



What are PANS and PANDAS?

PANS – Paediatric Acute-Onset Neuropsychiatric Syndrome
PANDAS - Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

PANS and PANDAS are conditions that often appear very suddenly and affect the physical and mental health of children and young adults. They develop in the wake of common infections (such as Covid-19, chicken pox, influenza, or strep A in PANDAS cases), when the infection subsequently causes a misdirected immune response and/or brain inflammation.

Onset of symptoms is often (but not always) abrupt. Overnight, children with PANS and PANDAS can go from being happy, healthy, and well-adjusted to being desperately ill. Symptoms such as severe obsessive-compulsive behaviours, motor and vocal tics, behavioural regression and crippling separation anxiety are a few of the most common symptoms. Rage, eating restriction, sleep disturbance and urinary difficulties are also frequently observed. Children with these conditions also suffer with extreme sensory sensitivities, hallucinations, self-harm and suicidal thoughts.

Lack of awareness and understanding in the UK at present means that many children are left undiagnosed and without access to appropriate treatment.

PANS and PANDAS are conditions with a very high risk of long-term disability, exclusion from society and failed education. Better awareness is needed in the UK to ensure that these children receive the simple treatments they need, and the right supports as they heal.

What are the impacts of these conditions?

Research in the US states that 1:200 children are affected¹. If comparable in the UK, it would mean that PANS and PANDAS are a part of everyday life for 51,000 UK children. Incidence is growing as the conditions become better understood, but the majority of children remain undiagnosed for too long.

The impacts of these conditions are devastating and wide-ranging both for the child affected, and for those caring for them. Children and families living with PANS and PANDAS experience the impacts in many different ways.

Health impacts

The symptoms of PANS and PANDAS are both physical and psychiatric. Symptoms may vary from one child to the next, or indeed (as this is usually a relapsing-remitting condition) from one relapse to the next.

Examples of the physical impacts of these conditions are onset of urinary incontinence, sensory sensitivities so severe that a child may be unable to tolerate clothing, motor tics which may be so violent they leave the child in pain, or sleep disturbance which alters the circadian rhythm so dramatically that functioning during daylight hours is impossible.

The neuropsychiatric symptoms leave many children housebound, unable to leave their parents' side, plagued by intrusive thoughts, unable to eat normally, and very often with uncharacteristic bouts of rage and aggression. Obsessive-compulsive behaviours are often so severe they take hours of each day to complete.

Educational Impacts

- Brain inflammation in these conditions causes numerous psychiatric, cognitive and physical symptoms. As a result of this, children can change rapidly from thriving in schools to developing severe and complex Special Educational Needs (SEN) across all four of the 'Broad Areas of Need' set out in the Special Educational Needs and Disabilities Code of Practice (2015)
- Lack of awareness amongst education professionals means that appropriate educational accommodations and modifications are not put in place to support the child. Sadly, it also means that inappropriate strategies are often unwittingly used in schools. This results in additional trauma

A third of affected children in the UK are reported to have missed at least 6 months of school. 19% of children were reported to have missed more than a year.²

- Attending school on a full or even part-time basis for children with PANS and PANDAS can sometimes be difficult and, for many, impossible. This leaves families struggling to cope with a child who is not physically or psychologically well enough to attend school, yet faced with external pressures (financial, social and even legal) to ensure that they still do so

Social impacts

For a child suffering with PANS and PANDAS, normal social activity is often severely impacted. Cognitive and behavioural decline make it difficult for sufferers to interact at the same level as their peers. Sudden onset of OCD behaviours and/or tics is difficult for children to adapt to, and extreme separation anxiety make both school and extra-curricular activities difficult to engage with.

Moreover, families and carers of sufferers also report high levels of social isolation. Caring for such very ill children is often an all-consuming occupation. Lack of awareness and understanding may lead to people incorrectly assuming a child's behaviours are down to poor parenting, or trauma in the home.

Financial impacts

Severity of symptoms in children and young people with these conditions often means that a parent or carer has no option but to leave paid employment to care for their child. The dramatic onset of these illnesses means that families are ill-equipped to cope with this sudden change in fortunes, and struggle to find the support to apply for financial assistance.

What support is available?

At present, awareness in the UK around these conditions is low but beginning to grow.

Children, young people and their families can be directed to PANS PANDAS UK. This is the only UK charity supporting children and families living with these conditions. They provide information, advocacy and community support to patients and carers. They raise awareness of the symptoms and treatment options for healthcare professionals so that they are better equipped to recognise when a child may have PANS or PANDAS.

PANS PANDAS UK also provide training in educational settings. Since 2021, the first CPD accredited teacher training package for these conditions has been rolled out in Norfolk to the Educational Psychology Specialist Support Team, the Medical Needs Team and the Inclusion and SEND teams.

“Amazing training. Will raise awareness and support with improved, earlier identification of potential PANS/PANDAS. We will consider commissioning training for our wider team and SEND Forum”

“A really emotive and informative session. Made more touching by the real-life stories shared. It's made me aware of the range of things to look out for but also how easily it can be misunderstood/misdiagnosed for something else.”

The [PANS PANDAS UK](#) website is also an excellent resource for educational and medical professionals looking for more information on PANS and PANDAS.

What medical provision is available?

Until very recently, targeted healthcare provision for these children has been patchy, with very few GPs recognising the symptoms and most children being referred exclusively to CAMHS, where lack of awareness has often led to misdiagnosis with late onset ASC (autism spectrum condition), or a psychiatric disorder such as OCD (obsessive-compulsive disorder or ADHD (attention deficit hyperactivity disorder).

Diane Palmer, Associate Director of Nursing at Norfolk and Suffolk Foundation Trust is building a pilot proposal for the UK's first dedicated and funded multi-disciplinary service for children with suspected or diagnosed PANS and PANDAS. Diane is exploring opportunities to work with scientific researchers to create clinical trials and is also building relationships with the Acute Trust paediatricians and neurologists.

Further information and resources

Resources for educational professionals

[Factsheet for Teachers](#)

[Awareness Poster for Schools](#)

[Supporting Children with PANS/PANDAS in Educational Settings: A Guide for Educational Professionals - Video](#)

[Twinkl Resource for Educators about PANS and PANDAS](#)

[Understanding the Impact of PANS, PANDAS and Long Covid in Schools - webinar](#)

Resources for school nurses

[Medical Professionals' Leaflet](#)

[Information for GPs Leaflet](#)

[The Mechanisms of PANS and PANDAS - video](#)

[A Guide for Health Professionals: Education and PANS PANDAS](#)

Resources for families

[Parent Information Leaflet](#)

[Parents' Guide to Education and PANS](#)

[Individual Health Care Plans. PANS and PANDAS: A Guide for Parents/Carers](#)

[Living with PANS and PANDAS Awareness Video](#)

[Twinkl Resource for Parents/Caregivers of Children with PANS and PANDAS](#)

[Leaflet for Friends and Family](#)

Further resources for SEND professionals, Speech and Language Therapists and Occupational Therapists

[Educational Resources for PANS and PANDAS \(padlet.com\)](#)