



The only UK charity supporting families affected by PANS and PANDAS.

Our community survey told us:

Just **2%** of families surveyed said their GP considered PANS or PANDAS

20% faced rejected paediatric referrals, while 70% waited longer than six months for their child to be assessed

Only **15%** were diagnosed by an NHS professional, with **45%** of families travelling more than 60 miles just to see a clinician with the appropriate expertise

69% of families felt they had no option but to seek private healthcare

PANS and PANDAS

Please use this briefing document to familiarise yourself with PANS and PANDAS prior to the upcoming backbench debate.

What are PANS and PANDAS?

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) and **PANDAS** (Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections) are post-infectious conditions which affect the brain. They are formally recognised as clinical syndromes by NHS England.

Onset is typically acute and causes **dramatic changes** in children and young people's physical and mental health. Symptoms include obsessive-compulsive behaviours, tics, eating restrictions, extreme anxiety, and sleep, sensory and urinary disturbances.

Who is affected by PANS and PANDAS?

PANS PANDAS UK currently supports 8,000 families, however low levels of awareness and difficulty accessing informed healthcare means this is unlikely to reflect the true scale of numbers affected. It is highly likely that there are multiple families living with PANS or PANDAS in every constituency.

Onset of PANS and PANDAS predominantly occurs in childhood, however both conditions may persist into adulthood, and some adult-onset cases have been described in research literature.

Lack of research funding means that there is currently no UK prevalence data for the conditions. The PANS PANDAS Steering Group are planning a nationwide surveillance study. Funding for this has had to be secured from a pan-European patient advocacy organisation.

Access to diagnosis, treatment and care

Early diagnosis and treatment are known to lead to improved outcomes. Currently, low awareness amongst health professionals and **huge variation in available care** is causing rejected referrals, prolonged waits for appropriate assessment, delayed or mis-diagnosis and worsened outcomes for patients. Data from the 2026 'Speak Up' survey from PANS PANDAS UK found that 53% waited more than a year for a diagnosis and 37% waited more than two years.

"We were watching our baby break down in front of our eyes and disappear in every single way. If she had been diagnosed and treated earlier, her life would never have been this hard."

Sarah, mum of Olivia who was only diagnosed with PANS after ten years of symptoms.

"I imagine people think that if I was braver, tougher, stronger... then I wouldn't have suffered all these years. Like it's my fault that I am not getting well, that I've caused this."

Evie, a PANDAS PANDAS UK Youth Board member. Evie was diagnosed with PANDAS aged 15, nine years after onset.

Our community members also shared the:

Education impact

48% of affected children missed more than six months of school

35% of affected children missed more than one year of school

Emotional impact

43% of parents said their child has talked about killing themselves

61% said their child has expressed a desire to 'not be here anymore'

Financial impact

30% of families experienced a financial impact of more than £50,000 and 12% more than £100,000; so far.

For more information, visit www.panspandasuk.org or contact our Health Lead, Katy: katy.hindson@panspandasuk.org

Delayed diagnosis and treatment

PANS and PANDAS are conditions with a **very high risk of long-term disability, exclusion from society and failed education**. Children and young people with undiagnosed and/or untreated PANS or PANDAS may struggle to attend school, experience significant decline in their cognitive and physical functioning and experience severe psychiatric symptoms.

The emotional impact on families is traumatic and life-changing. 81% of parents surveyed reported feeling anxious, isolated and lonely.

The financial implications for both families and the public purse are staggering. 36% of families had one or more parent or carer leave their job permanently to care for their child. Many have lost more than three months of work, with 15% remaining off work for more than one year.

Debate priorities

This is a key opportunity to raise the experiences of the children and families in your constituency. We ask that you use this debate to:

- **Call on the Government to end the postcode lottery** for diagnosis and treatment through the standardisation of care. **Publication of a UK clinical guideline for PANS and PANDAS is anticipated in Autumn 2026**. It is imperative that there is a clear commitment from the NHS for this to be embedded within services to improve patient experiences and outcomes
- **Call for mandatory training**. Improved professional awareness would lead to earlier identification, improved patient outcomes and reduced burden on families and the healthcare system
- **Question research priorities and call for improved funding**

to address the significant gaps in research identified in the **NIHR-funded Evidence and Gap Map (EGM)**. The need for clarity about treatment for PANS and PANDAS is also reflected in the James Lind Alliance top 10 priorities for childhood neurological disorders. Funding further research into the conditions is essential to reduce suffering and shape future clinical guidance.



"There is a need for more rigorous, prospective studies to evaluate the effectiveness of treatments for PANS and PANDAS such as antibiotics, behavioural interventions, and psychiatric medication"

The Isca Evidence team.

- **Signpost to Local Authority Guidance** – publication is anticipated in Summer 2026. Local Authority guidance is critical to ensure schools and services meet their statutory duties for children with PANS and PANDAS. Without clear direction, families face unlawful decisions, inconsistent provision, and barriers to essential assessments and support, all of which lead to significant educational harm.

Find out about how PANS and PANDAS should be included in the NHS 10 Year Plan in our

Count Us In: A Manifesto for PANS and PANDAS.

