PANS+ SCOTLAND

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

Briefing statement for MSPs and MPs

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)
PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections)

1. **What are PANS and PANDAS?**
   PANS, and its better-known sub-condition, PANDAS, are believed to be the result of a misdirected immune response to a pathogenic trigger (for example chickenpox, tonsillitis, or covid-19), leading to the abrupt onset of a range of challenging neuropsychiatric symptoms. For some the conditions are episodic (coming and going with onset of triggers). For others, the symptoms are chronic (unrelenting with time).

2. **What are the symptoms?**
   - **Primary symptoms:** Rapid onset of OCD, tics, or extreme food restriction**.**
   - **Secondary symptoms:**
     - **Mental health symptoms** including anxiety, emotional liability, aggression, severely oppositional behaviours, and/or depression.
     - **Behavioural (developmental) regression** such as speaking with a 'baby voice'.
     - **Cognitive challenges**, leading to deterioration in school performance.
     - **Sensory or motor abnormalities.**
     - **Physical symptoms** including sleep disturbances and toileting issues.
   - Full diagnostic criteria: https://www.pandasppn.org/what-are-pans-pandas/

3. **Who do they affect?**
   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 both be taken into adulthood.

4. **How common are they?**
   - PANS and PANDAS are considered to be rare conditions, however there are no published studies, either in the UK or internationally, to determine prevalence. Estimates range between 1 in 1000 to 1 in 7000.
   - Parents report cases in which children initially received ASD or ADHD diagnoses following symptom onset, but were later diagnosed and treated for PANS or PANDAS, with partial or complete improvement. These accounts raise important questions about whether there are other children across Scotland who may have unrecognised PANS or PANDAS. They also prompt consideration of whether COVID-related PANS could be contributing to the post-pandemic rise in ASD and ADHD referrals in Scotland.

5. **What is the impact of the conditions on those affected?**
   - Those affected may be unable to eat normally, sleep, or manage daily tasks. In some cases, hospital admission for tube feeding has been required.
   - They may be unable to attend school (or work), and there is little understanding of how to support those who are able to attend, or how to support the education of those who are unable to attend.
   - They can develop complex tics, severe pain and can suffer seizures.
   - They can lose their sense of self – with a complete change in personality.
   - They can struggle to be in contact with friends or family and will often stop any social activities.
   - Children miss out on their childhood, and their health and wellbeing can be significantly impacted across all SHANARRI indicators. https://pansplus.scot/girfec-toolkit/the-shanarri-indicators/
   - In addition to the mental health symptoms of the condition, those affected can develop poor mental health due to the challenges of the condition, the lack of support, and medical trauma.

6. **What is the impact on the family?**
   - Parents may have to give up work to look after an ill child or may need to take significant time off. Adults may be unable to work. This can put substantial financial strain on families.

- Parents, carers, siblings, and close family members are often the target of severe behavioural symptoms, such as verbal, emotional, or physical abuse.
- Separation anxiety, which is common in children and young people with PANS or PANDAS can mean that parents and carers can struggle to get respite.
- Due to lack of knowledge, understanding and acceptance of the conditions, parents / carers have been subject to safeguarding referrals and accusations of Fabricated or Induced Illness (FII). Many other parents are fearful that this will happen to them.
- Families are spending tens of thousands of pounds on private healthcare – primarily through doctors in the South of England. Local healthcare teams may not then accept private diagnoses.
- All family members can struggle with their mental health, and family relationships can break down, siblings in particular can struggle to access adequate support for their mental health.

7. Is there a treatment?

- Yes. Typical treatments include anti-inflammatories, antihistamines, anti-biotics to treat lingering infections, steroid bursts, and SSRIs. Some families have also found effective treatment through alternative medicine practitioners.
- International peer-reviewed guidelines have been signposted by the PANS PANDAS Steering Group (PPSG) for diagnosis and treatment in the UK. In practice we hear from parents that these are rarely being followed. https://panspandasuk.org/wp-content/uploads/2024/04/PPWG-Statement.pdf

8. Why aren't those affected in Scotland being treated?

- There are currently no clinical guidelines for PANS or PANDAS in the UK. They are, however, under development through the PANS PANDAS Steering Group, and are due to be published in Autumn 2026. They are expected to be endorsed by the Royal College of Paediatrics and Child Health and signposted by NICE. https://panspandasuk.org/wp-content/uploads/2025/12/PPSG-Update-December-2025.pdf
- The Cabinet Secretary for Health and Social Care has stated that they are monitoring the guideline development. https://panspandasuk.org/post/scottish-government-outlines-support-for-families/
- An FOI request across regional health boards showed the variation in support across Scotland. https://pansplus.scot/2025/12/11/foi-response-from-scottish-health-boards/

9. What is being done elsewhere?

- An All-Party Parliamentary Group (APPG) has been operational at Westminster for several years, advocating for support for PANS PANDAS children and their families. With Health, Education and Social Care being devolved matters, this work has primarily focused on England.
- NHS England have been engaging with PANS PANDAS Charities since 2020.
- The clinical directors for Children and Young People, and for Children and Young People's Mental Health within NHS England released a statement in support of the work of the PANS PANDAS Steering Group.
- The Education, Health and Social Care Working Group, sitting under the PPSG have developed guidance for schools in England, which has been shared across local authorities.
- NHS England has a paediatric neurology clinic treating PANS and PANDAS in Birmingham. Some patients in other parts of England have been able to access an IFR referral to the clinic.

10. PANS+ Scotland's call to action.

We need to act NOW to ease the suffering of those affected and prevent future suffering of countless others. Acting now will also promote equity with those affected in England. Through inaction, children and young people with PANS and PANDAS across Scotland are being denied their rights under the UNCRC.

As a starting point, we are calling for:

- The engagement of NHS Health Boards across Scotland to prepare for the publication of the guidelines, and to consider what steps, if any, could be taken now to ease the suffering of those affected.
- Information on PANS and PANDAS to be shared with GPs and school doctors/nurses, as well as through Turas, NHS Inform and The Knowledge Network.
- Engagement with Education Scotland ASN teams, the Scottish Association of Social Workers, and COSLA to ensure awareness of the conditions across schools, social work and local authorities. GIRFEC-aligned resources to support this are already in place.
- Enable those affected in Scotland to access the NHS neurology clinic in England via the IFR process.
- Shared care agreements supporting treatment plans from private specialists.