



PANS PANDAS Steering Group

The PANS PANDAS Steering Group (PPSG) works to improve standards of care for people living with PANS/PANDAS with the support of NHS England.

The PPSG oversees four working sub-groups, including the Consensus Guideline Development Group which is undertaking work in 2024 to develop a guideline based on existing knowledge of the conditions which will address the current variation in care occurring across the UK.

Scan this QR code to read the latest PPSG statement and for more information for health professionals or visit www.panspandasuk.org/for-gps



PANS PANDAS UK
awareness support education

About us

It is our mission to raise awareness of these life-changing conditions, to engage and inform health, social care and education professionals and to support young people and families living with PANS and PANDAS. Together we are building brighter futures for all those affected.

Contact us

-  info@panspandasuk.org
-  www.panspandasuk.org
-  [@PandasPans](https://www.instagram.com/PandasPans)
-  [PANS PANDAS UK](https://www.facebook.com/PANS.PANDAS.UK)

GP Information Leaflet (2024)
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Charity number: 1178484

For GPs



PANS PANDAS UK
awareness support education



PANS & PANDAS

Information Leaflet for GPs and Paediatricians

PANS

Paediatric Acute-Onset Neuropsychiatric Syndrome

PANDAS ICD-11: 8E4A.0 / 8A05.10

Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

 www.panspandasuk.org/for-gps

PANS and PANDAS are post-infectious disorders in which severe symptoms of obsessive-compulsive behaviours, tics or eating restrictions develop suddenly.



DIAGNOSTIC CRITERIA

PANS

An abrupt, acute, dramatic onset* of obsessive-compulsive disorder or severely restricted food intake along with two or more of the following symptoms which are not better explained by a known neurologic or medical disorder:

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

There is no restriction for age of onset in PANS

Recent research supports the theory of a misdirected immune response that weakens the blood-brain barrier, causing basal ganglia inflammation and impacting movement, cognitive perception, habit, executive function, and emotion.

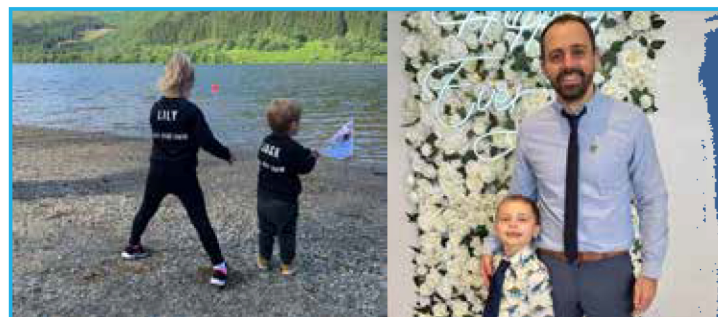
PANS/PANDAS are diagnoses of exclusion, often resembling autism, OCD, ADHD, depression, Tourette's syndrome and bipolar disorder. However, PANS/PANDAS are characterised by acute and profound change.

PANDAS

PANDAS is a subset of PANS, and is considered when there is a temporary correlation between streptococcal infection and onset of symptoms.

- Presence of OCD and/or tics, particularly multiple, complex or unusual tics
- Symptoms of the disorder first become evident between 3 years of age and puberty
- Acute onset* and episodic (relapsing-remitting) course
- Association with neurological abnormalities

***The requirement within the diagnostic criteria for an abrupt or acute onset was originally stipulated in order to create a well-defined cohort of patients for research purposes. It is beginning to be acknowledged that onset may not always be as rapid as the diagnostic criteria currently state, however they have yet to be updated to reflect this.**



Appropriate first stage tests that may be considered

- Throat, nasopharyngeal or peri-anal swab to rule out strep
- U+E, LFT, FBC, ASOT, CRP, TFT, Anti-Dnase B Titres, Mycoplasma Titres, ANA, Vit D3, Total IgE, Immunoglobulin and Immunoglobulin sub-sets
- Tests to rule out other infections based upon medical and family history

First stage treatments that may be considered

- Initiate treatment immediately – do not wait for test results
- Initial Antimicrobial therapy. Choose one of the following and administer orally for 14 days: Penicillin V, Amoxicillin, Co-amoxiclav, Cephalexin, Clindamycin, Azithromycin, Clarithromycin
- Follow up with patient to see if remission/improvement occurred. Consider continued antibiotic or prophylaxis
- Referral to paediatrician for ongoing treatment
- OCD often benefits from CBT or counselling

Consider PANS and PANDAS carefully. Urgent intervention is essential for the best possible prognosis.

