

In summary

- Understand and recognise the condition and diagnostic criteria.
- At the earliest suspicion conduct a comprehensive baseline assessment
- Recognise and support the symptoms as immune mediated in origin.
- Be conscious of the impact on attendance and prioritise health needs.
- Be aware of the holistic impacts across multiple functional domains.
- Consider the unique trajectory of the condition on the child including triggers.
- Provide appropriate, responsive and flexible adaptations.
- Include a plan for exacerbations and identifying the early warning signs.
- Facilitate academic and social recovery during periods of remission and provide extensive SEMH support including for secondary sequelae.
- Ensure that medical professionals, families, and schools work collaboratively with informed practice around the symptoms.

Where can I find more information?

Websites

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

PANDAS Network, School resources from the US available at <https://pandasnetwork.org/education/>

The Children's e-Hospital, Advice for teachers and schools available at <http://www.e-hospital.co.uk>

PANDAS PPN, School resources from the US available at <https://www.pandasppn.org/school>

Books

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

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



Registered Office: c/o Baldwins Accountants,
1 Pegasus House, Pegasus Court, Tachbrook
Park, Leamington Spa, Warwickshire, CV34 6LW
Charity Number: 1178484

- 🌐 www.panspandasuk.org
- ✉ schools@panspandasuk.org
- 📘 PANS PANDAS UK Support Group
- 📱 @PandasPans
- 📷 @Pans_Pandas_UK
- 🌐 PANS PANDAS UK

PANS and PANDAS factsheet for Teachers

What are PANS and PANDAS?

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)

This is a neuropsychiatric condition which is triggered by a misdirected immune response.

PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections)

PANDAS is a subset of PANS. Similarly, it is a neuropsychiatric condition which is triggered by a misdirected immune response to a streptococcal infection.

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.

One of the **red** and **two of the blue** symptoms.

One of the **red** symptoms. *In many cases children also see many of the blue co-morbid symptoms but they are not necessary for a diagnosis.*

PANS: No age restriction **OCD** or **severely restricted food intake**

PANDAS (Children only) **Motor/vocal tics** or **OCD**

- Anxiety
- Motor or sensory abnormalities including tics
- Emotional lability and/or depression
- Irritability, Aggression, and/or severely oppositional behaviours
- Behavioural (developmental regression)
- Sudden deterioration in school performance
- Insomnia and /or sleep disturbances
- Enuresis and/or urinary frequency

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- Food restrictions

Whilst not part of the diagnostic criteria in approximately 25% of cases there have been reports of psychosis and/or hallucinations

*www.pandasnetwork.org/statistics/

What should Teachers be aware of?

PANS/PANDAS can only be diagnosed by a medical professional; however, schools can help by providing supporting information for parents/caregivers. The conditions are listed under a code in the WHO ICD11 diagnostic manual, but access to a diagnosis and treatment in the UK is currently highly challenging. Evidence suggests that early diagnosis and treatment leads to much better outcomes. Schools have a unique role in this.

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PANS/PANDAS can be present **alongside** other conditions such as ASD and ADHD, **or they can present as** ADHD and ASD. The key is the timing of onset and recognising the constellation of symptoms. Children with PANS/PANDAS are also sometimes misdiagnosed as having Tourette's Syndrome, ADHD, Anorexia Nervosa, ARFID, Generalised Anxiety Disorder, OCD and Autism amongst other conditions.

PANS/PANDAS often impact on multiple functional domains including cognitive, social, physical, emotional and behavioural.

PANS/PANDAS often impact on multiple functional domains including cognitive, social, physical, emotional and behavioural. Each pupil will be affected on an individual basis and the trajectory of the condition is likely to be unique to them. For some, the condition may be episodic with the pupil returning to baseline following a flare. For others, it may

be a mixture of chronic and flare symptoms, or it may be chronic static or chronic progressive. Progress and attainment may well follow an atypical pattern of regression and recovery. Disorders such as dysgraphia or handwriting regression that 'appeared' with onset will also reflect these patterns. Each child will additionally have their own set of triggers, these could be infection based and/or psychological. Stress and lack of sleep are likely to exacerbate symptoms.

Settings should be aware that the presenting symptoms are immune mediated, i.e., that the symptoms are not caused directly by the infection, but by the body's abnormal immune response affecting the brain.

School accommodations should be aware that a child's ability to function may well be variable from day to day, and certainly within periods of remission and a flare.

School accommodations should be aware that a child's ability to function may well be variable from day to day, and certainly within periods of remission and a flare. This variability relates to highly specific skills such as writing, working memory and executive functioning in addition to other neuroimmune impacts that may include 'brain fog,' alongside concentration and attention difficulties.

During periods of remission or following treatment the improvements can be striking. Schools therefore need to continue to support and respect the child's full academic potential.

Once PANS or PANDAS is suspected, detailed assessments should be undertaken as soon as possible to establish a comprehensive and holistic baseline.

Once PANS or PANDAS is suspected, detailed assessments should be undertaken as soon as possible to establish a comprehensive and holistic baseline. If the child has moved setting since onset, the previous setting should be consulted alongside school progress data. Schools should listen to the parents/caregivers and be aware of the current medical issues around diagnosis and treatment. As with all conditions, children should be appropriately supported based on their presentation, and do not require a medical diagnosis.

PANS/PANDAS often impacts substantially on attendance.

PANS/PANDAS often impacts substantially on attendance. Children can suffer from severe anxiety including separation anxiety, violent and aggressive outbursts, severe sleep difficulties, intrusive thoughts, compulsions, tics, and in some cases even auditory, visual, and tactile hallucinations*. These all need to be understood as immune mediated. The primary medical aim is to reduce the immune mediated response. Schools should provide compassion alongside supportive modifications. Health needs should be prioritised. All pupils should have a plan in place for acute symptom exacerbations including early warning signs, and how these will be communicated.

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PANS/PANDAS are complex brain conditions and require a collaborative approach from parents, educators, and medical professionals. The pupil is likely to require different approaches and supports depending on their health status and the trajectory of the condition. The efficacy of traditional accommodations need to be considered within the context of the condition, i.e., the primary cause, trajectory, and atypical patterns of regression/improvement. This includes managing the significant pastoral needs including secondary sequelae following a 'flare.' Settings should also be aware of the significant impact on siblings alongside the caregiver burden for families.



*hallucinations must be investigated by a medical professional.