



**A caregivers guide to
education for children
with PANS or PANDAS**

What are PANS and PANDAS?

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)

PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections)

PANS and PANDAS are post infectious autoimmune and/or neuroinflammatory medical conditions that affect both physical and mental health.

These conditions, often triggered by common infections such as strep throat, chickenpox, or influenza, primarily affect children*, with the onset of PANDAS typically occurring between the ages of 3 and 13. However the symptoms can persist into adulthood, and PANS can also affect adults.

An exacerbation of symptoms is known colloquially as a 'flare'.

How will these conditions affect my child in school?

Children with PANS or PANDAS can abruptly go from doing well in school to experiencing a range of difficulties. These can include developing obsessive thoughts and behaviours, tics, anxiety, behaving in a younger way, anger, eating issues and problems sleeping. In some cases, children can develop unexpected special educational needs.

Sometimes children also have sensory issues, hallucinations and thoughts of harming themselves. These issues can come and go with symptoms changing a lot over time. Any child with these symptoms should be medically evaluated

Many symptoms of PANS and PANDAS can directly impact on how a child manages the school environment.

Families, professionals and children alike are often deeply confused by the changeable symptoms and the devastating impact.

Not all children will have all of the signs, and some children will have more than one condition.

Early identification and treatment is known to lead to better outcomes.

PANS and PANDAS are medical conditions and schools should follow the statutory requirements for supporting children with medical conditions.

*The term children/child will also be used to refer to young adults

Spotting the signs

- Multiple unexplained changes
- Difficulty separating from parent/caregivers
- Anxiety
- Handwriting difficulties
- Memory and organisation issues
- Behaving in a younger way
- Toileting issues
- Sensory needs
- Concentration difficulties
- Intrusive thoughts and compulsions
- Restricted eating
- Changes in fine or gross motor skills

My child has received a PANS or PANDAS diagnosis. What do I tell the school?

Currently it is still challenging in the UK to receive a diagnosis, and therefore parents/carers and school are likely to have already identified concerns. Request a meeting with the SENDCO (Special Educational Needs and Disabilities Co-ordinator).

Take some information about PANS and PANDAS along, and before the meeting talk to your child (as appropriate) and identify their needs.

Think around potential strategies that you feel might be supportive. At the meeting outline the diagnosis, the health care involvement, and discuss the areas of difficulty that your child is experiencing. Agree on a support plan. Decide on how you will communicate, review, and assess the support.

Key issues to be discussed could include; a flexible nurturing response, plan for a flare, input from medical professionals, and the school's need to be aware of and to report triggers including infections (as necessary for individual children). The setting should be aware that some children with these conditions may mask in schools.

The setting can also implement an individual health care plan (IHCP) outlining the medical needs. This should include the diagnosis or suspected diagnosis, symptoms, medication information and early signs of deterioration. Parents/carers should be aware of their responsibility to inform the school about changes to medication and presentation.



My child does not have a formal diagnosis of PANS or PANDAS, but I strongly suspect it, and they are really struggling in school. What can I do?

Having a confirmed diagnosis is helpful, but is not a requirement for support in schools which is needs based. Similarly, as with a diagnosis, talk to your child (as appropriate) and document the issues at home and school. Sometimes children with PANS or PANDAS present differently in different settings, and this is not unusual.

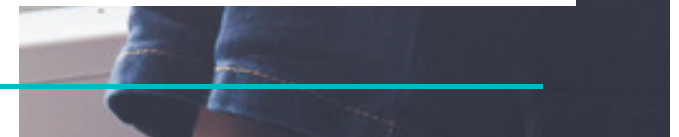
Ask for a meeting with the school SENDCO. At the meeting talk through the needs together and agree on supportive strategies. State that you suspect PANS or PANDAS as a diagnosis, but are currently awaiting formal assessment (if this is the case).

Share the educational information on PANS and PANDAS, and ask the school to provide professional evidence for you to take along to a GP. Ensure that schools are aware of the potential breadth of signs, and that they give due attention to all of the symptoms.



Ask for a collaborative approach to support your child

Listen to the school's perspective on the difficulties to see whether your child is masking or not. If they are, this is helpful to know. Children who mask often then release the emotional pressure at home. Ensuring that the provision is supportive should ideally mean acknowledging that pressure in different contexts is too high. Agree the support that will be implemented and agree on a communication, review and evaluation plan. The key issue is that the child should be supported based on their accurately identified needs.



My child with doesn't sleep. How can I get them to school?

PANS or PANDAS can often cause sleeping difficulties, and these can be severe. Children with PANS or PANDAS often cannot sleep due to severe anxiety, OCD, and 'wired brains' to name a just a few factors.

Many children with PANS or PANDAS are taking sleep medications and some require multiple medications

The sleep difficulties are not the result of poor sleep hygiene. Parents/carers should openly communicate with schools about the extent of the difficulties. There is a little doubt that the other debilitating PANS or PANDAS symptoms will be further compounded through exhaustion. Input from medical professionals will be helpful, and schools can support by being flexible and understanding about children's attendance and/or their need to access frequent breaks throughout the day.

My child is struggling to regulate their mood and behaviours. What should I do?

Distressed behaviour and moods can be a symptom of PANS or PANDAS. Some children are deeply regretful following incidents. Other children when suffering an exacerbation also express a wish to harm themselves or others, or start to do so. Health needs should be the priority.

Appropriate strategies in school include a cohesive and collaborative safety plan of potential triggers and responses. The focus should be on early intervention and support, close observation, safe containment and compassion.

The medical focus should be on access to effective treatment to reduce the symptoms. If a child is struggling immensely to cope, then parents/carers educators and medical professionals should decide collaboratively the best way forward, and assess whether the child is well enough to be in school.



My child has severe PANS or PANDAS related OCD. How do we manage this in school?

Again the school should be aware that the OCD is related to the condition.

Parents and carers need to talk to their child as appropriate, document the OCD and meet with the SENDCO. At the meeting discuss how the OCD manifests itself in the school setting, and individual triggers and effective strategies.

Arrange to review and assess the provision. Recognise that mental rituals (i.e., unseen by others) are equally debilitating, and also need to be recognised and addressed.

PANS and PANDAS OCD also needs to be understood in terms of shifting and changing symptoms. Ideally the school, parents and health practitioners should all work together. In the case of debilitating severity, health needs should be prioritised.

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My child is struggling with their learning

Some children with PANS and PANDAS can start to struggle with their learning in school. Every child is different but common issues include a deterioration in handwriting or maths skills.

Children can also start to struggle with understanding and following instructions, or remembering the different parts of a task. They may seem very disorganised and also find concentrating difficult.

Children with PANS and PANDAS often quickly become very tired in school as they are often managing multiple symptoms whilst trying to concentrate and learn.

Work closely with the SENDCO; it is important that these difficulties are quickly spotted so that support can be put in place, and also that this information is shared with the child's health team.

Does my child with PANS or PANDAS need an EHCP?

An education, health and care plan (EHCP) is for children and young people aged up to 25 with complex needs who require more support than is available through special educational needs (SEN) support. EHC plans identify educational, health and social care needs, and set out the additional support to meet those needs.

If children are not achieving as they were prior to PANS or PANDAS or even coping in school, despite the SEN support given by the school, then parents should discuss an application with the school. The child does not need a formal diagnosis. Either the school, medical professionals or the parent/carer can make the application. Each Local Authority has an online SEND Local Offer that provides the information. Needs in PANS or PANDAS can be more abrupt and severe than in many other conditions and will require an agile response.

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My child does not want to go school. What can I do?

This is a common and difficult issue for children living with PANS or PANDAS. The symptoms can be severe, highly distressing and debilitating.

Firstly, communicate with the school and keep a record if possible. Always contact them on the day of absence in accordance with their individual attendance policy.

Request a meeting with the SENDCO to discuss and agree the way together.

Depending on the severity of the symptoms, reasonable adjustments can include flexible starting times, a trusted adult to meet your child, frequent breaks in the day, and a reduction in academic expectations.

If your child is in a severe exacerbation request a longer term medical assessment as to whether they are well enough to be in school. Their health and access to effective treatment is the priority.

After a total of 15 days absence for the same condition, children can be referred for medical needs tuition.

Re-integration into school following a flare

Any professionals supporting children with PANS or PANDAS who are struggling to attend school should be aware of the complexity of the condition.

Following a flare, families often report that they feel under pressure for their children to return to school too quickly, and that re-integration plans were managed for them rather than by them. Flares can be long and very severe. The child and family may look the same, but are likely to have been deeply affected.

Factors to be aware of include:

- Multi-factorial impact of flares on a child
- Past history of school experiences
- Past history of support from health and education professionals
- Access to effective treatment

Consider:

- Importance of strong relationships
- Agency and voice of the child and family
- A focus on long term positive engagement with education

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