Clinical Guidelines

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

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

CPD Training

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

MIMS LEARNING

Evie developed PANS when she was five. Overnight, she suddenly became too terrified to leave her house and attend school.

About PANS PANDAS UK

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

www.panspandasuk.org

info@panspandasuk.org

CAMHS Information Leaflet (2025)
Greville House, 10 Jury Street, Warwick, Warwickshire, CV34 4EW
Charity number: Eng - 1178484 | Scot - SC053206

PANS PANDAS UK

PANS and PANDAS

Information Leaflet for CAMHS

PANS
Paediatric Acute-Onset Neuropsychiatric Syndrome

PANDAS ICD-11: 8E4A.0 / 8A05.10
Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

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

Evie, age 12, missed two years of primary school and required a specialist setting for secondary education.

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.

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.

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 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.

PANS and PANDAS are medical conditions with psychiatric symptoms

Refer to a paediatrician for ongoing medical treatment.

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

Managing psychiatric symptoms in PANS or PANDAS

A multidisciplinary approach with input from colleagues working in physical and mental health services is recommended.

Appropriate mental health support is a key part of this multidisciplinary model as psychiatric symptoms of PANS and PANDAS are complex in nature. For instance, **research has demonstrated that children with PANS require lower-than-typical doses of psychotropic medication in order to minimise severe side effects.**

Psychotherapy, specifically CBT (including ERP), is considered a beneficial method of improving OCD symptoms in PANS and PANDAS. Therapies, such as, counselling, may be necessary for coping with experiences of profound change and trauma.

Consider PANS and PANDAS carefully.

Urgent intervention is essential for the best possible prognosis.