PANS+ SCOTLAND

Action for Paediatric Acute-onset Neuropsychiatric Syndrome and other immune-mediated neuropsychiatric conditions in Scotland

22nd December 2025

General Statement for the Additional Support Needs Tribunal Scotland

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)

What is PANS?

PANS and its better-known sub-condition, PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections) are believed to be the result of a misdirected immune response to a pathogenic trigger, leading to the abrupt onset of a range of challenging symptoms, including obsessive compulsive disorder (OCD), tics and restricted food intake, alongside cognitive, behavioural, and neurological symptoms. (PANDAS Physicians Network)

The conditions primarily impact Children and Young People, however adults can develop PANS, and if untreated or not fully responsive to treatment, the conditions can also be taken into adulthood.

What are the Symptoms?

The following definitions are taken from the Nordic Guidelines (Pfeiffer HCV, Wickstrom R, Skov L, et al., 2021), which are one of the international peer-reviewed guidelines recommended by the PANS PANDAS Steering Group (2023), in the absence of UK led clinical guidelines.

<u>PANS Diagnostic Criteria:</u>

1. Abrupt, dramatic onset (culmination within 72 h) of obsessive-compulsive disorder or severely restricted food intake.
2. Concurrent presence of additional neuropsychiatric symptoms, with similarly severe and acute onset, from at least two of the following seven categories:
    i. Anxiety,
    ii. Emotional liability and/or depression,

iii. Irritability, aggression and/or severely oppositional behaviours,
iv. Behavioural (developmental) regression,
v. Deterioration in school performance,
vi. Sensory or motor abnormalities and
vii. Somatic signs and symptoms, including sleep disturbances, enuresis or increased urinary frequency.

3. Symptoms are not better explained by a known medical disorder, such as Sydenham's chorea, systemic lupus erythematosus, Tourette disorder or others.

PANDAS Diagnostic Criteria:

1. Presence of Obsessive-Compulsive Disorder and/or a tic disorder: The patient must meet lifetime diagnostic criteria (DSM-III-R or DSM-IV) for obsessive compulsive disorder or a tic disorder.
2. Paediatric onset: Symptoms of the disorder first become evident between 3 years of age and the beginning of puberty
3. Episodic course of symptom severity: Clinical course is characterized by the abrupt onset of symptoms or by dramatic symptom exacerbations. Symptoms usually decrease significantly between episodes and occasionally resolve completely between exacerbations.
4. Association with group A Beta-haemolytic streptococcus infection: Symptom exacerbations must be temporally related to group A Beta-haemolytic streptococcus infection, that is associated with positive throat culture and/or significantly elevated anti- group A Beta-haemolytic streptococcus antibody titres
5. Association with neurological abnormalities: During symptom exacerbations, patients will have abnormal results on neurological examination. Motoric hyperactivity and adventitious movements (including choreiform movements or tics) are particularly common.

Diagnosis and Treatment

Accessing diagnosis and treatment through the NHS in Scotland can be difficult, as there are no UK clinical guidelines for PANS, however these are under development through the work of the PANS Clinical Guideline Development Group (2024), and there is an interim statement in place to guide clinicians when faced with a patient presenting with symptoms of the conditions.

Many families feel they have no choice but to seek private healthcare, with the specialists in the conditions being based in the south of England.

Families in Scotland not only face challenges in accessing treatment, but due to the lack of knowledge and understanding of the conditions across health, education and social

care, there is little support for them in managing symptoms. This challenge has been acknowledged by Neil Gray MSP, The Cabinet Secretary for Health and Social Care (PANS PANDAS UK, 2024).

What impact does PANS have on a Child or Young Person's education?

In order to understand the impact on education, it is also necessary to understand the impact on a child or young person's wellbeing, as that will play a significant part in their ability to engage in education. An overview of the impacts of PANS on a child or young person's wellbeing was created in collaboration with parents across Scotland. The impact was considered against each of the SHANARRI wellbeing indicators. (Scottish Government, 2022).

In considering these impacts it is important to remember:

1. PANS, and other immune-mediated neuropsychiatric conditions are medical conditions, and while symptoms and behaviours may be similar to other conditions, treatment, accommodations and supports may differ.
2. The Scottish Government Learning Directorate (2015) *Guidance on education for children and young people unable to attend school due to ill health* should be considered.
3. PANS impacts every child or young person in a different way. The conditions are relapsing and remitting, so each child will have differing symptoms, or differing severities – which may change over time. The course of their symptoms will also differ from one child to the next, with some children exhibiting a flare and recovery pattern, while others have a chronic or progressive pattern. (Aspire, 2025)

PANS through the lens of the SHANARRI wellbeing indicators

SAFE

- There are multiple factors associated with PANS which can impact on a child's safety, most notably Intrusive thoughts; OCD; Tics; Eating restrictions and Self-injurious behaviour. Worry around these symptoms can also impact on a child's feelings of safety even when the symptoms are not present.
- The lack of understanding about the conditions from family and friends and scepticism from professionals can also impact of feelings of safety. In some cases, safeguarding concerns and allegations of Fabricated or Induced Illness (FII) have been raised.
- In addition, the impact of the conditions on families have led to financial instability, parents giving up work to look after their child, and in some cases the

family home has been sold to fund treatment. This can also lead to feelings of insecurity.

HEALTHY

- It is important to remember that PANS is a medical condition, and the priority in supporting the health of a child with symptoms of PANS is diagnosis and treatment.
- This is something that is currently difficult to achieve on the NHS, with parents reporting that most children and young people are being referred onto either Mental Health or Neurodevelopmental pathways, where treatments and accommodations are ineffective.
- Some symptoms may also make it challenging to make healthy choices such as: Anxiety; Eating issues; Headache; Intrusive thoughts; OCD; Pain; Psychosis; Seizures; Sleep issues; Tics

ACHIEVING

- PANS can have a significant impact on a child or young person's ability to attend school or engage in learning, and their ability to do so will largely depend upon the degree to which their symptoms have been managed. (Greene, JC 2016).
- Symptoms such as OCD, Anxiety, Executive functioning difficulties, Visual processing difficulties, Auditory processing difficulties, and issues with short-term, long-term and working memory will all make engaging in learning challenging.
- Changes in fine and gross motor skills, emotional and social regression, mood swings and oppositional behaviours, speech and language changes and sensory sensitivities can lead to significant challenges within the school environment.

NURTURED

- The lack of knowledge and understanding of PANS, and the symptoms themselves can significantly impact a child's feelings of being nurtured.
- This is exacerbated by the fact that many families find themselves in a battle for healthcare and education support, adding to the trauma of an already extremely challenging situation.
- There may also be strained relationships with caregivers and professionals if condition driven behaviours have been misunderstood.

ACTIVE

- It is common for children with PANS to withdraw from activities which they previously enjoyed.
- Many have pain, fatigue, and dizziness which may impact their ability to participate in activities.

- OCD, Anxiety, Changes in fine and gross motor skills, emotional and social regression, mood swings and oppositional behaviours, changes and sensory sensitivities can also lead to significant challenges in participating in activities.

RESPECTED

- The lack of knowledge and understanding of PANS, along with past scepticism of the conditions can lead to disagreements and misunderstandings with professionals. This can lead to children feeling that they are not being listened to or believed.
- The significant change in a child or young person's overall presentation can lead to unwanted attention and can make them vulnerable to bullying.

RESPONSIBLE

- Children and young people in an acute episode of PANS often have compulsive behaviour which they cannot control, and they should not be held responsible for that behaviour.
- Many also have symptoms of demand avoidance, making offering the opportunity to demonstrate responsibility a challenge.

INCLUDED

- Many of the symptoms and circumstances around PANS lead to both children and their families becoming socially withdrawn.
- Children may withdraw in school due to stigmatisation.
- Many parents have to give up work to look after their child, and in some cases this leads to financial hardship.
- This can leave families struggling to afford small luxuries that support feelings of inclusion, such as days out.

Supporting a Child or Young Person with PANS in Education

- Use the Child's Plan process and GIRFEC National Practice Model (Scottish Government, 2022) to bring together the team around the child to thoroughly analyse the impact that the condition is having on the child or young person's life.
    - Use the SHANARRI indicators to consider the impact of the child or young person's symptoms on their well-being. This will be most effective as a discussion with the team around the child, including the child and parents/carers.
    - Use the My World Triangle to think about what the child or young person's world looks like, and how it has changed. Think about what helps them now, as well as the impact on their wider family. What are their short and long-term goals?

    - Use the Resilience Matrix to identify the most challenging aspects in the child's life, as well as any mitigating factors. In complex cases this can also assist in helping to consider where support could be put in place to mitigate against the most challenging factors.
    - Consider what supports might help mitigate the challenges identified against the SHANARRI indicators. Use information gathered in the My World Triangle and Resilience Matrix to take a child-centered view on identifying possible supports.
    - Review and prioritise the identified supports, taking a step-by-step approach so as not to overwhelm the child or young person. Their voice in this process is vital. Identify which supports to try first, what they will look like, and when they will be reviewed. These should be documented as part of the Child's Plan.
- Use this process to determine what the most suitable learning environment for the child would be e.g. Mainstream classroom, ASL classroom, online, outreach program, individual tutoring.
    - It is worthwhile to consider options which are not currently within the school's gift – this is an assessment of need.
    - If there is no availability for a learning environment that meets the child's needs, consider if there are barriers to the child attending a different setting that it might be possible to overcome.
    - PANS is a medical condition, so the Scottish Government Learning Directorate (2015) *Guidance on education for children and young people unable to attend school due to ill health* may provide access to resources or pathways that may not have otherwise been possible.
- Due to the relapsing and remitting nature of PANS, a flexible approach is required. It is recommended that resource-heavy accommodations are trialled in advance of a longer-term intervention, and that consideration is given as to what steps will be taken if the intervention is ineffective.
- Consider the impact that PANS will have on a child or young person's ability to engage in learning. This will vary from one child to the next depending upon their symptoms. It is likely that considerable modifications to teaching resources will need to be made for a child with PANS in comparison to their peers.

Prepared by

Gillian Mathewson, Founder and Chair of Trustees PANS+ Scotland

Relevant Qualifications and Experience:

- Open University - PGDE Mathematics (2013-2014)
- GTC Registered (146307)
- Teacher of Mathematics (2014–2020)
- Principal Teacher of Mathematics (2020–2022)
- Tapestry Partnership – Leading Learning Improving Pedagogy (2015-2016)
- SCEL Teacher Leadership Programme (2016-2017)
- Tapestry Partnership – Leading Learning in the School (2017-2018)
- Excelerate Programme (2019-2022)
    - PBL Works - Project Based Learning 101 (Nov 2019)
    - PBL Works - Project Based Learning 201 (Feb 2021)
- University of the Highlands and Islands - Child and Adolescent Mental Health CPD Module SCQF Level 10 (2024)
- PANS PANDAS UK – Teacher Trainer (2023–2025)
- PANS PANDAS UK – Representative for Scotland (2024-2025)
- Parent with lived experience.

References

Aspire, (2025). *PANS PANDAS Disease Course* [Online]. Aspire. Available at: https://aspire.care/symptoms-diagnosis/pans-pandas-disease-course/ (Accessed: 16 October 2025).

Greene, JC, (2016). *PANS, CANS and Automobiles*. 1st ed. Sarasota, FL: First Edition Design Publishing Inc.

PANDAS Physicians Network, *What is PANS/PANDAS?* [Online]. Available at: https://www.pandasppn.org/what-are-pans-pandas/ (Accessed: 16 October 2025).

PANS PANDAS Steering Group. (2023). *PPSG Statement* [Online]. theppsg.org.uk. Available at: https://panspandasuk.org/wp-content/uploads/2024/04/PPWG-Statement.pdf?_gl=1*s7wdsi*_ga*Njk4MTYyMzEzLjE3NjAxNTYzODM.*_ga_0J49JKSEBQ*czE3NjE0NjM5NjgkbzMkZzEkdDE3NjE0NjM5ODEkajQ3JGwwJGgw (Accessed: 16 October 2025).

PANS PANDAS Steering Group, (2024). *PANS Clinical Guideline Development Group* [Online]. www.theppsg.org. Available at: https://theppsg.org.uk/guidelines/ (Accessed: 16 October 2025).

PANS PANDAS UK, (2024). *Scottish Government Outlines Support for Families* [Online]. PANS PANDAS UK. Available at: https://panspandasuk.org/post/scottish-government-outlines-support-for-families/ (Accessed: 16 October 2025).

Pfeiffer HCV, Wickstrom R, Skov L, et al. Clinical guidance for diagnosis and management of suspected Pediatric Acute-onset Neuropsychiatric Syndrome in the Nordic countries. *Acta Paediatr*. 2021; 110: 3153–3160. **https://doi.org/10.1111/apa.15875**

Scottish Government (2022): *Getting it Right for Every Child* [Online] Available at : https://www.gov.scot/policies/girfec/ (Accessed 17 October 2025)

Scottish Government Learning Directorate, (2015). *Guidance on education for children and young people unable to attend school due to ill health* [Online]. Scottish Government. Available at: https://www.gov.scot/binaries/content/documents/govscot/publications/advice-and-guidance/2015/06/guidance-education-children-unable-attend-school-due-ill-health/documents/00479700-pdf/00479700-pdf/govscot%3Adocument/00479700.pdf (Accessed: 17 October 2025).