

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 constant care and worry, the quality of life for caregivers and families is severely impacted. This commitment can result in physical, psychosocial, emotional, and financial burdens, such as continuous monitoring, the need to co-sleep, and fear of their Dravet syndrome family member's death.^{1,2,3,4}

What is Dravet syndrome?

Dravet syndrome is a rare, devastating and life-long form of epilepsy that begins in infancy, and is marked by severe, prolonged, and often treatment-resistant seizures; frequent hospitalisations; and significant cognitive, motor, and behavioural impairments. Patients with Dravet syndrome have an increased risk of death (about 20% higher than other epilepsies), primarily from SUDEP (sudden unexpected death in epilepsy) or a medical emergency called status epilepticus.^{1,3}

**1 in
20,000-40,000**

people in Europe have Dravet syndrome¹

More than 90%

of children with Dravet syndrome live with persistent seizures⁵

40 seizures/month

average number of seizures children with Dravet syndrome experience,⁶ lasting >20 minutes in up to 49% of patients⁷

The Emotional Toll on Caregivers



66% of caregivers reported suffering from depression⁸

Constant Worry



2 of the most straining aspects of caregiving are lack of sleep and inability to stop worrying⁹

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

The Impact on the Working Day



81% of parents stopped working due to their caregiver responsibilities⁵

48 full working days of 8-hours are missed each year¹⁰

The Burden Ripples Through the Entire Family



79% of siblings aged 9-12 feared that their sibling might die¹¹

35% of adult siblings reported having a history of clinical depression¹²

THE ADDITIONAL IMPACT OF DRAVET SYNDROME

The lives of patients with Dravet syndrome, and those of their caregivers and families, are both directly and indirectly impacted by the physical and emotional demands of the disease.¹⁰

Direct Impact¹⁰ (i.e., patient care)



In-home medical care visits

Doctor visits

Emergency room visits

Hospitalisations

Complementary healthcare
(i.e., chiropractic services)

Indirect Impact¹⁰ (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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