



DRAVET
Syndrome UK



Understanding the mental health toll of caring for someone with Dravet Syndrome and how you can help

A guide for professionals

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.

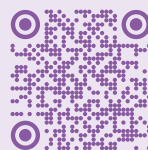
Why it matters

Parenting or caring for a child or adult with Dravet Syndrome is emotionally, physically, and psychologically exhausting. The study "Trauma, coping, and adjustment when parenting a child with Dravet syndrome" found that parents and carers often experience high levels of anxiety, depression, and trauma-related symptoms, made worse by sleep deprivation and ongoing stress.

“ 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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DSUK Resources

1. Understand the emotional and psychological impact

Recognise that Dravet Syndrome creates chronic emotional strain, ongoing trauma, and significant personal losses for families.

Be aware that:

- Parents are often in a state of continuous alert due to the unpredictability and severity of seizures.
- Many families live with daily grief; grieving the life they imagined for their child, the loss of typical developmental milestones, and the emotional toll on the wider family.
- The trauma is ongoing. Parents may witness multiple medical emergencies and carry a persistent fear of SUDEP (Sudden Unexpected Death in Epilepsy).
- Mental health struggles such as anxiety, depression, and complex PTSD are common and often unrecognised because parents remain focused on their child's survival.
- Parents' and carers' mental health needs are just as urgent as the physical healthcare needs of the person they care for.

“ I didn't realise how much I'd changed until I was completely burnt out. My whole focus was on keeping my child safe. ”

– Parent, DSUK Community

2. Make a meaningful referral

Refer to psychological support services such as IAPT (Improving Access to Psychological Therapies), but clarify the complexity and trauma of the caring role.

Recommend trauma-specific therapies:

- Trauma-focused Cognitive Behavioural Therapy (CBT)
- EMDR (Eye Movement Desensitisation and Reprocessing)
- Bereavement counselling (including anticipatory grief)
- Carer or parent-focused counselling

Help with access to:

Local authority carer assessments - These identify the carer's own needs and can lead to practical support like respite, equipment, or direct payments.

Child and Family Assessments (for children) - Requesting this from Children's Services ensures that the child's needs and family circumstances are assessed together, leading to joined-up support.

Care Act Needs Assessment (for adults) - For an adult living with Dravet Syndrome, this assessment can identify their care and support needs and what help can be provided under the Care Act.

Disability benefits - Parents and carers may be eligible for financial support such as DLA, PIP, or Carer's Allowance, which can ease financial pressure and allow them to focus on care.

Respite care or short breaks - Time away from caregiving can help carers rest and maintain their own wellbeing. Encourage families to explore both formal respite services and local charity-led schemes.

Peer support networks (local and national) - Connecting with others who understand their experiences can reduce isolation and provide emotional relief, shared advice, and solidarity.

3. Check in regularly

Parental mental health support should be ongoing, not treated as a one-time conversation. Offer check-in appointments and make mental health an ongoing part of the family's care plan.