Clinical guidelines

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

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

PPSG
PANS PANDAS STEERING GROUP

More information

Scan for more information for health professionals, or visit www.panspandasuk.org/for-gps

Our MIMS online learning module contains information about PANS and signposts international guidelines for both conditions.

MIMS LEARNING

We encourage all healthcare professionals seeking to learn more about PANS and PANDAS to complete this training module.

About us

Our mission is to raise awareness of PANS and PANDAS, to engage and inform health, social care and education professionals and to support young people and families living with these life-changing conditions. Scan below to learn more about PANS PANDAS UK:

Together, we are building brighter futures for all those affected.

Contact Us

www.panspandasuk.org

info@panspandasuk.org

GP information leaflet (June 2026)
Greville House, 10 Jury Street, Warwick, Warwickshire, CV34 4EW

Charity number:
Eng - 1178484 | Scot - SC053206

PANS and 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

Created in collaboration with
Professor Rajat Gupta, Paediatric Neurologist, Birmingham Children's Hospital

www.panspandasuk.org/for-gps

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

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

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.

Fluctuating presentation: Families report that symptoms can fluctuate over time and may be masked outside the home. Periods of worsening may last days, weeks or months. Presentation in school or clinic may not reflect the level of distress or impairment seen at home.

Diagnostic criteria:

PANS

An abrupt, acute, dramatic onset* of obsessive-compulsive behaviours 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 depression
- Irritability, aggression, and severe oppositional behaviours
- Behavioural (developmental) regression
- Sudden deterioration in school performance
- Motor or sensory abnormalities
- Insomnia and sleep disturbances
- Enuresis and urinary frequency.

There is no restriction for age of onset in PANS.

PANDAS

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

- Presence of obsessive compulsions and/or tics, particularly multiple, complex or unusual tics
- Symptoms of the disorder first become evident between three 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 criteria currently state, however they have yet to be updated to reflect this.

More information, training and resources available at www.panspandasuk.org/for-gps

Diagnosis and treatment

Appropriate first stage tests that may be considered:

- Swab to assess for bacterial infections
- Additional swabs depending on presentation
- Urinalysis, if deemed appropriate
- Blood tests: U+E, LFT, FBC, ASOT, CRP, TFT, RBG, Ferritin, ANA, Vit D3, Total IgE, IgG
- Consider further immunological blood tests depending on presentation, including immunoglobulin sub-sets C3 and C4,
- Tests to assess for other infections, based upon medical and family history.

Initiate treatment immediately. Do not wait for test results.

First stage treatments that may be considered:

- 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 or improvement has occurred
- Consider the need to continue antibiotics (treatment dose or prophylactic dose)
- Referral to paediatrician, immunology and/or neurology for ongoing treatment
- Psychological support may be appropriate once the organic cause has been assessed and treated
- **PANS and PANDAS are clinical diagnoses.** Referral for multidisciplinary assessment should be considered where clinically indicated, even in the absence of evidence of an active infection.

Consider PANS and PANDAS carefully.

Urgent recognition, assessment and intervention are essential for the best possible outcome.