

Supporting the family:

- Understanding that PANS and PANDAS like other medical conditions, are not caused by poor parenting.
- Respecting that parents/caregivers have the most insightful perspective about their child both pre and post onset.
- Importance of a highly supportive and close relationship with parents/caregivers including regular and transparent communication
- Appreciation of the often-devastating impact of PANS and PANDAS on the whole family. The knowledge that it can challenge the most resilient of family units.
- Awareness that the conditions can affect more than one child in a family.

References - [*www.pandasnetwork.org/statistics/](http://www.pandasnetwork.org/statistics/)

For further information:

Resources: websites

PANS PANDAS UK <https://www.panspandasuk.org/>

Education <https://www.panspandasuk.org/for-educators>

- A [15-minute overview presentation](#) for Education Professionals: 'Supporting children with PANS and PANDAS in Educational settings.'
- Individual Health Care Plans: [A guide for Parents/Careers](#)
- An [educational Padlet](#). This contains all our UK resources and further resources from our international counterparts
- PANS and PANDAS: [Factsheet for Teachers](#)
- A brief guide to PANS/PANDAS: [Parents/Caregivers](#)
- [Awareness raising posters](#)
- '[Living with PANS/PANDAS](#)': A candid and moving 10-minute documentary featuring the voices of parents with children affected by PANS/PANDAS

Author Tina Coope, on behalf of the charity PANS PANDAS UK. Many thanks to Kate McCaul



PANS and PANDAS: Advice for good practice in Schools

What are PANS and PANDAS?

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome) and PANDAS (Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections) are a set of neuropsychiatric conditions that may include OCD, tics, severe eating restrictions and other cognitive, behavioural, and neurological symptoms. **They can only be diagnosed by a medical professional.**

Triggers may include strep throat, influenza, hand foot and mouth disease, chicken pox, pneumonia, Covid 19, allergens, anxiety, trauma, or other environmental factors. Despite the term paediatric in the name, PANS also affects adults.

In simple terms in PANS and PANDAS, the immune system attacks a small part of the brain called the basal ganglia which controls voluntary motor movements, procedural learning, habits, and emotions.

While there are no official statistics for the prevalence of these conditions in the UK, US researchers estimate that 1 in 200* children may be affected to some degree.

- Children with PANS and PANDAS frequently suffer from a constellation of diverse symptoms. These can include behavioural, social, emotional, cognitive, and physical changes.
- Symptoms can relapse and remit in type, duration, frequency, and severity.
- Some sufferers experience debilitating flares, whilst others function enough to be able to attend school, but not at their previous levels of functioning.

PANS and PANDAS are complex brain conditions, and schools play a crucial role in supporting early identification, addressing the barriers to learning and holistically supporting the child and their family. Effective support requires close collaboration with multiple professionals, alongside a whole school approach.

(The following suggestions are not intended to be definitive, but a starting point for good practice in schools).

Advice for Schools

How can we support Children with PANS and PANDAS in Education?

PANS PANDAS UK are advocating for a whole school collaborative approach including the following aspects.

Awareness and understanding:

- A highly supportive head and Senior Leadership Team who understand PANS and PANDAS and support their staff to understand the conditions. A commitment to ongoing staff training
- Requirement for skilled support and accommodations for symptoms that are due to a physiological reaction (an autoimmune and inflammatory process). Understanding the difference between 'I can't' and 'I won't'.
- Awareness of the importance of a child centred compassionate and nurturing approach.
- Highly flexible and adaptive responses to continually changing needs.
- Understanding that children can recover and make dramatic gains. This includes cognitively.
- Knowledge that assessment outcomes should only be seen as a snapshot. Long-term decisions should be made with caution.
- Comprehensive knowledge of the multiple and complex barriers that children with PANS and PANDAS face in attending and negotiating an educational setting.
- Understanding that some children with PANS and PANDAS mask or partially mask in school.
- Awareness that there will be good and challenging days, or good and challenging periods, and that progress for a child with PANS and PANDAS is unlikely to be linear.

- Awareness that some of the symptoms in PANS PANDAS are similar to many other conditions, and require careful and skilled evaluation.

Prioritising health needs:

- Prioritisation of health needs, alongside supporting the child's wellbeing and ability to access education, in both the short and longer term.
- Knowledge that the conditions have the potential to impact on attendance. This will be due to periods of being unwell, alongside attending multiple medical appointments.
- Understanding the crucial role of educational professionals to provide evidence and observations supporting parents/caregivers and clinicians.
- Willingness to collaborate with the child's medical team (and any other professionals who are involved) and to commit to attending multi-agency meetings and agreeing on a consistent approach.
- Recognising that PANS and PANDAS can potentially impact on children in multiple different ways. Some affected children may require assessments from Educational Psychologists, Speech and Language Therapists, and Occupational Therapists.
- Awareness that some children might suffer from longer term secondary impacts, including trauma.

Supporting wellbeing

- Ability to build key relationships with the child, and to ensure that they feel safe and secure.
- Understanding that the child does not operate in a vacuum and supporting a focus on the holistic wellbeing of the child at both home and school.
- Recognition of the crucial role of therapeutic and pastoral support for children with PANS and PANDAS.
- Recognition of the need to regularly assess, document and support the social, emotional, cognitive, physical, and behavioural impact of the conditions on the child. PANS and PANDAS are often relapsing and remitting conditions and it is important to assess and track affected children regularly, and in particular following a 'flare.'

Effective support requires close collaboration with multiple professionals, alongside a whole school approach