



# What are PANS or PANDAS?

We hear from Tina Coope, parent and educational lead at PANS PANDAS UK (PPUK) about why awareness of these conditions is so low and what teachers can be looking out for.

As part of my CPD as a SEN teacher, I regularly attended courses about ADHD, sensory processing disorder (SPD) and autism, amongst other conditions. However, there were no such available courses on Paediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections (PANDAS). So much so that when a close family member suddenly developed severe neuropsychiatric

symptoms, I initially had no idea what had happened.

## WHAT ARE PANS AND PANDAS?

PANS and PANDAS are post-infectious autoimmune conditions which affect both physical and mental health. They can be triggered by common infections such as strep throat, chickenpox, or influenza. It is also important to be aware that some children/young people are developing PANS post-Covid. These conditions mainly affect children, and onset usually happens between the

ages of three and 13, but PANS can also affect adults. Awareness about the conditions is low across the range of education, health and social care professionals.

Families who have experienced this firsthand are often clearly able to articulate the 'change' in their own child, but this is often less straightforward for schools. Firstly, if the school did not know the child before the onset of reported symptoms, and secondly, if this pattern of a 'sudden change' is not part of the teacher's professional understanding.



BIO

### TINA COOPE

Tina Coope is a former teacher, who until a few years ago taught across a number of settings including both special and mainstream schools. At the age of seven, Tina's daughter developed the sudden onset of severe neuropsychiatric symptoms. In 2020, she became the education lead for the charity PANS PANDAS UK; the only one of its kind in the UK supporting families living with PANS and PANDAS.

**WHAT MIGHT YOU SEE IN THE CLASSROOM?**

While children need to meet the diagnostic criteria for a formal diagnosis, there is such a wide-ranging spectrum of potential and often seemingly diverse symptoms that there is no one 'typical' presentation.

A child may well quickly change from loving school and thriving in the classroom to developing a myriad of new-onset confusing changes in areas of their learning, physical development, emotions and behaviours. For example, newly struggling to separate from their primary caregiver at the school gate and severe regression in handwriting can both be warning signs. Symptoms may also include extreme obsessive, compulsive behaviours, motor and vocal tics and behavioural regression (such as baby talk). Rage, restrictive food intake, sleep disturbance and urinary problems are also frequently observed.

**WHAT DO SCHOOLS NEED TO BE AWARE OF?**

I had been taught that learning difficulties were typically developmental with a reasonably stable picture of progression. Crucially though, I did not know then that children can also develop acute onset learning difficulties. Developmental checklists and historical attainment and markers can be very helpful as there may be no early signs of issues. In more complex cases where children have co-occurring conditions, a detailed timeline of symptom emergence can also be useful. It is important to be aware that every child is different. Children living with PANS and PANDAS can get better.



Education support is needs-led rather than diagnosis-led. While the support required in class can echo support for other needs, it is essential to recognise the unusual characteristics of these conditions.



Given the general lack of clarity about these conditions, the current lack of UK-led education research is unsurprising. The statistics that do exist are disquieting. Children affected by these conditions can go from achieving above age-related expectations in mainstream schools to, in some cases, achieving below age-related expectations and requiring specialist provision. Pre-onset, nine per cent of children were below the expected standard academically; following onset, this increased to 53 per cent.

Short-term and long-term school attendance is also significantly affected. Clearly much more research on this cohort of children is needed.

**WHAT CAN SCHOOLS DO TO HELP?**

Teachers are often in a unique position to spot the early signs and provide professional evidence for families to take to their GP. A good starting point is to undertake some early observations. Establish the child's baseline before the first suspected symptoms of the condition appeared.

PANS and PANDAS are complex and it is not unusual to have interprofessional debate and for home and school to be reporting a very different presentation in the

child, as some may mask their symptoms. Again, there is the need for more research.

Education support is needs-led rather than diagnosis-led. While the support required in class can echo support for other needs, it is essential to recognise the unusual characteristics of these conditions. As soon as you suspect that a child in your class may have PANS/PANDAS, it is important to act quickly. Children with these conditions can deteriorate abruptly and unexpectedly develop SEN.

It is also important to ensure that you are following the guidance to support children with medical conditions. PANS and PANDAS are medical conditions and should be supported as such. Children do not require a formal diagnosis to receive support in school, and many children with PANS/PANDAS fulfil the criteria to have an Individual Health Care Plan. Close collaboration with families and any further health or social care professionals is crucial.

**WHERE CAN I ACCESS FURTHER INFORMATION/ TRAINING?**

Further education resources are available at the **PANS PANDAS UK website**, including a link to sign up to free CPD-accredited training. A multidisciplinary guidelines development group supported by NHS England and The Royal College of Paediatrics and Child Health (RCPCH) also commenced work in early Spring 2024, putting an end to the current variation in care for children with the conditions or suspected conditions.