



PANS PANDAS UK
awareness support education

A brief Guide to Education and PANS/PANDAS

Parents/Caregivers

Charity Number: 1178484

What are PANS and PANDAS?

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)

This is a neuropsychiatric condition which is triggered by a misdirected immune response.

PANDAS (Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections)

PANDAS is a subset of PANS. Similarly, it is a neuropsychiatric condition which is triggered by a misdirected immune response to a Streptococcal infection.

While there are no official statistics for the prevalence of these conditions in the UK, US researchers estimate that 1 in 200* children may be affected to some degree.

*<https://pandasnetwork.org/statistics/>

How will these conditions affect my child in school?

Key symptoms that may affect children include severe anxiety, separation anxiety, eating restrictions, tics and OCD. There may also be emerging aggressive behaviours, signs of regression, and new cognitive deficits in working memory, executive functioning, maths, and handwriting. Some children suffer severe sleeping difficulties and 'brain fog.' Many children also develop sensory issues for example misophonia, (sensitivity to sounds) and new onset fidgeting with concentration and attention issues. Hallucinations (tactile, visual, and auditory) and psychosis-type symptoms can also present in a minority of children.

Many of these symptoms can directly impact on learning. These types of difficulties are not new to schools, but have only more recently been recognised as a constellation of symptoms within a PANS/PANDAS diagnosis.

Parents/caregivers and their children are often deeply confused by the debilitating nature of the symptoms, and the globally devastating impact. This brief guide attempts to address some of the most common educational issues but is by no means exhaustive. A hallmark educational sign for PANS/PANDAS is that

children can stall and regress in their learning. This is unusual. Children affected can also develop a spiky cognitive profile and can fluctuate dramatically in their learning skills.

It is now also recognised that many affected children will develop special educational needs or disabilities (SEND). Some children with PANS/PANDAS are furthermore aware that they could previously access academic work at a higher level. The impact of this should not be underestimated.

This brief guide attempts to address some of the most common educational issues but is by no means exhaustive

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

Currently it is 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/PANDAS along, and before the meeting talk to your child (as appropriate) and try to 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 and share your understanding of the condition so that the school are aware of the potential impact. Decide on how you will communicate, review, and assess the support. Key issues to be discussed could include, flexible nurturing response, plan for an exacerbation, 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 should also implement a care plan outlining the medical need. 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/PANDAS, but I strongly suspect it, and they are really struggling in school. What can I do?

Having a confirmed diagnosis is helpful, but not a requirement for obtaining additional support. Similarly, as with a diagnosis, talk to your child (as appropriate) and write a list about the issues in school. These could include anxiety around attending school, sleep difficulties and concentration issues.

They might also have concerns around managing OCD thoughts, hallucinating, difficulties with following instructions and writing for example. Ask for a meeting with the school SENDCO. At the meeting talk through the list together and agree on supportive strategies. State that you are suspecting PANS/PANDAS as a diagnosis but are currently awaiting formal assessment (if this is the case).

Share the educational information and explain at the meeting the specific symptoms that your child is suffering from, and how this is impacting on them.

Ask for a holistic and 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 (for a likely multitude of reasons) is too high. This can most effectively be addressed through close communication between home and school. Agree the support that will be implemented and agree on a review and evaluation plan. The key issue is that the child should be supported based on their presenting needs.

My child does not want to go school as they are so anxious. What can I do?

This is a common and difficult issue with children affected by PANS/PANDAS. The anxiety can be severe and debilitating. It is likely to be a complex interplay of primary immune mediated symptoms, and secondary issues from a multitude of debilitating symptoms. 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 forward together. Depending on the severity of the anxiety, 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.

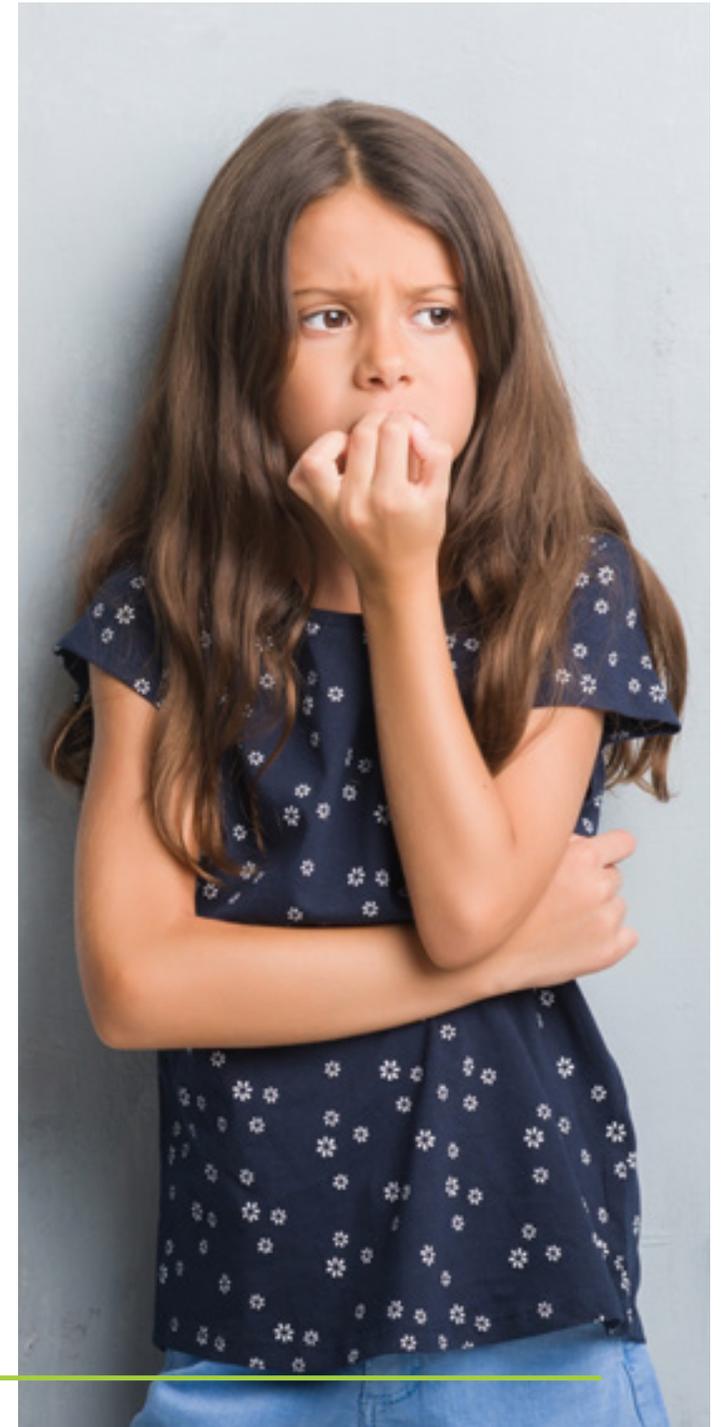
If your child is in an exacerbation and suffering debilitating anxiety as a result, request a medical assessment as to whether they are well enough to be in school. If not, obtain medical evidence and allow them time to heal at home. The primary aim should be focused on reducing the immune mediated response.

It is important to be aware that once an exacerbation is reducing in intensity, some children continue to suffer with the secondary effects of anxiety.

It is important to be aware that once an exacerbation is reducing in intensity, some children continue to suffer with the secondary effects of anxiety. This is likely to be due to the traumatic experiences and fear of the symptoms returning, fluctuations in the immune mediated process, and/or issues such as having missed out on parts of the curriculum and social contact. In this case, it may well be helpful to have 'a return to school' meeting to discuss a graded and supported approach.

Before the meeting think about what you feel might support your child at school during this phase. Examples include a chance to work through the distressing experiences of having PANS/PANDAS, reduced curriculum expectations, flexible timetable, a trusted team of adults, a time out card, and an agreed plan of how the reintegration is to be reviewed.

In some children, their anxiety is further complicated by their PANS/PANDAS trajectory which may well lead to some symptoms becoming chronic. An informed, compassionate, and collaborative approach is required from parents/ caregivers, schools and health professionals.



My child with PANS/ PANDAS doesn't sleep. How can I get him/her to school?

PANS/PANDAS can often cause sleeping difficulties, and these can be severe. Affected children cannot sleep due to immune mediated symptoms leading to severe anxiety, OCD, and 'wired brains' for example to name a just a few factors.

**Many children with
PANS/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/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 hallucinating in school. What can I do?

This is a very difficult and traumatic symptom for children to manage particularly when not with their parents/caregivers. The first step is for the school to understand the hallucinations as a symptom of the immune mediated process. The child should have access to a trusted adult, and together they should develop individualised strategies for managing them.

Suggestions include distraction and redirection, going for a walk, having a safe space, or having a drink and a snack. Schools should make a note of the type of hallucination, duration and severity and share these with home. All children who are suffering from hallucinations require a medical evaluation.



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

Firstly, the school should be aware that the OCD is related to the condition and can therefore follow an atypical pattern of waxing and waning dramatically in severity. Parents/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, and about compulsions as relevant, 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 need to be recognised and addressed. The 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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and health practitioners
should all work together**

Since the onset of PANS/PANDAS, my child has demonstrated aggressive behaviours and is struggling to manage in school. What should I do?

Schools should again recognise that the aggression is a symptom of PANS/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 if a child is still in school include a cohesive and collaborative safety plan of potential triggers and responses. The focus should be on close observation, safe containment and compassion.

The medical focus should be on reducing the immune mediated response. If a child is struggling immensely to cope, then parents, educators and medical professionals should decide collaboratively the best way forward.

Does my child with PANS/PANDAS need an EHCP?

An education, health and care (EHC) plan is for children and young people aged **up to 25** who need more support than is available through special educational needs support. EHC plans identify educational, health and social care needs, and set out the additional support to meet those needs. The key question is whether the child needs more support for the educational needs than the school can offer through SEN support. **If children are not achieving as they were prior to PANS/PANDAS or even coping in school, despite the SEND 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. There is also an independent SEND Support Service (often called SENDIASS) in each area to assist parents and carers with the application and process.



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My child with PANS/PANDAS cannot manage school at all. What should I do?

If your child is in an acute exacerbation, then the priority is to ensure medical support and treatment to reduce the immune mediated response. Every case is different, and parents/carers will know their child best, but if severely unwell the child should be signed off by a medical professional. Parents/carers should stay in close communication with the school. Schools are required by law to enforce attendance, which is why parents/carers require medical evidence to support their child's absence.

Transition to the next stage of school or college education is another issue worth mentioning in this context. Careful preparation is needed for children with PANS/PANDAS. Parents/carers should think well in advance about the most effective provision for their children. This should be acknowledged as a hugely stressful process given the unpredictability of the condition. It is important that professionals who are conducting assessments and observations have a thorough understanding of PANS/PANDAS, and the challenges that it can present.

If your child is chronically unwell and unable to manage school despite medical care for PANS/PANDAS (which is currently highly challenging to access) and schools' reasonable accommodations, then parents/carers should seek advice and assess the available models of education and priorities for their children. There is currently no doubt that for

children affected by PANS/PANDAS, it is a difficult path to negotiate between their education, health, care and social needs. The devastating impact of the condition in conjunction with the unclear trajectory of symptoms clearly demands a flexible approach. Parents/carers should be aware that the schools have a legal responsibility to provide education for their child and to make reasonable adjustments.

There are a range of alternative support systems for children not in school, and those not on a school roll (Children Missing Education – CME). Some of these include Medical Needs provision, Home Tuition, Education Other than At School (EOTAS), Special Schools including hospital schools, alternative provision and Pupil Referral Units. Parents/carers also have a legal right to opt to educate their children at home, 'electively home educate' and this means taking full responsibility for meeting their child's educational needs at home. It is important to understand the full implications before opting for this.

NB: Parents/carers should be aware that settings with similar names may operate very differently in different parts of the country. Consult your Local Offer for SEND to understand and explore the options in your area.

Key Points for Parents/Caregivers and Educators

- **Settings should be aware that the presenting symptoms are immune mediated**, i.e., that the symptoms are not caused directly by the infection, but by the body's abnormal immune response affecting the brain.
- **PANS/PANDAS can impact on attendance.** Often this impact is significant. This is due to debilitating and distressing symptoms, in addition to appointments with multiple medical providers.
- **PANS/PANDAS symptoms may wax and wane.** The support needed for a child may well differ from day to day or within longer periods. Some children suffer from severe exacerbations that may last for several months. Others manifest with a more chronic presentation, or a mixed profile of both chronic symptoms and exacerbations. Once appropriately treated the improvements can be striking.
- **Affected children often do not follow a typical trajectory in terms of progress and attainment.** Their progress may wax and wane along with the symptoms.
- **Children affected by PANS/PANDAS should be assessed on their attainment and presentation prior to onset** rather than as an absolute judgement. This is important.
- **Children affected by PANS/PANDAS are likely to demonstrate needs in multiple areas;** these include Social, Emotional and Mental Health, Cognition and Learning, Communication and Interaction and Sensory or Physical Needs.
- **Children affected by PANS/PANDAS are often also diagnosed with mental health difficulties** as the primary presentation may be psychiatric. Commonly (but by no means exhaustively) this includes Generalised Anxiety Disorder, early onset psychosis and OCD. Children are also often diagnosed with ASD, ADHD, Anorexia Nervosa, ARFID, or Tourette's Syndrome. The key to an accurate diagnosis is to be aware of the onset, pattern and duration of symptoms and to consult a medical professional.
- **Children with other conditions such as ASD, or ADHD can also develop PANS/PANDAS.**
- The condition is often highly debilitating, **and siblings and the affected child are likely to benefit from extensive nurturing** and supportive therapies in school.
- **Parents/caregivers of affected children are often themselves exhausted and bewildered** and should be treated with understanding, compassion, and the clear acknowledgment that they know their child best. Currently diagnosis and treatment for PANS/PANDAS is challenging which is further intensifying the difficulties for families to access appropriate support.
- **Both education professionals and parents/carers can access further information from www.panspandasuk.org**

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