

“It’s like my child woke up as a completely different person.”

Supporting someone with PANS or PANDAS can be challenging and may feel isolating for the whole family.

On our website, you will find more information and resources to help you understand how to support your child, yourself and your family.

More information

Expert webinars



Find support



Resources for young people



Resources for caregivers



Who we are

It is our mission to ensure that everyone in the UK affected by PANS or PANDAS receives effective and equitable care.

We will achieve this by supporting individuals and families, influencing policy and improving understanding through our work in the community, healthcare and education.

Contact Us

 www.panspandasuk.org

 info@panspandasuk.org

Parent Information Leaflet

Greville House, 10 Jury Street, Warwick, CV34 4EW

Charity numbers:
England - 1178484 | Scotland - SC053206



PANS and PANDAS

Information for parents and carers

PANS

Paediatric Acute-onset Neuropsychiatric Syndrome

PANDAS

Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections



Does my child have PANS or PANDAS?

PANS and PANDAS are triggered by an unusual or misdirected immune response to infections and viruses, such as influenza, chicken pox and, in the case of PANDAS, strep infections.

If you suspect PANS or PANDAS then it is likely that your child is demonstrating one or more of these these symptoms:

- Obsessive compulsive behaviours
- Multiple, complex or unusual tics
- Anxiety, fear, panic
- Emotional lability
- Irritability, aggression, oppositional behaviours
- Developmental regression
- Sudden deterioration in school performance
- Restrictive eating
- Hyperactivity
- Insomnia and sleep difficulties
- Enuresis or urinary frequency

Additional symptoms often reported by parents include hallucinations and psychosis.



Diagnostic criteria:

PANS

- To be diagnosed with PANS, an individual needs to develop one of these major symptoms: **obsessive compulsive behaviours or restricted food intake**, and at least two other symptoms from the PANS or PANDAS symptom lists.
- Symptoms often develop suddenly (usually within 24-48 hours)* and very severely.
- Symptoms may appear to get better before getting worse periodically; this is referred to as a 'relapsing-remitting course'.

PANDAS

- To be diagnosed with PANDAS, a person needs to develop one of these major symptoms: **obsessive compulsive behaviours or tics**. However, many people with PANDAS also have other symptoms from the PANS or PANDAS symptom lists.
- Like PANS, symptoms often develop suddenly* (usually within 24-48 hours) and very severely and may relapse and remit periodically.
- In PANDAS, the development of symptoms happens after a 'Group A Streptococcal (GAS) infection', more commonly known as 'strep'. Strep infections cause many common illnesses such as strep throat (a mild sore throat), impetigo, cellulitis, tonsillitis, scarlet fever and pneumonia.

PANDAS is a paediatric diagnosis, but in PANS onset can happen at any age

*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

Next steps:

If you think your child may have one of these conditions, the first step is to go and see your GP. Take our GP Information Leaflet with you, which can be downloaded and printed from our website, to help you talk about the conditions.

It can be helpful to write down detailed notes of your child's daily behaviour and include any illness they experienced before symptoms began. Your GP may perform a number of tests and may refer your child for further assessment and investigation.

Tests your GP may consider:

- Swabs 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
- 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.

Important notes:

- PANS and PANDAS are clinical diagnoses; this means they are not diagnosed by tests, but by looking at symptoms and history
- In both PANS and PANDAS, symptoms typically begin in the days, weeks or months after an infection, so the absence of current infection does not mean they do not have either condition
- Children will present with differing, often fluctuating, symptoms, and do not have to have every symptom to be diagnosed
- Therapeutic support may help a child manage their symptoms, but the physical cause of the illness needs to be addressed, otherwise the psychiatric symptoms may continue.