



Working with schools to support your child

It is essential for families, schools, and health professionals to work together, share information, and adapt support as both the child's and young person's presentation, and the wider evidence base, continue to evolve. This flexible, collaborative approach helps ensure every child and young person feels understood and supported.

We have designed this checklist to help you work effectively with your child's or young person's education setting when PANS or PANDAS is diagnosed or suspected.

1. Keep a log of changes at home

Record any changes you notice in your child or young person. Aim to capture a full and detailed picture of what is happening over time.

Include changes across all areas of life, such as:

- Sleep patterns
- Eating and appetite
- Mood and emotional wellbeing including obsessive or intrusive thoughts
- Behaviour and anxiety levels
- Physical changes and functioning for example, tics, changes in co-ordination and handwriting
- Schoolwork and concentration
- Friendships and social interaction
- Interests and activities

Keeping a clear record helps professionals understand the pattern, severity, and progression of symptoms. To help, we have created a resource to help parents, carers and schools called 'spot the early signs of PANS or PANDAS', available on our website.

2. Arrange a meeting with the education setting

Request a meeting with:

- Your child's or young person's class teacher, form tutor or Head of Year
- The professionals responsible for additional or special educational needs support (for example, Special Educational Needs Coordinator (SENCO, England and Northern Ireland), Additional Support Needs Coordinator (ASN, Coordinator, Scotland) or Additional Learning Needs Coordinator (ALNCo, Wales).
- Before the meeting, you may find it helpful to share brief information on PANS or PANDAS with the school so staff can come prepared and the discussion can be more productive.

During the meeting:

- Share your observations from home
- Listen to the school's observations
- Discuss any concerns openly

Important: Children and young people with PANS or PANDAS may mask their symptoms in school, meaning they often hide signs of distress during the day. What practitioners observe therefore can differ greatly from how the child or young person presents at home

3. Ask the setting to establish a baseline

A baseline is a record of your child's or young person's usual level of functioning prior to the onset of symptoms. Schools should compare existing data from before symptoms began with current information for example classwork, assessments, test results, or handwriting samples to help demonstrate any changes in functioning.

It should consider the whole child or young person, including:

- Learning skills (for example, reading, writing, maths)
- Social skills (interaction with peers and adults)
- Emotional wellbeing (mood, anxiety, confidence)
- Physical health and functioning (energy levels, motor skills, toileting)

Share any previous reports, assessments, or work samples and ensure evidence is kept up to date and accessible.

Why a baseline is important

PANS and PANDAS can cause sudden and noticeable changes in a child's or young person's abilities, emotional wellbeing, and thinking skills. These shifts can happen very quickly and may affect how they learn, concentrate, or manage everyday tasks at school and home.

It is important to capture all new changes and give equal weighting to each one. If some difficulties are overlooked or considered less important, the picture of your child's or young person's needs can become skewed. This can lead to inappropriate referrals or signposting to the wrong diagnostic pathway, for example assuming difficulties are due to anxiety alone, or, thinking your child's or young person's messy handwriting is just a fine motor problem, when in fact it may be linked to bigger changes in memory, attention, or processing caused by the condition.

A balanced baseline helps professionals:

- Spot changes quickly
- Understand what is new and what is typical
- Avoid misdiagnosis or fragmented support
- Plan and provide interventions that address all areas of need, not just the most visible ones
- Track progress and recovery accurately over time
- Measure how much the condition has affected learning, social skills, and wellbeing
- Map longer-term impairments or progress over time.

Without a baseline, it's much harder to see the full impact of the condition on your child or young person. Teachers and other professionals may not be able to compare current functioning with their usual abilities.

4. Request a supporting letter

You could ask the education setting to provide a letter for your GP or medical professional.

This letter may include:

- Symptoms or needs observed and when they began
- Support or adjustments tried and your child's or young person's response
- A summary of typical functioning before the first reported symptoms

The school's level of concern and willingness to provide further information (with consent).

5. Share information with the setting

- Share medical letters where available
- If a diagnosis is suspected, explain symptoms and provide observations and relevant resources
- Continue to share updates and observations from home
- Help staff understand that symptoms are medical in origin, not behavioural or parenting issues
- Signpost staff to our educational resources and teacher training.

6. Explain symptoms patterns

Ensure education staff understand that:

- Symptoms can mimic ADHD, Autism or anxiety. While there may be some overlap with familiar support strategies, children or young people with PANS or PANDAS may also require different or more tailored approaches to meet their needs effectively. Children and young people can, of course, be neurodivergent and have other conditions. Please refer to our resources about PANS, PANDAS and Neurodivergence for more guidance.
- PANS and PANDAS are often relapsing conditions. Symptoms can vary over time.
- Support needs may change depending on whether a child or young person is in a flare or recovering.
- Support should always be matched to your child's or young person's current needs.

7. Inform schools about PANS PANDAS UK training

Schools may also find it helpful to access PANS and PANDAS training. Awareness sessions can give staff the knowledge and confidence to recognise symptoms, understand fluctuating needs, and respond in a calm, supportive way during flares.

Training can also reduce misunderstandings, improve communication, and help schools put appropriate strategies in place more quickly. Families can signpost

staff to available training opportunities. Settings can choose to access these as part of their ongoing professional development. Training information can be found at www.panspandasuk.org/training

8. Request reasonable adjustments

Reasonable adjustments are adaptations schools must make to ensure pupils with disabilities or health conditions are not disadvantaged compared to their peers. Support is always based on the child's or young person's needs as they present day-to-day. Schools do not need a confirmed diagnosis to provide help, and support should not be delayed while medical assessments are ongoing. Children and young people may sometimes push themselves to 'power through', even when this impacts their recovery. While adults may need to help pace demands to support health, emotional wellbeing, and consistent progress, this should always be done with the child or young person's voice, feelings, and readiness in mind.

Support may be provided through:

- SEN Support (England and Northern Ireland)
- Additional Support Needs (ASN) arrangements (Scotland)
- Additional Learning Needs (ALN) support (Wales)

Where needs are more complex, statutory plans may be considered:

- England- **Education, Health and Care Plan (EHCP)** - Legal plan for children and young people (0-25) with significant SEN or disabilities.
- Scotland-Co-ordinated Support Plan (CSP) - Multi-agency statutory plan for pupils with complex, long-term Additional Support Needs.
- Wales- Individual Development Plan (IDP) - Statutory plan for learners (0-25) with Additional Learning Needs under ALN Act 2018.
- Northern Ireland - Statment of Special Educational Needs - Legal document detailing SEN and required provision, issued by Education Authority

9. Consider medical needs in school

Discuss whether an Individual Health Care Plan (IHCP) (or equivalent) is appropriate.

- A confirmed diagnosis is not required for medical support to be put in place
- Plans should reflect fluctuating symptoms.

10. Collaborate and review

Ongoing collaboration helps ensure support remains appropriate as your child's or young person's needs change.

- Agree on support measures together
- Maintain regular, clear communication
- Set review dates
- If your child or young person is masking, ensure this is reflected in the support
- Keep a clear evidence trail of needs, adjustments, and outcomes



Thank you for reading

All information supplied by PANS PANDAS UK, the only UK charity supporting families affected by PANS or PANDAS.

For more information about PANS or PANDAS, visit www.panspandasuk.org/what-are-pans-and-pandas

To access our training for educators, visit www.panspandasuk.org/training

Please note: This information applies to education settings across England, Scotland, Wales, and Northern Ireland. Where processes or terminology differ, this is clearly explained. The information provided on this page is for general educational purposes and is not a substitute for medical or legal advice. Always seek guidance from qualified health professionals for concerns about a child or young person's health and refer to local statutory guidance for policy requirements.