



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 the entire family unit - the commitment to caring for a child with Dravet syndrome 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).



In the UK, it is estimated that Dravet syndrome affects approximately **1 in 19,000 people**¹

Many Parents Experience the Impact At Work



75% stopped working because of their caregiving responsibilities²



86% reported that caring for a child with Dravet syndrome had **influenced their career choices**



53% missed an average of **6 hours of work in the past 4 weeks** to care for the needs of their child

The Responsibility of Care Consumes Significant Amounts of Time



1 hr. or less per day is the only time **69%** of caregivers report having completely for themselves²



Patients visited a pediatric neurologist on average **3 times per year**

Many Caregivers Lack Systems of Support

39%

received support from **their family**

26%

received support from **social services**

21%

received support from **privately sourced caregivers**

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 UK at <https://www.dravet.org.uk/> to learn more about ways to manage caring for a loved one.



This infographic was sponsored by, and developed in collaboration with, Zogenix International Limited.

References:

1. What is Dravet Syndrome? Dravet Syndrome UK. Accessed on Feb. 15, 2018 via <https://www.dravet.org.uk/families/what-is-dravet-syndrome>.

2. Irwin J, Pagano K, Lagae L, Gibson E, Battersby A. "The clinical and socioeconomic impact of Dravet syndrome in the UK." Presented at the ILAE British Chapter Annual Scientific Meeting, 4 - 6 Oct. 2017; Leeds, United Kingdom.