

PANS and PANDAS: A Summary for Teachers



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What are PANS and PANDAS?

PANS – Paediatric Acute-onset Neuropsychiatric Syndrome

PANDAS – Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

PANS and PANDAS are post infectious autoimmune and/or neuroinflammatory medical infections 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.

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

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

What are the symptoms?

Children with PANS and PANDAS can quickly change from thriving in school to developing a broad range of symptoms including:

- Extreme obsessive-compulsive behaviours
- Motor and vocal tics
- Severe generalised and separation anxiety
- Behavioural regression
- Emotional regulation issues
- Restricted food intake
- Sleep disturbance
- Urinary problems
- Development of learning difficulties

The key is to note any new difficulties that represent a change from the child's typical level of functioning.

The signs of PANS and PANDAS are often missed. The conditions are very easy to confuse with neurodevelopmental conditions, attachment or behaviour disorders, or even as a result of poor parenting.

Children can of course have more than one condition, or have other contributing factors in their lives.

It is crucial for educators to be aware of the early signs and to understand how PANS or PANDAS can present in the classroom. Early identification and support leads to better outcomes.

Not all children will have every symptom. The severity of the symptoms can also vary greatly from child to child, and within the same child at different stages of the condition.

A child with PANS and PANDAS may

- Demonstrate multiple unexplained changes in different areas of their functioning that might not be perceived as linked, for example working memory changes, restricted food intake and the development of tics.
- Present with much more severe symptoms at home than at school or vice versa.
- Struggle with their attendance and separating from their primary caregiver.
- Develop sudden and unexpected special education needs.
- Develop needs in areas that would not be expected for their age group, for example a deterioration in fine or gross motor skills in an older child.
- Fluctuate significantly in terms of symptoms and their ability to access work.
- Report very unusual symptoms such as feeling, seeing or hearing things that are not there and/or feeling unsafe for example.
- Newly display behaviours more commonly found in a much younger child.
- Move further away from their pre-onset baseline.

Key Facts

- PANS and PANDAS are medical conditions and can easily be missed. Maintain professional curiosity. Educational professionals may be the first to spot the symptoms.
- Usually, children with PANS and PANDAS unexpectedly develop multiple symptoms. The symptoms can both interact with each other, and also have a cumulative impact on the child.
- Children with PANS and PANDAS are often self-aware of their change in functioning at school. This is extremely distressing for them.
- Due to low levels of awareness, it is currently difficult in the UK to get a timely diagnosis and treatment for PANS or PANDAS. The conditions are recognised by the NHS.
- PANS and PANDAS are health conditions – ensure that you are following the statutory requirements for supporting children with medical conditions.



Good Practice

There is a lack of education research around supporting children with PANS and PANDAS and this is likely to be an evolving picture

PANS and PANDAS are complex

- Learn about the conditions and disseminate awareness amongst colleagues.
- Be aware of the diagnostic criteria to ensure due attention is given to the potential breadth of symptoms.
- Work as an informed team with any other professionals involved in the child's care.
- Health needs should be the priority. Focus on long term positive engagement with education. Ensure that any supporting professionals have the full picture of needs and impacts.

School and family relationships are crucial

- Children can present very differently at school and at home.
- A school is unlikely to recognise the full impact of the condition without close communication with the family.
- No one could see PANS or PANDAS coming. It can challenge the most resilient of families. Provide understanding for the whole family and additional support for siblings.
- Adopt a reflective and pupil-led approach: having a trusting and supportive relationship in school is key.
- Put in proactive support early, for example a detailed Individual Health Care Plan. Include a plan about attendance which is often affected.



The conditions are usually relapsing and remitting

- Undertake observations and provide professional evidence. Write a supporting letter for families to take to a GP including presentation of the child pre- suspected onset, a list of new symptoms, steps in place to support the child and the response of the child to those steps.
- Assessments are only a snapshot in time. It is very easy to under or over-estimate a child's level of needs.
- Provide accommodations that are sufficiently flexible to support a child during different phases of the condition i.e., when acutely unwell, during recovery and when recovered.
- Establish the child's baseline including their pre-onset attainment, progress and attendance levels.
- Assess whether the child is going 'back to baseline' following a flare and ensure that this information is shared with family/health care team.



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