

THE IMPACT OF CARING FOR A LOVED ONE WITH DRAVET SYNDROME

Caregivers and families play a huge role in the health and well-being of children and adults with Dravet syndrome. Due to the need to be “on guard” 24/7, the quality of life for caregivers and families is severely impacted. This commitment can result in physical, psychosocial, emotional, and financial burdens, such as constant monitoring, the need to co-sleep, and fear of death.¹

What is Dravet syndrome?

Dravet syndrome is a rare, devastating, and life-long epileptic encephalopathy that begins in infancy and is marked by frequent treatment-resistant seizures, significant developmental and motor impairments, and an increased risk of sudden death.¹

1 in 15,700

approximate number of infants born in the U.S. with Dravet syndrome²

5-6,000

number of patients diagnosed in the U.S., with ~50 new cases per year³

40 seizures/month

average number of seizures children with Dravet syndrome experience,³ lasting >20 minutes in up to 49% of patients⁴

The Emotional Toll on Caregivers



66% of caregivers reported suffering from having depression¹

Less Time for Oneself



77% of caregivers reported only having 1 hour or less per day for themselves, as being a caregiver takes up a significant amount of time⁵

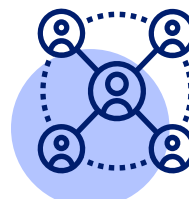
Many Parents Experience the Impact at Work



81% of parents stopped working due to their caregiver responsibilities⁵

48 8-hour work days are missed each year⁶

The Burden Ripples Through the Entire Family



79% of siblings aged 9-12 feared that their sibling might die⁷

35% of adult siblings reported having a history of clinical depression⁸

THE ADDITIONAL IMPACT OF DRAVET SYNDROME

The lives of Dravet syndrome patients, and those of their caregivers and families, are directly and indirectly impacted by the physical and emotional demands of the disease.

Direct Impacts⁶ (i.e., patient care)



In-home medical care visits

Doctor visits

Emergency room visits

Hospitalizations

Ground and air ambulance

Complementary healthcare
(i.e., chiropractic services)

Indirect Impacts⁶ (i.e., day-to-day effects)



Missed work due to caregiver responsibilities

Decline in workplace productivity due to absenteeism and presenteeism

Loss of leisure time

Emotional and psychological demands

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5. Lagae L, Brambilla I, Mingorance A, et al. DISCUSS Dravet –Key Socioeconomic Findings From a Large Multinational Survey of Dravet Syndrome Caregivers. Presented at the 12th European Paediatric Neurology Society Congress. 2017 June 20-24; Lyon, France.
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