

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 children and young adults with Dravet syndrome.

The disease affects not only 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 15,700 births in the US²

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

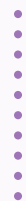


77 eight-hour work days of lost productivity at work per year⁶

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

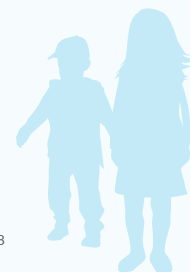
The Burden Ripples Through the Entire Family

79% of young siblings (ages 9-12) expressed **fear** that their sibling might die⁷

58% of siblings (ages 9-12) reported **feeling worried or scared** when their sibling has a seizure⁷

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

35% of adult siblings reported a **history of 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 dravetfoundation.org to learn more about ways to manage caring for a loved one.

References:

1. Dravet C. The core Dravet syndrome phenotype. *Epilepsia*. 2011;52(suppl 2):3-9.
2. Wu YW, Sullivan J, McDaniel SS, et al. Incidence of Dravet syndrome in a US population. *Pediatrics*. 2015;136(5):e1310-e1315.
3. Villas N, Meskis MA, Goodliffe S. Dravet syndrome: characteristics, comorbidities, and caregiver concerns. *Epilepsy Behav*. 2017;74:81-86.
4. Campbell JD, Whittington MD, Kim CH, VanderVeen GR, Knupp KG, Gammaitoni A. Assessing the impact of caring for a child with Dravet syndrome: results of a caregiver survey. *Epilepsy Behav*. 2018;80:152-156.
5. Lagae L, Irwin J, Gibson E, Battersby A. Caregiver impact and health service use in high and low severity Dravet syndrome: a multinational cohort study. *Seizure*. 2019;65:72-79.
6. Whittington MD, Knupp KG, Vanderveen G, Kim C, Gammaitoni A, Campbell JD. The direct and indirect costs of Dravet Syndrome. *Epilepsy Behav*. 2018;80:109-113.
7. 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.
8. 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.

ZOGENIX