

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.

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 multi-professional collaboration alongside a whole school approach.

This is an evolving area.



Books

PANS, CANS and Automobiles: Greene, J. (2016) First Edition Design Publishing, Florida USA

PANS and PANDAS in a School Setting (2017) A handbook for educators. Edited by Patricia Rice Doran, Jessica Kingsley Publishers, London and Philadelphia

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PANS and PANDAS: Advice for good practice in Schools

What are PANS and PANDAS?

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)

PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections)

PANS and PANDAS are post infectious autoimmune and/or neuroinflammatory medical conditions that affect both physical and mental health.

These conditions, often triggered by common infections such as strep throat, chickenpox, or influenza, primarily affect *children, with the onset of PANDAS typically occurring between the ages of 3 and 13. However the symptoms can persist into adulthood, and PANS can also affect adults.

An exacerbation of symptoms is known colloquially as a flare

- Children with PANS and PANDAS frequently develop 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 children experience debilitating flares, whilst others function enough to be able to attend school, but not at their previous levels of functioning.

*The term children will also be used to refer to young adults.

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 flexible skilled support and accommodations for a changeable picture of needs.
- Understanding the difference between **'I can't'** and **'I won't'**.
- Awareness of the importance of a child centred compassionate and nurturing approach.
- Understanding that children can recover and make dramatic gains. This includes cognitively.
- Knowledge that assessment outcomes should only be seen as a snapshot.
- 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.
- 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 periods, and that progress for a child with PANS and PANDAS is unlikely to be linear.
- Awareness that many of the symptoms in PANS PANDAS share overlapping profiles with other conditions, and require careful and skilled evaluation.

Prioritising health needs:

- Prioritisation of health needs and access to effective treatment.
- A focus on long term positive engagement with education.
- Knowledge that the conditions have the potential to impact on attendance. This can 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)
- Recognising that PANS and PANDAS can potentially impact on children in multiple different ways. Some children with the conditions may require assessments from Educational Psychologists, Speech and Language Therapists, and Occupational Therapists.
- Awareness that some children can experience 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.

Whilst some of the content may also be relevant across Scotland, Wales and Northern Ireland, this information is based on the Education system for England

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