

Updated 20/01/25



Supporting children and young people with suspected or diagnosed PANS or PANDAS

Local Authority Update

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A viral or bacterial infection can affect the brain and cause the onset of both psychiatric and physical symptoms in children and young people (CYP)

PANS PANDAS UK is supporting around **7000** families reporting the onset of neuropsychiatric symptoms in their CYP

Some Local Authorities are unaware of recent developments leading to significant challenges addressing the conditions

Conditions are often misdiagnosed leading to delay in treatment and inappropriate labelling of needs

There is general acceptance that delayed intervention can increase risk of long-term impacts

Prompt diagnosis facilitates faster symptom resolution, enabling a quicker return to school

WHY IS THIS UPDATE NEEDED?



Local Authorities may be supporting an increasing number of children and young people with suspected or diagnosed PANS and PANDAS.

All professionals across health, education and social care should be aware of the conditions.

Significant developments have recently taken place, of which Local Authorities may not yet be fully abreast.

These developments supersede previous understanding that the conditions are not accepted by the NHS.

This short overview will give a brief update and signpost to further information.

WHAT ARE PANS AND PANDAS?



PANS

Paediatric **A**cute-onset **N**europsychiatric **S**yndrome

PANDAS

Paediatric **A**utoimmune **N**europsychiatric
Disorders **A**ssociated with **S**treptococcal **I**nfections

- As with **medical conditions** which affect both physical and mental health, a post infectious and/or immune cause targeting the brain may be implicated.
- **Triggered by common infections** (for example strep throat, chickenpox, or influenza) and can only be diagnosed by a medical professional.
- Conditions mainly affect children, and **onset usually happens between 3 and 13 years**.
- **PANS however can also affect adults**, and symptoms do not suddenly remit at 16. Conditions are usually relapsing and remitting, (symptoms go up and down) and an exacerbation of symptoms is known informally as a flare.

The PANS PANDAS Steering Group (PPSG) was formed in 2022. Their work is supported by National Health Service England (NHSE)

The PANS PANDAS Steering Group comprises representatives from the following organisations:

PANS PANDAS UK
British Paediatric Neurology Association
Royal College of Psychiatrists
Royal College of Paediatrics and Child Health
Royal College of Nursing
Royal College of Occupational Therapy
Royal College of General Practitioners
British Paediatric Allergy, Infection and Immunology Group
British Association of Social Workers

Some useful related resources

Resources for health professionals
<https://panspandasuk.org/support-resources/for-health-professionals/>

PANS PANDAS Steering Group

<https://panspandasuk.org/pans-pandas-steering-group/>

Royal College of Occupational Therapists:
PANS/PANDAS Standards of Care-

<https://tinyurl.com/yxsbsmdf>

British Paediatric Neurological Association

<https://bpna.org.uk/?page=pans-pandas>

Royal College of Nursing

<https://www.rcn.org.uk/news-and-events/Blogs/pans-pandas-a-mysterious-and-debilitating-paediatric-disorder-180523>

Some key developments

September 2023 - Maria Caulfield, then Parliamentary Under Secretary of State for Health, acknowledged PANS and PANDAS as NHS-recognised diseases in a Parliamentary debate

November 2024 - Meeting with the Department for Health and Social Care. Baroness Merron, the Parliamentary Under-Secretary of State for Health and clinical directors from NHS England commended the work of the charity and agreed to enabling further meetings

December 2024 - Letter from the Department for Health and Social Care (DHSC) acknowledging their position

January 2025 - All Party Parliamentary Group (APPG) reformed with Chair Wendy Chamberlain MP

January 2025 - Letter from the APPG to the Education Secretary Rt Hon Bridget Phillipson.

Some useful related resources

Sir Keir Starmer : PANS PANDAS Awareness Day 9th October 2024

<https://www.youtube.com/watch?v=iM2LvJPTzGc>

House of Commons Debate Pack- 8th September 2023

<https://researchbriefings.files.parliament.uk/documents/CDP-2023-0174/CDP-2023-0174.pdf>

Progress in Parliament: Nov 2024

<https://panspandasuk.org/post/progress-in-parliament/>

PANS,PANDAS All Party Parliamentary Group

<https://panspandasuk.org/support-resources/pans-pandas-all-party-parliamentary-group/>

DHSC letter : December 2024

<https://panspandasuk.org/wp-content/uploads/2024/12/DHSC-response-to-PPSG-letter-Dec-2024.pdf>

APPG Education letter : January 2024

<https://panspandasuk.org/wp-content/uploads/2025/01/Letter-FAO-DFE-v2.pdf>

Children and young people with undiagnosed and/or untreated PANS or PANDAS may struggle to attend school, experience significant decline in their cognitive and physical functioning and experience severe psychiatric symptoms.

PANS and PANDAS UK Manifesto

https://panspandasuk.org/wp-content/uploads/2024/11/Count-us-in-A-Manifesto-for-PANS-and-PANDAS-2024-1_compressed.pdf

Families report many children and young people with PANS or PANDAS develop special educational needs and disabilities (SEND) having previously not needed any SEND support.

Early Day Motions

[UK Parliament](#) > [Early Day Motions](#) > [Diagnosis and support for PANS and PANDAS](#)

Diagnosis and support for PANS and PANDAS

EDM 708: tabled on 14 December 2022

Tabled in the 2022-23 session.

This motion has been signed by 7 Members. It has not yet had any amendments submitted.

Early Day motion in Parliament raised by Michelle Scrogham MP entitled [Care for PANS and PANDAS](#)

Research group

Application for a UK-wide surveillance study to BPSU (British Paediatric Surveillance Unit) and CAPSS (Child and Adolescence Psychiatry Surveillance System) has been submitted. Subsequent research will centre around early phase treatment and will map out service development.

Clinical Guidelines Development Group

Work commenced in Spring 2024 to develop a set of Royal College of Paediatrics and Child Health (RCPCH) accredited UK clinical guidelines.

Education, social care & health group

Work is underway to create guidance and a position statement for Local Authorities to support children and young people with diagnosed or suspected PANS or PANDAS.

Service Pathway Specification Group

Will follow on from the guidelines development group and assess whether a specialist service will be commissioned through NHSE, or if there may be a need for enhanced clinical pathways for local and tertiary multidisciplinary teams (MDT).

The PANS PANDAS Steering group is overseeing four integrated and parallel working groups across health, social care and education

How do PANS and PANDAS affect children and young people in Education?

Children and young people living with PANS and PANDAS can abruptly go from doing well in school to experiencing a wide range of difficulties. These can include:

developing obsessive thoughts and behaviours, tics, anxiety, age regression, emotional dysregulation, handwriting deterioration, executive functioning difficulties, sensory needs, eating issues and problems sleeping.

Families often report that children and young people may:



Experience long delays in diagnosis and/or misdiagnosis



Struggle to attend school and become isolated



Develop unexpected SEND



Experience poor educational outcomes

PERCEPTION OF NEED SHAPES THE SUPPORT

PANS and PANDAS have overlapping symptomology with many other conditions and neurodivergences. CYP can also have multiple long-term conditions.



Families report that overlap, coupled with limited awareness is contributing to delays in treatment, inequitable support, unintended harm and long-term poor outcomes for children and young people.

There is general acceptance that delayed intervention can increase risk of long-term impacts.

Some useful related resources

Further Education Information- <https://www.panspandasuk.org/education>

Edpsy blog <https://edpsy.org.uk/blog/2024/understanding-pans-and-pandas/>

What are PANS and PANDAS? https://issuu.com/nasenconnect/docs/nasen_summer24_singlepages_3839eece822706/41

CPD online accredited teacher training- <https://panspandasuk.org/events/>

Position Statement on FII <https://www.panspandasuk.org/fii-position-statement>

Emotionally Based School Avoidance (EBSA)- Sarah Johnson (references PANDAS)

https://www.phoenixeducationconsultancy.com/files/ugd/bbe3de_7aad6df8df5f4bb89b1ef696f6a75fa0.pdf

Have you heard of PANS and PANDAS?-<https://senresourcesblog.com/2023/10/02/have-you-heard-of-pans-or-pandas>

PANS, PANDAS & Fabricated or Induced Illness: A Guide for Social Work, Healthcare & Education Professionals

<https://panspandasuk.org/wp-content/uploads/2024/06/FII-Report-2024-PANS-PANDAS-Fabricated-or-Induced-Illness.pdf>

PANDAS is recognised by the World Health Organisation (WHO)

Two entries under the ICD11 code

Paraneoplastic or autoimmune disorders of the central nervous system, brain or spinal cord



8E4A.0

Tics due to paediatric autoimmune neuropsychiatric disorders associated with streptococcal throat infections appears under Infectious or postinfectious tics



8A05.10

ICD-11

International Classification of Diseases for Mortality and Morbidity Statistics

Eleventh Revision

Some useful related resources

MIMS Learning, online 0.5 hr CPD free training module for all UK health professionals

<https://panspandasuk.org/wp-content/uploads/2024/11/Training-Modules-in-Health-and-Education-Transforming-Support-for-PANS-and-PANDAS-Flyer-A5.pdf>

Listing of PANS and PANDAS on Contact- <https://contact.org.uk/conditions/pans-paediatric-acute-onset-neuropsychiatric-syndrome-and-pandas-paediatric-autoimmune-neuropsychiatric-disorders-associated-with-streptococcal-infections/>

Presentation on PANS/PANDAS at the annual British Paediatric Neurological Society

<https://www.panspandasuk.org/post/pans-and-pandas-in-the-spotlight-at-bpna-conference>

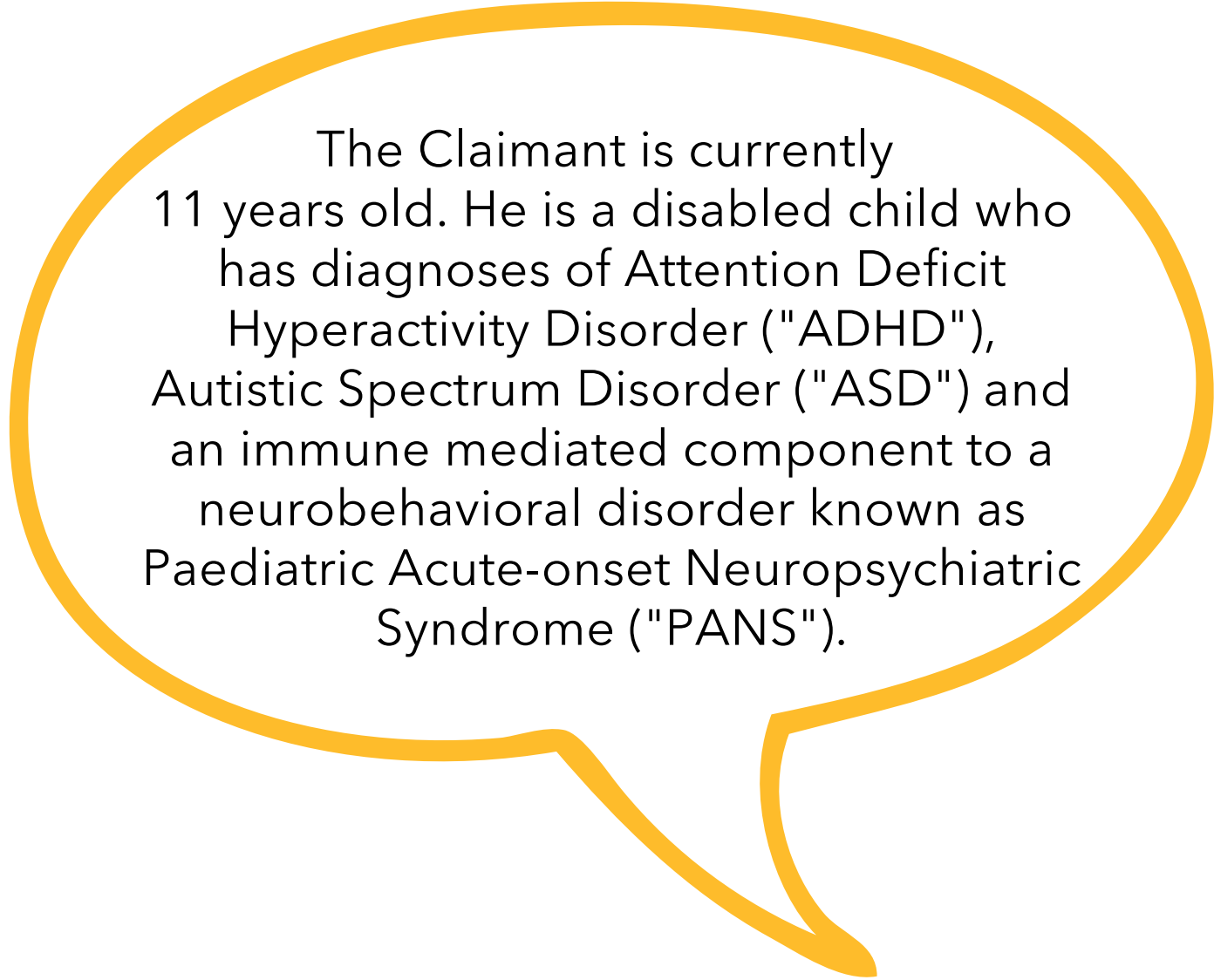
Diagnosis is reflected in EHCP tribunals

Recent High Court Judicial Review found that a Local Authority failed to provide the special educational support (section F) required in a child's EHCP (Education Health and Care Plan) EOTIS package. **Reaffirms that Local Authorities are under 'absolute duty' to secure special education provision.**

In relation to PANS, the case highlights the importance of:

- **needs linked to the diagnosis of PANS being recognised and met**
- **the detrimental impact on the child when these needs are not met**

PANS (and PANDAS) are medical diagnoses and should be included in Section C of an EHCP.



The Claimant is currently 11 years old. He is a disabled child who has diagnoses of Attention Deficit Hyperactivity Disorder ("ADHD"), Autistic Spectrum Disorder ("ASD") and an immune mediated component to a neurobehavioral disorder known as Paediatric Acute-onset Neuropsychiatric Syndrome ("PANS").

Some useful related resources

<https://www.bailii.org/ew/cases/EWHC/Admin/2024/1928.html>

Oliver Persey of Garden Court Chambers, and solicitor, Adam Mercer of Sinclairslaw, explain the case to Special Needs Jungle

<https://www.specialneedsjungle.com/4-tips-absolute-duty-special-educational-provision-ehcp/>

For more information and details about the case-

<https://www.gardencourtchambers.co.uk/news/high-court-reaffirms-that-local-authorities-are-under-absolute-duty-to-secure-special-educational-provision-and-grants-a-mandatory-order>

<https://www.bbc.co.uk/news/articles/c0472r42ldno>



The purpose of this information is to support Local Authorities' understanding of the current position and status of PANS and PANDAS in England. PANS and PANDAS are recognised by NHS England

- There is general acceptance that delayed intervention can increase risk of long-term impacts. More research is needed.
- Systemic and integrated streams of work across health, social care and education are underway in the UK.
- PANS and PANDAS have overlapping symptomology with many other conditions and neurodivergences. Symptoms can easily be misconstrued leading to a delay in treatment, trauma and poorer outcomes.
- Whilst the research and information about PANS and PANDAS is evolving, all professionals who are supporting children and young people with PANS and PANDAS have a responsibility to access further information, training and resources in the interim.
- PANS and PANDAS are medical conditions. Professionals have a duty of care and must adhere to the relevant legislation.

Awareness posters for schools

<https://panspandasuk.org/wp-content/uploads/2024/05/Schools-Poster-A4-DIGITAL-VERSION.pdf>

SEND in the Expert podcast on PANS/PANDAS with Georgina Durrant

<https://podcasts.apple.com/gb/podcast/send-in-the-experts-with-georgina-durrant/id1598292028>

PANS and PANDAS: Developing Awareness and Effective Practice in Education

<https://www.edpsyched.co.uk/blog/pans-and-pandas>

Home and school: Spotting the early signs of PANS and PANDAS

<https://panspandasuk.org/wp-content/uploads/2024/04/Home-School-Spotting-the-Early-Signs-FINAL-Digital-Only.pdf>

Good Practice in Schools guide

<https://panspandasuk.org/wp-content/uploads/2024/04/PANS-and-PANDAS-Advice-for-good-practice-in-Schools-DIGITAL-VERSION.pdf>

PANS PANDAS Summary for Teachers

<https://panspandasuk.org/wp-content/uploads/2024/06/PANS-and-PANDAS-A-Summary-for-Teachers-FINAL-Digital.pdf>

Parents/caregivers guide for education and PANS and PANDAS

<https://panspandasuk.org/wp-content/uploads/2024/04/Education-Guide-PANS-and-PANDAS-Parents-Caregivers-DIGITAL-VERSION.pdf>

PANS PANDAS UK padlet

https://padlet.com/schools20/7of26s8jr28lsulj_

A guide for health professionals about PANS and PANDAS and Education

<https://panspandasuk.org/wp-content/uploads/2024/05/A-guide-for-Health-Professionals-Education-and-PANS-PANDAS-DIGITAL-VERSION.pdf>

Individual Health Care Plans: A guide for parents/caregivers

<https://panspandasuk.org/wp-content/uploads/2024/04/Individual-Health-Care-Plans-DIGITAL-VERSION.pdf>



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