



DRAVET
Syndrome UK

Understanding the mental health toll of caring for someone with Dravet Syndrome

A guide for parents and carers

What is Dravet Syndrome?

Dravet Syndrome is a rare, lifelong and life-limiting neurological condition that causes severe, difficult-to-control seizures. It also brings a range of other challenges including developmental delays, mobility issues, behavioural difficulties, and problems with sleep, speech, and feeding.

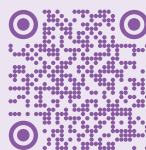
Why it matters

Caring for a child or adult with Dravet Syndrome is incredibly demanding. On top of daily care, the emotional and psychological impact is profound. A recent study, "Trauma, coping, and adjustment when parenting a child with Dravet syndrome", found that many parents and carers experience anxiety, depression, and trauma or PTSD. The ongoing stress and lack of sleep only make things harder.

“ Even when families find ways to adapt, the psychological load remains heavy. Parents need support for themselves - not just as carers, but as people. ”

- Trauma, Coping, and Adjustment Study (Mercier et al 2025)

Sources: Mercier, A. et al. (2025) 'Trauma, coping, and adjustment when parenting a child with Dravet syndrome', *European Journal of Paediatric Neurology*, 54, pp. 96–106.



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Common experiences

- Living in constant alert due to unpredictable and severe seizures.
- Repeated trauma from medical emergencies and the persistent fear of SUDEP (Sudden Unexpected Death in Epilepsy).
- Grief for the life you imagined for your loved one and the emotional toll on the wider family.
- Exhaustion, isolation, and burnout.
- Parents are often in a state of continuous alert due to the unpredictability and severity of seizures.
- Mental health struggles such as anxiety, depression, and complex PTSD are common and often unrecognised because parents remain focused on their child's survival.

A letter from an expert

If you need help explaining why support is important, DSUK can provide a letter written by Professor Liam Dorris, Consultant Paediatric Neuropsychologist, Royal Hospital for Children.

This letter advocates for mental health support for parents and carers and can be shared with your GP or any professional involved in your care.

Tear-Off: Take this to your appointment

I care for a child or adult with Dravet Syndrome. This includes:

- Managing life-threatening seizures and medical emergencies.
- Living with sleep deprivation and chronic stress.
- Coping with emotional trauma and grief.
- Navigating multiple services while feeling isolated.

Ways to get help

- Speak to your GP about a referral to counselling or trauma-informed therapy such as Cognitive Behavioural Therapy (CBT) and EMDR (Eye Movement Desensitisation and Reprocessing).
- Ask for a carer's assessment from your local authority – this helps identify your needs and can give you access to support like home help, respite care, or equipment.
- Request a child and family assessment (for children) – This ensures the needs of the whole family are considered, not just the child's. It can lead to joined-up support that recognises and responds to your emotional and practical challenges.
- Look into disability benefits – financial support can reduce stress and allow you to prioritise your family's care.
- Explore respite care or short breaks – Taking time for yourself is essential to continue providing care.
- Join peer support networks – Connecting with others in similar situations can bring comfort, reduce isolation, and offer valuable advice.
- Contact DSUK's Family Support Team to help you navigate options.

What to do in a crisis

- If you're in immediate danger or feeling suicidal, call 999 or go to A&E.
- Contact Samaritans 24/7 on 116 123
- Speak to your GP urgently.
- Text SHOUT to 85258 for immediate mental health support.

Talking points

- "I need support for my own mental health."
- "Could I be referred to trauma informed counselling?"
- "I'd like to access a carer's assessment and support options."

You deserve support and your mental health matters. Just as you advocate for your loved one's health, you deserve care too.