Dravet Syndrome UK

Family Survey Report 2025/26

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ABOUT US

Dravet Syndrome

Dravet Syndrome is a rare, life-long and life-limiting neurological condition, affecting one in every 15,000 people in the UK. As well as severe, difficult-to-control seizures, Dravet Syndrome encompasses intellectual disability and a spectrum of associated conditions (known as 'comorbidities'), which may include autism, ADHD, behaviours that challenge and difficulties with speech, mobility, feeding and sleep.

Every individual living with Dravet Syndrome is unique and the balance of symptoms and comorbidities varies widely. What remains constant is the condition's complexity and unpredictability, creating daily challenges that extend far beyond seizure management.

Dravet Syndrome UK

Dravet Syndrome UK (DSUK) was founded in 2008 by parents seeking support, information and community around this little-understood condition. Today, much more is known about Dravet Syndrome, and our reach has grown to over 600 families across the UK.

We are the only UK charity dedicated to improving the lives of those affected by Dravet Syndrome. Our mission is to bring hope to families through three pillars of work:

SUPPORT

Emotional, practical and financial support for families at every stage

EDUCATION

Raising awareness and understanding among professionals and the public

RESEARCH

Funding vital medical research to improve diagnosis, treatment and outcomes

INTRODUCTION

This report presents findings from DSUK's 2025/26 Family Survey, capturing the experiences of DSUK-registered families across diagnosis, healthcare, therapies, social care, education and mental wellbeing. Short quotes from respondents are included throughout this report to illustrate key themes in their own words.

As we look to develop our next five-year strategy, we sent this survey to collect up-to-date insights on the needs and experiences of families living with Dravet Syndrome in the UK. These findings will help ensure that our work continues to reflect and respond to what matters most to the people we support.

Responses highlight significant areas of unmet need. Families continue to face persistent gaps, particularly around therapy access, respite care, mental health support and the transition to adulthood, that affect daily life and long-term wellbeing.

These findings build on our 2021 survey [1], which highlighted the scale of caregiver burden and inconsistent support services. Four years later, while there has been progress in some areas, many pressures remain. Insufficient support and its impact on family and caregiver mental wellbeing are still defining themes.

We hope these insights spark important conversations, strengthen services and help direct resources to where they are needed most. Overall, the report provides the most up-to-date available UK data on the experiences of families living with Dravet Syndrome, offering a robust evidence base to shape DSUK's priorities, support families navigating services, and inform the wider policy and clinical landscape around Dravet Syndrome.

We are deeply grateful to every family who took the time to share their experience. Their voices are at the heart of this report, and their responses will directly shape our work in the years ahead.






METHODS AND RESPONDENTS

An online survey for DSUK-registered families was open from June 2025 to February 2026. The survey was hosted on SurveyMonkey and shared via social media, newsletters and our private online forum.

The objectives of this survey were to:

- Ensure families living with Dravet Syndrome feel heard and actively contribute to DSUK's mission.
- Gain a deeper understanding of the health, education, and social support needs of families affected by Dravet Syndrome.
- Inform DSUK's strategy for improving health, education, and social care services and support.
- Obtain data insights to strengthen fundraising efforts and demonstrate the impact of DSUK's support.

Questions were a combination of open ended, single and multiple choice. The survey covered: diagnosis, presentation and progression, healthcare support (child and adult), education and transition, social care and respite support (child and adult), mental wellbeing of parents and siblings, sleep, financial circumstances, and DSUK support.

In total, 65 respondents completed the survey; 94% were parents of people living with Dravet Syndrome, whose ages ranged from 0 to 51.

Open-ended responses were reviewed to identify recurring themes and select illustrative quotes. Quantitative data from closed questions were summarised as frequencies and percentages. Where comparisons are made between subgroups, these are presented descriptively. Given the sample size, findings are presented as patterns rather than statistically significant findings, and should be interpreted accordingly.

Like many rare disease surveys, there was a demographic skew toward White families and those with higher-than-average household incomes. This likely reflects engagement bias, where families with the capacity to complete detailed surveys may differ systematically from those experiencing the greatest disadvantage. Findings therefore likely primarily reflect the experiences of currently engaged DSUK-registered families and should be interpreted accordingly. While this limits generalisability, the consistency of themes across multiple sections strengthens

FINDING 1

Earlier diagnosis, but post-diagnosis support remains limited

Diagnosis appears to be happening earlier (fig.1). 64% of children under 5 received a confirmed Dravet Syndrome diagnosis before their first birthday, and genetic testing was reported by 98% of respondents. This suggests professionals may be getting better at recognising Dravet Syndrome quickly, which is important for accessing appropriate treatment and support.

However, many families still face uncertainty. Around a quarter of respondents were given unclear labels such as "SCN1A-epilepsy" or "suspected Dravet Syndrome" instead of a confirmed diagnosis. While this can be appropriate in very young children before developmental delays become apparent, families need clear communication, realistic expectations and support during this time. Prolonged uncertainty can delay access to services and increase anxiety.

> *"We knew she had Dravet Syndrome but the neurologist said she wasn't severe enough developmentally (she was 1.. so early days). I think she was holding off the diagnosis to not scare us, but it actually hurt more knowing it was coming and not being able to get any support.*

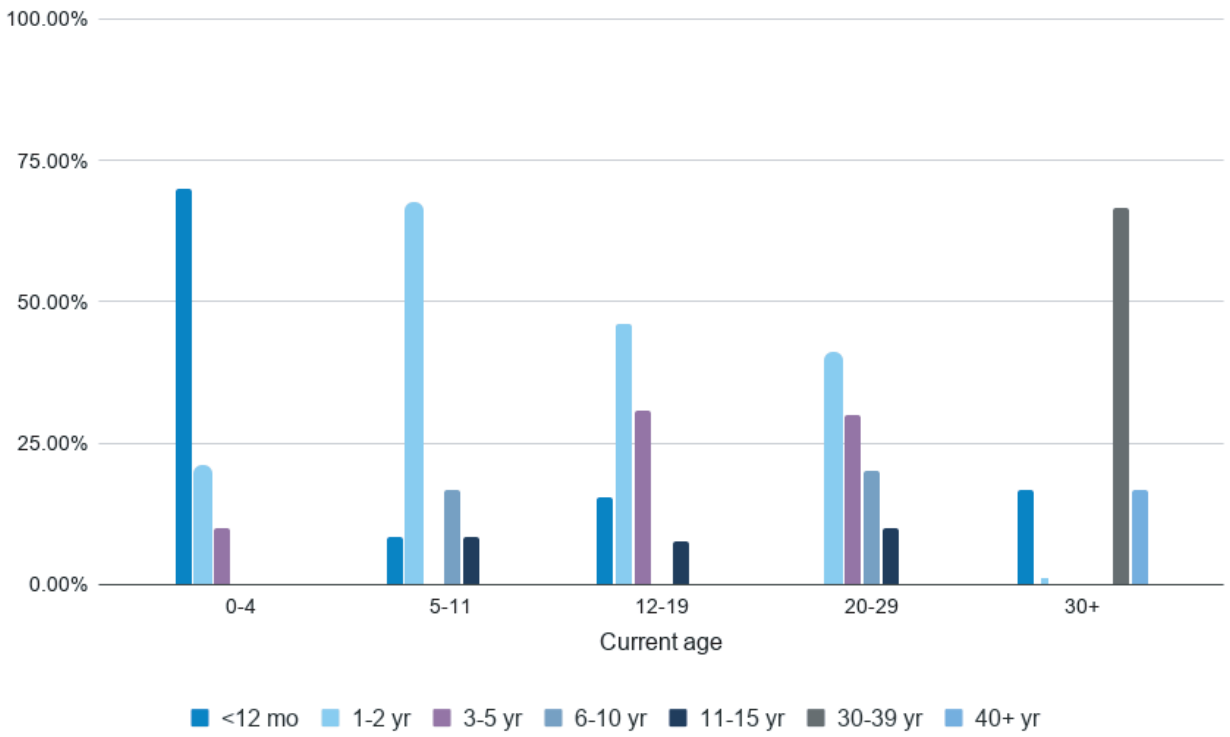

Figure 1. *Current age of respondents compared with age at diagnosis, shown as a percentage of respondents in each current-age group.*

Diagnosis also needs to be followed by proper support. As in the 2021 survey [1], fewer than half of respondents were offered genetic counselling to help them understand what this diagnosis means for their family. Those who received genetic counselling were twice as likely to say they fully understood the diagnosis. This suggests that diagnosis is not always matched by early, family-focused support.

Families with young children were particularly underserved, with no under-5s in our survey having a funded care package, respite care, a Child and Family Assessment or dedicated social worker. Fewer than one in ten received unpaid care from family and friends. If this pattern of earlier diagnoses continues without better post-diagnostic support, more families could risk reaching crisis point before help arrives.

> *Everything support wise is a battle and I keep asking and asking but getting nowhere or just on waiting lists. In the meantime things get worse where early intervention/ support would improve things.*

Insights to take forward

Building on our current professional education to support early diagnosis, areas for development include:

- The development of a structured post-diagnosis resource for families, covering what to expect, what to ask for and how to access support in the early months after diagnosis.
- The role of genetic counselling at diagnosis, and how neurological and genetic services can make this a routine offer.
- How local authorities can ensure families with children under 5 are not excluded from social care assessment and support.

FINDING 2

Sleep is badly disrupted, and night-time worry never really stops

SLEEP DISRUPTION affected **83%** of respondents

For many, sleep disruption became a long-term pattern rather than a short phase: 52% of respondents caring for adults still co-sleep and night-time seizures rose from 53% of respondents caring for children to 77% for adults.

Half of all respondents had to stay alert for seizure monitors or alarms. On top of seizures, parents reported sleep being impacted by worry about their child's immediate safety and long-term future.

> *[We have a] constant state of alertness that other parents don't have.*

Overnight respite was the most frequently requested support from respondents in open-ended questions. Around 32% of respondents said they need it but did not receive it, and

FEWER THAN A QUARTER of respondents received **any overnight respite** at all

> *I desperately need overnight respite. Social care does not realise the health impact to me that being up every night for prolonged periods is having.*

The gap between need and provision suggests overnight respite may still be treated as a discretionary service rather than a clinical necessity. This is particularly concerning given that sleep deprivation has well-documented effects on cognitive function, mental health and the capacity to provide safe, consistent care.

> *If I was not so sleep deprived I think my mental health would be better and I would better be able to help myself and access the services that would help me.*

Insights to take forward

We will continue to provide free seizure monitors to all newly registered families for additional peace of mind at night. Building on this, these findings point to a number of areas for us to develop:

- The case for overnight respite to be recognised as a clinical need for Dravet Syndrome families, and included routinely in care plans.

- Practical guidance to help families evidence night-time need and request appropriate support.

FINDING 3

The toll on carers is huge, but the right support remains out of reach

Two-thirds of carers reported that caring for someone living with Dravet Syndrome has a 'huge' impact on their mental health, yet

74% of those most affected received no or **MINIMAL SUPPORT**

This points to a significant and persistent gap between the emotional toll of caring and the support families are able to access.

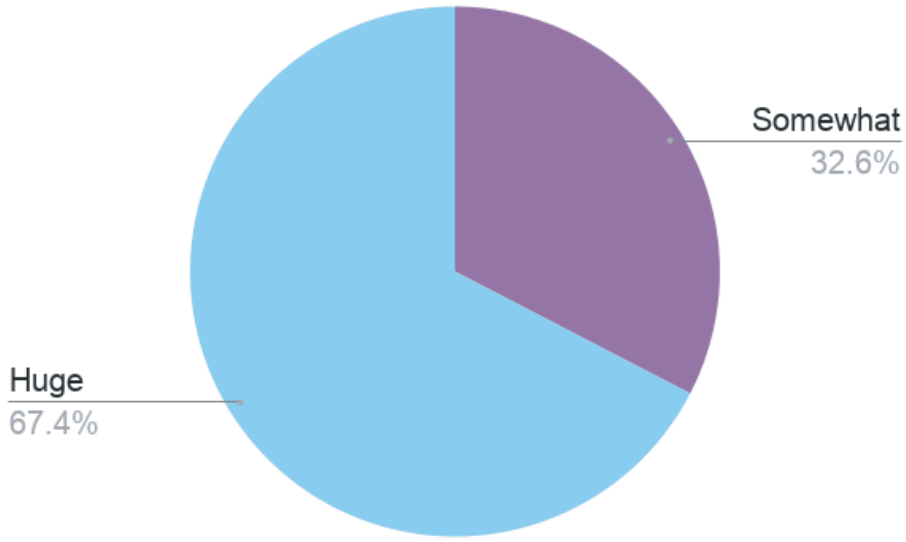

Figure 2. *Responses to the question: "What impact has Dravet Syndrome had on your mental wellbeing?" Response options were: huge, somewhat, little and not at all.*

40% of eligible carers (parents of adults) had not had a Carer Assessment; a quarter had not done so because they were unaware they were entitled to one. Almost half of carers have never been offered mental health support, and fewer than one-third access NHS-funded care. Where support was available, counselling and talking therapies were the most valued: 45% of carers who had accessed support rated these as the most helpful form.

> *I have asked for counselling but got given a list of phone numbers and told we have to pay privately for it.*

The financial and employment impact compounded the picture; respondents were four times more likely to have no working parent, and 3 times less likely than the genera population to have both parents in full-time employment. Single parents are twice as likely not to be in work. Caregiving becomes all-consuming and time away from caring, even work, is reduced.

> *[Child's] illness has turned our life upside down, we live every day following a strict routine because of him, every day is the same. We never socialise. Everything at home spins around [the child] , what we eat, what we watch, what we do. I spend most of my day feeding him and looking after him, we don't have any time for anything else.*

The impact extends beyond parents with 50% of respondents say Dravet Syndrome hugely impacts sibling wellbeing, but 51% get no support. This broader family impact is consistently underacknowledged in service planning and deserves greater attention.

Insights to take forward

In 2025, we highlighted research on the mental health impacts of caring for a child living with Dravet Syndrome and developed resources for parents and healthcare professionals to encourage access to support. The experiences shared in this survey highlight further priorities for action, including:

- How health and social care services can proactively offer Carer Assessments and funded counselling to carers of people living with Dravet Syndrome.
- The development of dedicated sibling resources to address a consistently unmet need.

FINDING 4

SUDEP is a constant fear, and families want honest, ongoing conversations

Worry about Sudden Unexpected Death in Epilepsy (SUDEP) affected the sleep of 96% of parents of children and 58% of parents of adults. More than half of respondents wanted more open conversations about SUDEP and practical risk-reduction strategies, including those caring for adults and those who had already had multiple discussions. The need for ongoing dialogue does not diminish over time.

> *"The professional often didn't want to discuss SUDEP risks or potential worst outcomes... all this did was create more anxiousness.*

These responses suggest that the challenge is not only whether SUDEP is discussed, but how and how often. Families value honest, ongoing conversations that combine sensitivity with clear, practical information. Risk conversations need to be revisited throughout the lifespan and at key transitions, rather than treated as a one-time task.

Insights to take forward

Responses shared here points to a number of areas for us to action:

- The development of updated family-facing materials on SUDEP and risk reduction, including guidance on revisiting the conversation at key life stages.
- How clinicians can treat SUDEP (and other mortality) discussions as a recurring part of routine care, not a one-time task at diagnosis.

FINDING 5

Comorbidities accumulate, but therapy access collapses

Most respondents reported that their family member displayed challenging behaviours, mobility issues, autism spectrum disorder or autistic features, intellectual disability and speech impairment. These caregiver-reported comorbidities showed developmental and behavioural difficulties are present from early childhood, with motor problems becoming more prominent from late adolescence onwards. Medical complications such as scoliosis, feeding difficulties and dysautonomia accumulate over time, creating an increasingly complex picture that extends well beyond seizure management.

Despite this, families face significant challenges in accessing therapeutic support for comorbidities. Intellectual disability and challenging behaviours are overwhelmingly identified as having the greatest life impact. Yet, fewer than a quarter of respondents' family members accessed neuropsychology or neuropsychiatric support.

> *Lack of knowledge about Dravet and what comes with it as [healthcare professionals] just see the seizures*

> *Everything is a battle and you have to constantly fight and push for the help and support and when it does come, it's slow, disjointed and inadequate.*

Long wait times were the biggest barrier to children accessing therapies for their comorbidities. For adults, it was services not being offered despite accumulating health challenges.

Respondents caring for adults living with Dravet Syndrome were

THREE TIMES MORE LIKELY TO RECEIVE NO ADDITIONAL THERAPIES than those caring for children.

Therapy provision collapsed at transition: physiotherapy dropped from 67% (children) to 46% (adults), speech and language therapy from 70% to 36%, occupational therapy from 57% to 36%. 14% of adults saw clinicians less than once a year. This indicates a sharp decline in therapy provision at transition that leaves adults living with Dravet Syndrome without the support they need precisely when complexity is increasing.

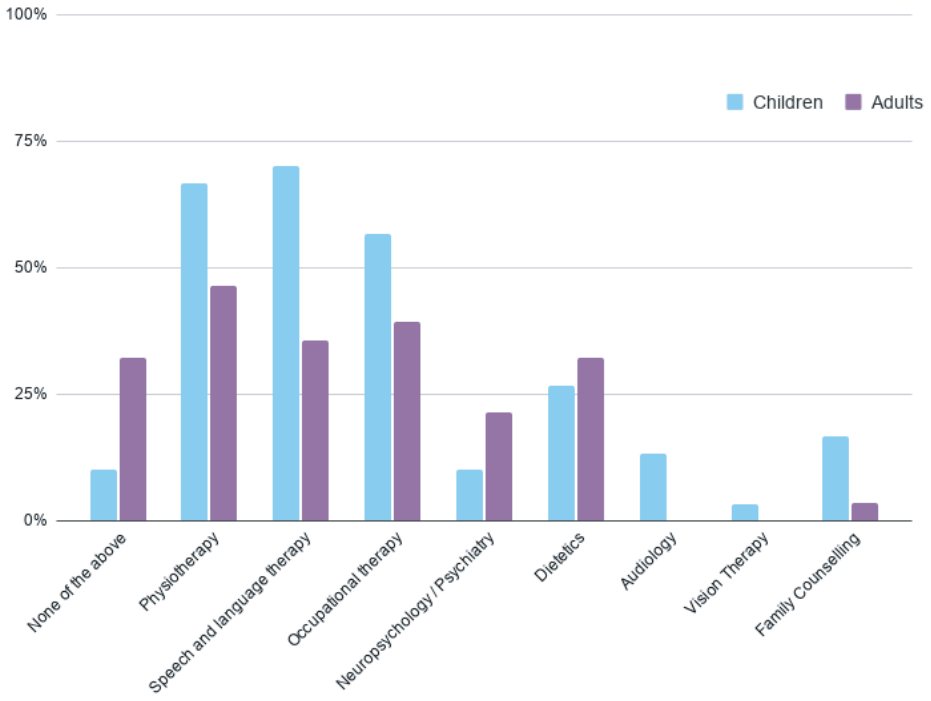

Figure 3. *Therapies accessed by children and adults living with Dravet Syndrome, as a percentage of respondents in each age group.*

> *"I feel that they don't seem interested when your child turns into an adult*

> *"[We have to] fight for everything - seems non existent in adults.*

Respondents who identified their consultant as having 'specific experience or expertise in Dravet Syndrome' were more likely to be offered additional therapies and reported greater confidence in their care. Specialist knowledge acts as a gateway to broader support which raises questions about equity of access for those without a specialist consultant.

Insights to take forward

We have reframed our communications and education to highlight the full impact of Dravet Syndrome beyond seizures, and are focusing on this area in our research. This picture raises a number of areas to explore:

- Mapping examples of specialist care and developing practical guidance for families on requesting therapies and navigating referral pathways.
- How adult neurology services can adopt a holistic approach to Dravet Syndrome care that reflects accumulating comorbidities, not just seizure management.

FINDING 6

Support exists, but too many families cannot access it

ONE-THIRD OF RESPONDENTS caring for children living with Dravet Syndrome received **no funded social care** support at all

and among those who do, over half say their package is inadequate. The most commonly cited barrier was simply not knowing what they are entitled to, indicating that a fundamental awareness gap that sits alongside, and compounds, the service gap itself.

> *We have been begging for support, a carer, anything to give us some help and had nothing*

Adult social care was more formalised, with higher rates of assessments (88%) and funded packages (80%), but this does not mean needs are being met; over 40% of respondents caring for adults say their funded care is inadequate. For adults, the most cited barrier was that support was available in principle yet could not be delivered in practice due to insufficient resources. This points to a system that recognises need but often cannot meet it.

Adult funding was further complicated by split responsibility: 50% of respondents reported local authority involvement and 33% reported NHS Continuing Healthcare, leaving families unclear about who was responsible for what. Transition into adult services is also poorly managed: while 92% of adults have transitioned, only 38% were proactively contacted by their local authority. The majority were left to navigate the process themselves.

> *Too much paperwork and no help with it.*

> *Having to reapply even though the condition is permanent.*

> *It is heartbreaking when you have to go through the challenges our young people go through. It makes it more real when you have to put it in writing.*

In education, Education, Health and Care Plan (EHCP) coverage appeared strong, with 87% of respondents caring for children in education reported having an EHCP, but a plan does not guarantee delivery; 70% of respondents still face challenges in securing the right educational support.

Lack of professional awareness of Dravet Syndrome is cited by half of respondents as a barrier, and 48% say that more suitable provisions, including consistent one-to-one support and increased access to special educational settings, would make a meaningful difference.

Across social care and education, the pattern is consistent: provision exists on paper far more reliably than it does in practice.

Insights to take forward

In 2025, we developed a comprehensive transition guide for families to explain the process and their rights, and hosted an EHCP webinar for registered families. This evidence raises a number of areas for further exploration:

- Ready-to-use templates, checklists and letters to help families navigate benefits, social care rights and appeals processes.
- How local authorities can make proactive transition planning standard practice for all young people living with Dravet Syndrome.
- The case for reducing the reassessment burden on families living with permanent, lifelong conditions.

FINDING 7

DSUK support makes a tangible difference

Empowerment of families is one of DSUK's strategic objectives in our 2021–2026 strategy. To measure progress towards this, we asked registered families whether DSUK has supported them to know and understand their rights and navigate life with Dravet Syndrome.

Respondents told us DSUK has had a positive impact on their experience.

67%
FEEL MORE
KNOWLEDGEABLE AND POSITIVE
about managing the condition

59% report greater confidence in navigating healthcare and support systems, and 37% say their mental wellbeing has improved through DSUK resources and community support.

> *I'm so glad we have Dravet Syndrome UK, before finding out about it, I felt so alone and misunderstood.*

> *I'd be lost without Dravet Syndrome UK.*

DSUK's website, Facebook group, and Family Guide were the most used resources, indicating clear, practical information and peer connection are valued. Events were described as improving outlook and giving families space to feel less alone.

> *The Center Parcs weekend was brilliant and we came away feeling like the future wasn't so bleak.*

> *The conference really gives me so much more information than I ever had.*

Respondents also highlight that simply knowing a specialist charity understands Dravet Syndrome helps them feel less isolated.

However, the survey also shows there are still families not yet reached by DSUK, or unsure what support is available. The families most in need are often least likely to engage, reinforcing the importance of proactive outreach rather than relying solely on self-referral. As noted in the Methods section, families with the most positive experiences of DSUK are more likely to have completed this survey.

Insights to take forward

Reflecting the impact families told us DSUK has had, these insights point to a number of areas for us to build on:

- Ensuring our resources remain current, accessible and responsive to what families tell us they need.
- Building on peer support networks and creating more opportunities for connection, both online and in person.
- Proactive outreach to unregistered and underserved families, including those facing socioeconomic or access barriers.
- Using insights from this and future surveys to shape our programmes.

This report reflects the experiences of 65 families living with Dravet Syndrome across the UK. Taken together, consistent themes across multiple sections point to systemic gaps that require coordinated action from health, education and social care services. DSUK remains committed to translating this evidence into meaningful change for every family living with Dravet Syndrome.

1. Freeman-Jones, E. et al. (2024) 'Caregiver burden and therapeutic needs in Dravet Syndrome - A national UK cross-sectional questionnaire study', European Journal of Paediatric Neurology, 53, pp. 138–143. doi:10.1016/j.ejpn.2024.10.010.

DRAVET Syndrome UK

Hope for families with life-limiting epilepsy

Dedicated to improving the lives of people affected by Dravet Syndrome through support, education and research

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