures, developmental delay, cognitive impairment, and an elevated risk of sudden unexplained death in epilepsy (SUDEP).¹

Dravet syndrome occurs in approximately



1 in 16,000 births in the U.S.²

Being A Caregiver For A Child With Dravet Syndrome Can Take An Emotional Toll



66% reported having **suffered from depression**³



33% have moderate to high levels of **anxiety or depression** due to the devastating nature of Dravet syndrome⁴

Many Parents Experience the Impact At Work



81% stopped working because of their caregiving responsibilities⁵



48 eight-hour work days missed per year⁶

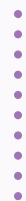


77 eight-hour work days of lost work productivity per year⁶

The Responsibility of Care Consumes Significant Amounts of Time



1 hr. or less per day is the only time 77% of caregivers report having completely for themselves⁵



256

eight-hour work days of lost leisure time per year⁶

The Burden Ripples Through The Entire Family

83% of siblings aged 9-12 **felt easily scared and fearful** their sibling will die⁷

67% of siblings reported **feeling worried or scared** when their sibling has a seizure⁷

74% of caregivers reported having concerns about the **emotional impact on siblings**³

37% of adult siblings reported having been **treated for clinical depression**⁸



It's important that people who care for children and young adults with Dravet syndrome learn ways to cope. Many advocacy groups offer tips and parent support groups to connect with other Dravet families.

Visit the Dravet Syndrome Foundation at <https://www.dravetfoundation.org/> to learn more about ways to manage caring for a loved one.

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References:

1. Dravet C. The core Dravet syndrome phenotype. *Epilepsia* 2011; 52(Suppl. 2): 3-9.
2. Wu, E., et al. (2015). Incidence of Dravet Syndrome in a US Population. *Pediatrics* 136(5): 1310-e1315. doi: 10.1542/peds.2015-1807. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4621800/>
3. Villas N, Meskis MA, Goodliffe S. Dravet syndrome: Characteristics, comorbidities, and caregiver concerns. *Epilepsy Behav.* 2017 Sep;74:81-86. doi: 10.1016/j.yebeh.2017.06.031. Epub 2017 Jul 18.
4. Campbell, Jonathan D., Whittington Melanie D., Chong, Kim, VanderVeen, Gina R., Knupp, Kelly, Gammaitoni, Arnold. "Assessing the impact of caring for a child with Dravet syndrome: Results of a caregiver survey." *Epilepsy & Behavior* 2018; 80: 152-156. doi: 10.1016/j.yebeh.2018.01.003.
5. Lagae L, Brambilla I, Mingorance A, Gibson E, Battersby A. "DISCUSS Dravet -Key socioeconomic findings from a large multinational survey of Dravet syndrome caregivers." Presented at the 12th European Paediatric Neurology Society Congress, June 20-24 2017; Lyon, France.
6. Campbell, Johnathan D., Whittington Melanie D., Chong, Kim, VanderVeen, Gina R., Knupp, Kelly, Gammaitoni, Arnold. "The direct and indirect costs of Dravet Syndrome." *Epilepsy & Behavior.* 2018 Feb 1; 80:109-113. doi: 10.1016/j.yebeh.2017.12.034. [Epub ahead of print].
7. Bailey L, Gammaitoni A, Galer B, Schwartz L, Schad C. "Interim Findings from the Sibling Voices Survey: Impact of Severe Childhood Epilepsy on Siblings 17 Years of Age or Under." Presented at the National Organization for Rare Disorders (NORD) and Orphan Products Breakthrough Summit, October 16-17, 2017; Washington, D.C.
8. Bailey L, Gammaitoni A, Galer B, Schwartz L, Schad C. "Interim Findings from the Sibling Voices Survey: Siblings of Epileptic Encephalopathy Patients Are at Risk for Depression and Anxiety." Presented at the Zogenix Scientific Exhibit Room (AES), December 3, 2017; Washington, D.C.