PANS and PANDAS: Emotionally Based School Avoidance (EBSA)

Purpose

Paediatric Acute-onset Neuropsychiatric Syndrome (PANS) and Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections (PANDAS) are complex medical conditions that can significantly impact a child's or young person's school attendance due to their unpredictable nature.

This guide was written by Tina Coope on behalf of PANS PANDAS UK. All quotes have been kindly provided by caregivers of children or young people affected by PANS or PANDAS. It aims to help schools and professionals understand how the sudden onset of PANS or PANDAS can quickly lead to attendance difficulties that can be misinterpreted as Emotionally Based School Avoidance (EBSA). Over time, these difficulties may develop into EBSA, creating a complex relationship that requires informed and tailored responses. The guide is grounded in evidence-based EBSA principles to promote positive outcomes.

The guidance and framework referenced in this document applies to England; however, many of the principles and best practice approaches outlined are relevant and adaptable for professionals in Wales, Scotland, and Northern Ireland. This is an evolving field and more research is required.

This guide is aimed at:

- Schools, for example teachers, SENCO's, education welfare officers, pastoral, and mental health leads
- Wider education professionals for example educational psychologists, inclusion teams, hospital education, alternative provision settings
- School Nursing Teams
- Allied professionals including GP's, paediatricians, CAMHS and social workers
- Parents and carers may also find it useful as a reference.

Thank you

Produced with many thanks for the professional contribution of Vicky Batlle, EBSA consultant, and to the the educational psychologists at Skylakes Psychology for their valuable insights and feedback.

This guide is intended for informational and advisory purposes only. It does not constitute medical, legal, or statutory guidance. While every effort has been made to ensure accuracy and relevance, PANS PANDAS UK cannot accept responsibility for decisions made based on this content. Professionals should always refer to current legislation, statutory guidance, and clinical advice when supporting children and young people. Families are encouraged to seek appropriate medical and educational input for individual circumstances.

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Understanding PANS and PANDAS

PANS and PANDAS are post-infectious autoimmune or neuro-inflammatory conditions that impact both physical and mental health. They can be triggered by common infections such as strep throat, Covid 19, chickenpox, or influenza, and must be diagnosed by a medical professional.

These conditions primarily affect children and young people with onset typically occurring between the ages of 3 and 13. They are usually relapsing and remitting, with symptom exacerbations commonly referred to as flares.

PANS: Paediatric Acute-onset Neuropsychiatric Syndrome)
PANDAS: Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

How do PANS and PANDAS affect children and young people in school?

Children and young people with PANS and PANDAS can experience a sudden decline in school performance and develop a wide variety of symptoms, including obsessive thoughts, tics, anxiety, regressive behaviours, anger, eating issues, and sleep problems. Additional signs may include sensory issues, and many symptoms can fluctuate over time. These conditions can also lead to emotional lability, behavioural regression, motor abnormalities, and cognitive changes, further impacting daily lives and overall well-being[1].

Affected children and young people can develop the acute onset of special educational needs and disabilities (SEND), often without any prior evidence of needs.

> Her symptoms of OCD were so severe that she was trapped at home for a year and couldn't attend school. She was not able to control or limit her OCD routines.
>
> Our lives literally stopped, and OCD routines controlled everyone in the home. It was hell.

Characteristics of PANS and PANDAS

Recognising the symptoms themselves is crucial, but understanding the characteristics of PANS and PANDAS is equally important, as they may not fit into typical SEND profiles. PANS and PANDAS affect each child and young person differently with some experiencing recovery while others face longer and more severe flare-ups.

> '[My] child has not returned to school since severe onset early 2020. Has been reviewed by county education board and they deemed he is medically unfit for education. Prior to onset no special needs support required. Top class student across all lessons.

Cyclical nature of PANS and PANDAS

The conditions can also be understood as cyclical. The cycle of PANS and PANDAS can repeat multiple times, with flares occurring at any point. Whilst in a severe flare a child or young person may be too unwell to access any forms of education.

The cycles of PANS and PANDAS can also vary significantly, from a child or young person experiencing one flare with a full recovery, to those experiencing multiple flare-ups with incomplete or partial recovery and ongoing functional impairments.

PANS and PANDAS may also be hidden disabilities. For some children and young people, the impact is largely invisible for example intrusive thoughts, sensory overload, fatigue, and fluctuating working memory. For others, symptoms are more overt: tics, sleep disturbance, restricted eating, or sudden deterioration of motor control. Many experience both, with symptoms shifting unpredictably across physical, cognitive, social, and emotional domains.

Identifying which phase of the condition that a child or young person is currently experiencing is crucial to recognising their barriers to school attendance. Each case of PANS or PANDAS is unique. During recovery, the repercussions of flares can have significant social and emotional impacts. Many children and young people are left balancing residual fluctuating symptoms, memories of past experiences and future uncertainty. These distinctive factors will need to be identified and understood generally in terms of school attendance difficulties.

It is also important to consider the needs of siblings. They may experience anxiety, confusion, or feelings of isolation during prolonged absences and flares. Providing emotional support and maintaining routines can help reduce the impact on siblings' wellbeing.

Key points

- **Impact on School Performance**: Children and young people with PANS and PANDAS can experience a sudden decline in school performance, developing symptoms such as obsessive thoughts, tics, anxiety, regressive behaviours, and sleep problems. School attendance is often significantly affected.

- **Cyclical Nature**: The conditions are cyclical, with flares that vary in severity and duration. Some children and young people may not fully recover to their original baseline following a flare.

- **Lingering and Chronic Symptoms**: Even during remission, some children and young people continue to exhibit symptoms requiring ongoing support. Chronic patterns may develop, necessitating continuous intervention.

- **Hidden Disabilities**: PANS and PANDAS are often hidden disabilities, making it challenging to identify and accurately address needs.

- **Social and Emotional Impact**: The conditions can have significant social and emotional repercussions, with children and young people balancing fluctuating symptoms, memories of past experiences, and future uncertainties.

Context and Challenges

PANS and PANDAS present profound challenges for children, young people, and their families. Some complexities are related to the symptoms and characteristics of the condition itself, while others are linked to the broader context.

Lack of diagnostic pathways

Despite recent progress across both health and education national workstreams, awareness remains low among professionals. There are currently no national incidence figures or clear diagnostic pathways, adding complexity for families and practitioners. Both Local Authority Guidance and Royal College of Paediatrics and Child Health (RCPCH) accredited UK clinical guidelines are pending in 2026.

For the latest updates on incidence data and diagnostic processes, professionals and families should refer to the PANS PANDAS UK website. Overlapping symptoms with other conditions and neurodivergence further complicate diagnosis, treatment, and support.

> Due to the lack of NHS diagnosis, teaching staff sometimes question the diagnosis.

> 'Do not have a PP [sic] diagnosis. Have had to rely on presentation of symptoms and ASD diagnosis to access support, although my child not currently in school to actually access it!'

Attendance patterns

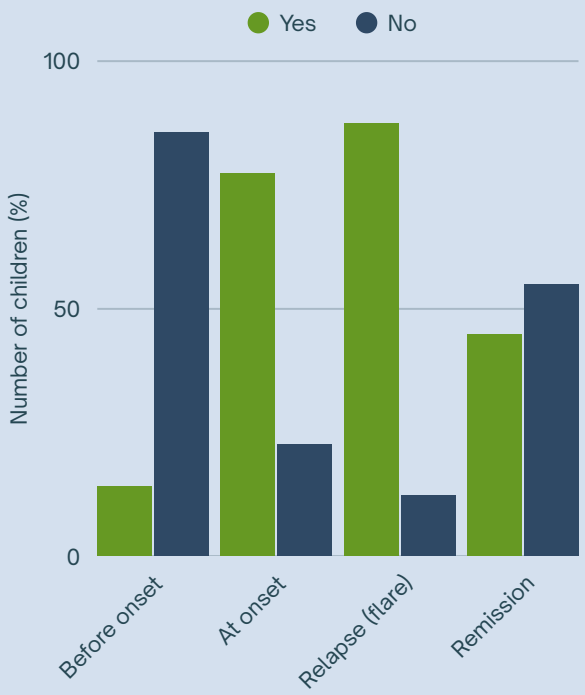
Whilst there is currently very little PANS- or PANDAS-focussed attendance data the charity PANS PANDAS UK undertook a research project in late 2022 where they interviewed 217 parents and carers[2].

Parent and carer reported outcomes identified three significant trends in relation to attendance:

- **Changes in attendance patterns** following the onset of the conditions.
- **Significant impacts of flares** on attendance.
- **Long-term impacts on attendance** even during periods of remission.

In addition, there are more than 7,500 families in the PANS PANDAS UK private Facebook group, and one of the most frequently discussed topics is school attendance, highlighting the potential scale and urgency of this issue.

This is an evolving picture, requiring further research to identify both the nature of attendance patterns and the factors underpinning this emerging trend.



Prior to onset, **86%** of children did not have school attendance issues.

At initial onset, **77%** of children experienced attendance issues.

There are **significant attendance differences** during subsequent relapse (flare) and remission.

Family reported themes

Common themes reported by families supporting children and young people with PANS or PANDAS include:

- **Extended Absences from School:** Children and young people often miss substantial time, sometimes months or even years due to delayed diagnosis and lack of timely treatment.
- **School-Based Trauma:** When children or young people are pressured to attend school while experiencing acute symptoms (such as OCD, severe anxiety, or tics), they can develop severe anxiety associated with the school environment, making future re-engagement extremely difficult.
- **Limited Awareness and Training:** Very few schools (or wider professionals) have received training on PANS and PANDAS, leading to widespread misunderstanding of symptoms and inappropriate responses.
- **Safeguarding Referrals:** Families report being referred for safeguarding concerns because schools misinterpret medical symptoms. A noticeable decline in attendance is a red flag, further contributing to these referrals.
- **Prosecution for Non-Attendance:** Parents and caregivers are sometimes prosecuted for their child's or young person's absence, despite the underlying medical nature of PANS or PANDAS.
- **Misapplied Strategies:** Families report being unfairly blamed or accused of being uncooperative when schools recommend attendance strategies designed for psychological barriers, rather than recognising the medical symptoms of PANS or PANDAS. These approaches often worsen distress and create additional barriers to re-engagement.
- **Exclusions from School:** Some children and young people are excluded because symptoms such as sudden behavioural changes or emotional dysregulation linked to PANS or PANDAS symptoms are misinterpreted.
- **Inconsistent Local Authority Support**: Families experience significant variation in alternative provision and support during long-term absences.
- **Loss of Education and Social Connection:** Extended absences result in missed learning and breakdown of peer relationships, increasing isolation and anxiety.
- **Mental Health Deterioration:** Prolonged misunderstanding and pressure can lead to severe anxiety and school-based trauma, requiring specialist intervention.
- **Financial and Emotional Strain:** Parents/carers often reduce working hours or leave employment to care for their child or young person creating financial challenges alongside emotional stress.
- **Lack of Multi-Agency Coordination:** Poor communication between health, education, and social care professionals leaves families to navigate complex systems alone.
- **Impact on Academic Outcomes:** Missed education and inadequate reintegration plans result in children or young people falling far behind academically, limiting future opportunities.
- **Risk of Misdiagnosis:** Symptoms are sometimes attributed to behavioural or psychological issues rather than underlying medical causes, delaying appropriate treatment.
- **Loss of Trust in Systems:** Families often report feeling disbelieved or dismissed by professionals, leading to breakdowns in relationships with schools and services.
- **Limited Access to Alternative Education:** Some families report that even when children or young people cannot attend mainstream school, alternative provision is delayed or insufficient.
- **Escalating Complexity Over Time:** The longer PANS and PANDAS symptoms are misunderstood and untreated, the more entrenched barriers to education become, making recovery and reintegration harder.

Family reported themes

Noticing patterns of attendance and early signs of difficulty in those with PANS or PANDAS can help practitioners tailor support more effectively

What you might see:

- School progress and attainment data may have slowed or even regressed
- If there were no earlier indicators of difficulty, previous attendance records are likely to show no concerns. Where there were earlier indications, a child and young person's attendance baseline may have declined following onset.
- Children and young people may abruptly require SEND support. For those children and young people with pre-existing needs, there may be an increase in severity and scope of needs.
- Children and young people may be displaying a wide scope of changeable, unusual, and shifting symptoms, for example acute onset of executive functioning difficulties, handwriting deterioration, sensory needs, and very severe separation anxiety.
- Parents and caregivers may be reporting a very different level of needs at home than the professionals are observing in the school setting. Something which is not unusual in PANS or PANDAS.
- Parents and caregivers might provide evidence of previous skills or achievements that their child or young person was capable of, which do not seem to match their current abilities.
- Children and young people may appear to improve slowly, be accessing school again and then very quickly deteriorate. Schools and professionals may interpret previous improvements as resulting from supportive accommodations rather than being part of a medical condition. Consequently, they may express surprise or uncertainty when those same accommodations do not appear effective during an unrecognised medical flare-up. The picture can seem to be inconsistent.
- A child or young person may have been diagnosed with, or be in the process of being diagnosed with, multiple conditions and/or neurodivergence that does not seem to fully align with their current presentation.

Understanding before acting

When the physical symptoms of a primary PANS or PANDAS flare, such as severe generalised or separation anxiety, are **misinterpreted by professionals** as secondary psychological barriers to school attendance, families have reported that unhelpful and sometimes harmful steps are advised and undertaken by professionals.
This can lead to several negative impacts:

- **Failure to Address the Root Cause:** The underlying medical condition is not identified or treated, resulting in ineffective interventions, deterioration, and prolonged symptoms.
- **Increased Disengagement:** Children and young people may become more disengaged from their education due to the mishandling of their condition.
- **Loss of Trust:** Trust between families, children, young people, and educational professionals can quickly erode.
- **Damaged Relationships:** Relationships between children and young people, their peers, and education can deteriorate.
- **School-Based Trauma:** Children and young people may experience long-term trauma related to their school environment and may be unable to re-engage once their symptoms have improved.

> He hasn't been to school properly for three years. He attended medical needs tuition briefly for a handful of short sessions but remained quiet and unable to fully engage.
>
> At the height of his illness, he was so out of control, any form of education was not achievable. Now we have trauma in the mix, he won't engage at all anyway.

This underscores the importance of accurately identifying the medically driven root causes of attendance issues in PANS or PANDAS cases.

Key points

- **Barriers to Attendance:** Children and young people with PANS or PANDAS face significant barriers to school attendance due to a combination of medical symptoms and secondary impacts. This can result in a complex interplay of physical and psychological symptoms.

- **Impact on Functioning:** Children and young people can quickly shift from thriving to struggling, in some cases developing SEND without prior evidence of needs.

- **Misinterpretation by Professionals:** Families report that PANS and PANDAS symptoms are often misinterpreted as psychological issues rather than medical, leading to ineffective and sometimes harmful interventions.

- **Negative Consequences:** Lack of support can result in prolonged symptoms, increased disengagement from education, loss of trust, damaged relationships, and long-term trauma

EBSA, PANS and PANDAS

Beyond the medical challenges posed by PANS and PANDAS, children and young people often face additional emotional and psychological barriers that make school attendance even more complex.

One term increasingly used to describe these situations is 'emotionally based school avoidance' (EBSA).

This term is often used to describe situations where a child or young person cannot attend school due to emotional and psychological difficulties.

There is ongoing professional debate about the terminology, as it can significantly impact how children and young people are perceived and responded to.

However, it reflects a positive shift away from earlier, more stigmatising language such as school avoidance, and is currently widely used.

Alternative terms

Alternative terms include '**emotional barriers to school attendance**,' which highlights the external and emotional factors impacting the child or young person, rather than locating the difficulty within them, and '**emotionally based school non-attendance**' (EBSNA), which similarly adopts a strengths-based and child-centred perspective.

General signs of EBSA

- Experiencing fear, anxiety, erratic behaviour, or expressing negative emotions about going to school.
- Symptoms of anxiety may include a racing heart, trembling, sweating, difficulty breathing, a fluttering sensation in the stomach, nausea, or tingling sensations.
- Complaining of stomach aches, headaches, or sore throats, often without any physical signs of illness.

EBSA and Flares

Typically, EBSA symptoms often intensify on weekday mornings and tend to lessen during weekends and school holidays. However, in PANS or PANDAS, residual symptoms of flares may remain long term and continue to be additional factors.

Stress is also very likely to influence PANS and PANDAS symptoms. Many families report an overall deterioration during periods of heightened stress. School-related factors may be a significant contributor to stress for some children and young people.

EBSA in relation to PANS and PANDAS

Whilst EBSA is now widely adopted as a framework for understanding and addressing school attendance difficulties, it does not encompass all attendance challenges, particularly where primary medical conditions such as PANS or PANDAS are the root cause of the absence.

In the case of PANS or PANDAS, it is important (and can be challenging) to define the distinction between medical symptoms meaning that a child or young person is too unwell to attend school, and the signs of EBSA.

> They try to get him to attend, but do not understand his medical needs.

EBSA does not describe the situation whereby medical symptoms of a condition mean that a child or young person is too unwell to attend school. For example, a child or young person experiencing a severe asthma attack who cannot attend school due to their symptoms would not be described as having EBSA. However, a child or young person with asthma might recover from their attack but still be unable to attend school due to secondary factors including:

- Some residual symptoms such as shortness of breath during physical activities
- Anxiety about the time missed in school and inability to understand the work
- Difficulty in re-engaging with friends and peers
- Anxiety about another attack.

If the secondary impact of having asthma is having a longer-term impact on the child or young person's ability to attend school, the term EBSA would now apply as **emotional and psychological barriers to attendance** have developed. It is important to note that these can occur alongside residual physical symptoms (that are manageable) for a child and young person in a school setting.

PANS and PANDAS have some parallels with asthma in relation to EBSA, but also some important differences. They are also **medical conditions that relapse and remit** (the symptoms come and go), and children and young people undergo often debilitating and unpredictable flares with severe symptoms.

Unlike an asthma attack, however, the symptoms of a PANS and PANDAS flare are often not correctly identified as medical symptoms of a flare.

Understanding EBSA

At the broader level, the lack of established diagnostic pathways, absence of national clinical guidelines, and limited professional awareness create significant barriers to timely recognition and support. More specifically, families report challenges such as:

- **Symptoms of flares** can be mistaken for other conditions and/or neurodivergent traits as there is some overlap
- **Overlap of primary medical symptoms** of PANS and PANDAS flares with common psychological signs seen in EBSA, such as severe generalised and separation anxiety can lead to misinterpretation of the root cause of needs
- **Hidden symptoms** of PANS or PANDAS, causing the extent and impact of the symptoms to be underestimated. Many children and young people are reported by parents/carers to mask their symptoms in school[4].
- **Variability of PANS and PANDAS symptoms** leading to under or over estimation of needs
- **Lack of diagnosis or misdiagnosis** which can result in untreated symptoms worsening, increasing complexity, and creating additional barriers to education and recovery.

Whilst EBSA provides a helpful lens for understanding emotional barriers to attendance, it should not be assumed to explain all cases particularly when primary medical conditions like PANS or PANDAS are driving absence.

Misunderstanding these factors can potentially lead to professionals inadvertently using the wrong approaches, misapplying laws and guidance, unmet needs, and a loss of trust between young person, their families, and professionals.

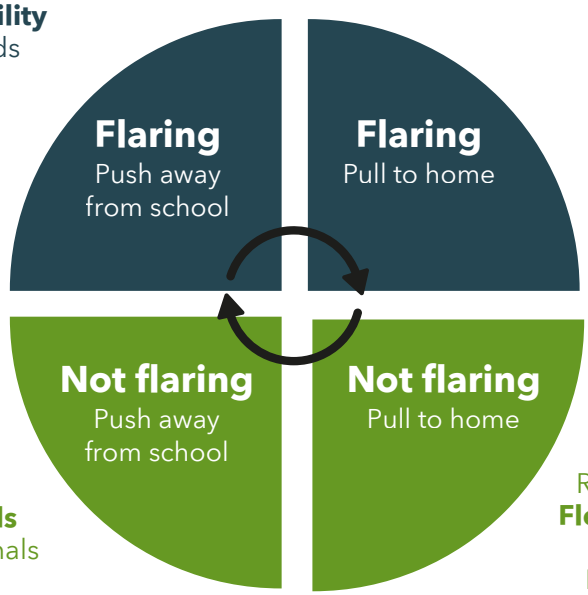
Accessing the right support for children and young people with PANS or PANDAS who experience both primary attendance difficulties due to medical symptoms and the secondary impacts of EBSA can be complex.

> We got a plan in place fairly quickly after a PANS diagnosis, but the preceding 7.5 years were seen as behavioural, not so much medical.

> Even] after diagnosis the school, up until recently, did not listen to our concerns. [They] kept referring to anxiety and behavioural issues.

Push and pull factors

Building on this distinction between **primary medical symptoms** and **secondary emotional impacts**, it is essential to recognise that the push and pull factors influencing school attendance in PANS and PANDAS cases go beyond psychological drivers to also include complex physical and medical elements. Understanding this broader scope ensures that the framework remains accurate for identifying potential issues.



Loss of trust in professionals
Severe separation anxiety
Decline in academic ability
Misinterpretation of needs
Internalised shame
Distressing symptoms
Fear of humiliation
Misdiagnosis
Friendship difficulties
Sensory overload

Reduction in symptoms that are exacerbated by school
Reduced pressure to conform
Multiple severe symptoms
Lower cognitive demand
Lower behavioural demands
Reduced sensory overload
Reduced pressure to mask
Regulated separation anxiety
Increased feelings of safety

Fear of future flares
Residual symptoms
Friendship difficulties
Feeling unsafe
Feelings of guilt
Fear of failure
Loss of educational skills
Loss of trust in professionals
Impact on self esteem
Traumatic memories

Lower cognitive demand
Reduced expectations
Increased sense of safety
Reduced sensory overload
Ability to pace recovery
Reduced pressure to re-connect
Flexible academic engagement
Reduced opportunity to fail
Regulated separation anxiety
Lower environmental demands

This is not an exhaustive list.
Click to view the full diagram and additional factors.

Primary vs secondary impacts

Many children and young people with PANS or PANDAS face significant and varied barriers to school attendance, driven by a complex interplay of medical, emotional, and social factors.

These can include the **primary medical symptoms** of the condition (often untreated) alongside the **potential secondary impacts** such as residual and/or chronic symptoms, trauma, missed time in school, anxiety, and fear of future flares.

Add in the lack of diagnosis and treatment, misidentified and/or unmet SEND needs, and it quickly becomes clear how many potential barriers can exist. Over time, these factors can create a complex mix of psychological and physical factors that are challenging to disentangle and can overlap.

Once the primary symptoms of a flare begin to decrease, children and young people with PANS and PANDAS can be left managing many **difficult symptoms, feelings, and emotions**. Alongside worries about reconnecting with peers and a sense of not belonging, they may also face the psychological impact of suddenly acquiring SEN/D.

This abrupt shift can feel **overwhelming and disorientating**, particularly when combined with memories of distress during the flare.

> Changes in behaviour I assume to be PANS were seen as part of his existing autism diagnosis or I suspect they thought he might be becoming psychotic.
>
> In general, the rapid onset of his regression, aggressive behaviour and eating problems were assumed to be either my fault, or psychiatric symptoms.

Children and young people often describe feeling that **'everyone has overtaken them,'** which can erode confidence and create a heightened sense of vulnerability.

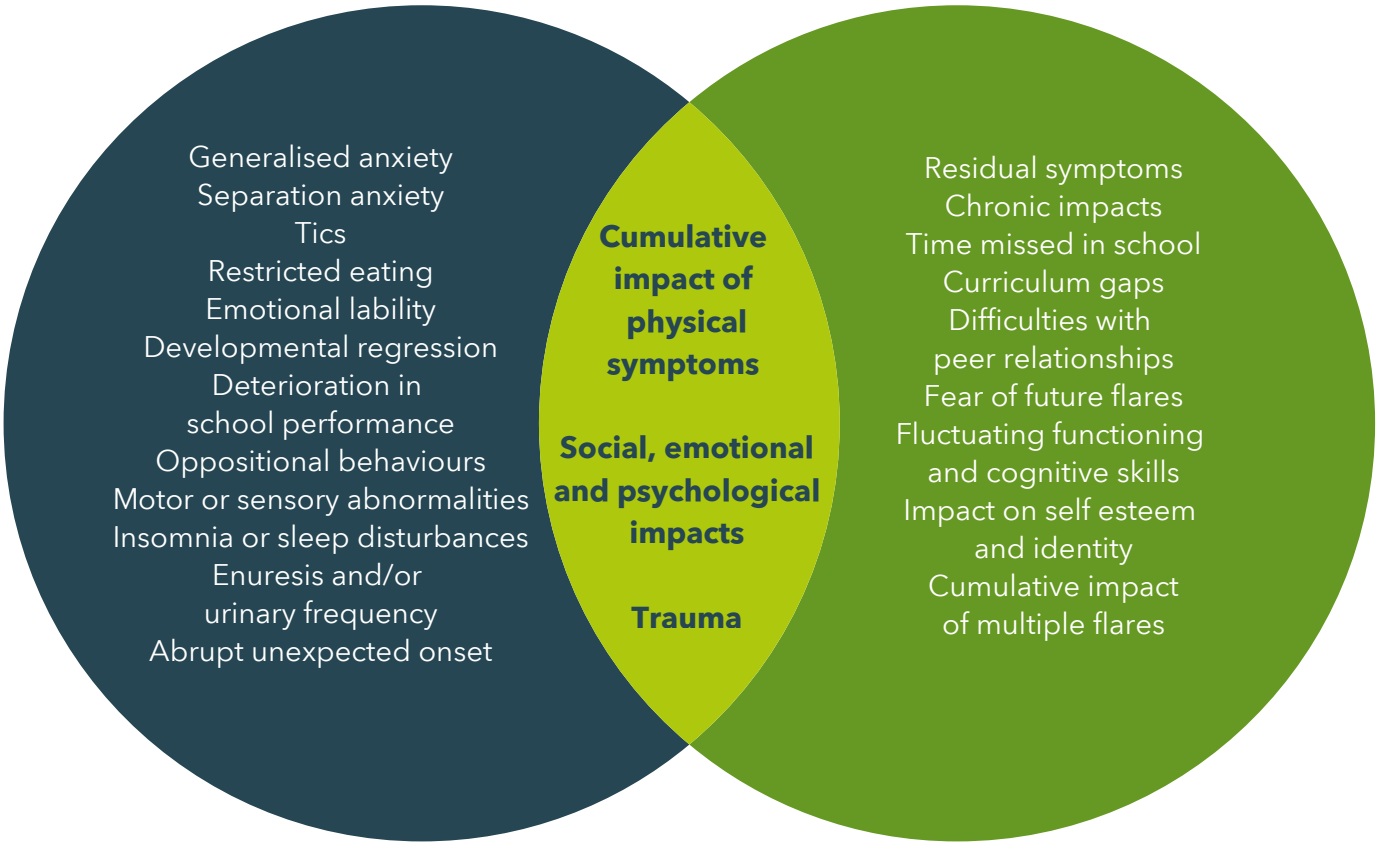
A trauma-informed perspective recognises that these experiences are not just academic setbacks, they represent profound disruptions to identity, safety, and trust, requiring sensitive, paced support that prioritises emotional security as much as educational progress. There is also often a haunting fear that the symptoms might return at any time.

These feelings of vulnerability and fear underline why proactive steps are so important. By acting early, schools and professionals can reduce the risk of EBSA developing alongside the medical challenges of PANS and PANDAS.

Connecting factors

It is not always easy to separate primary and secondary impacts.

This diagram shows how these factors connect. It maps out the sequence of events and illustrates how the medical symptoms, and the way they are managed, can ripple out into wider, longer-term challenges with school attendance.



Key points

- **EBSA:** Emotionally Based School Avoidance (EBSA) refers to a child or young person struggling to attend school due to emotional and psychological difficulties, not due to primary medical symptoms.
- **Secondary Impact:** Medical conditions including PANS or PANDAS can lead to EBSA, if secondary factors prevent school attendance following physical recovery.
- **Support Needs:** Effective support for EBSA in a child and young person with PANS or PANDAS requires timely diagnosis, recognition of medical symptoms, treatment and prioritisation of health needs, alongside educational support.
- **Attendance Trends:** Emerging data shows significant attendance difficulties both during flares and remission periods for children and young people with PANS and PANDAS. More research is required.

Reducing the risk

Having explored the distinction between primary medical symptoms and secondary emotional impacts, it becomes clear why proactive steps are essential to reduce the risk of EBSA developing alongside the medical challenges of PANS and PANDAS.

Good practice principles

Whilst recognising that national clinical guidelines for PANS and PANDAS are still in development, the following steps reflect good practice principles designed to support schools and professionals in responding effectively.

- **Exploring clearer pathways for assessment:** Where possible, establish accessible routes for timely medical assessment when PANS or PANDAS is suspected, to reduce uncertainty and avoid prolonged untreated symptoms.
- **Early multi-agency collaboration:** Encourage health, education, and social care professionals to work together as soon as symptoms emerge, rather than waiting for attendance to deteriorate.
- **Awareness checks in schools:** When sudden changes in behaviour, anxiety, or attendance occur, schools could consider whether underlying medical factors might be contributing, alongside psychological or social explanations.
- **Facilitating rapid access to medical input:** Support GPs and paediatricians with emerging guidance and resources so they can act promptly on referrals and investigations.
- **Open communication with families:** Schools should adopt a collaborative approach, listening to parents' observations and concerns about health and avoiding assumptions around non-attendance. They should recognise the impact on siblings and offer guidance or signposting for emotional support where needed.
- **Flexible attendance options:** During acute phases, consider sensitive adjustments such as reduced timetables or remote learning to maintain educational connection without causing additional distress.
- **Training for key staff:** Provide early awareness training for SENCOs, attendance officers, and safeguarding leads to help them recognise potential PANS or PANDAS symptoms and respond appropriately.
- **Psychological support for adjustment:** Offer emotional support for the child or young person and their family to manage the stress of sudden onset symptoms and disruption to daily life.
- **Avoiding premature enforcement measures:** Where health concerns are being explored, ensure attendance enforcement actions (such as fines) are paused until medical factors are clarified.
- **Maintaining peer connections:** Use strategies like virtual meetups or buddy systems to help children or young people stay socially connected during periods of absence.

These interconnected challenges underline why a proactive, structured approach is essential. The following best practices offer practical steps for schools and professionals to reduce risk and support children and young people with PANS or PANDAS effectively.

Information gathering

Accurately identifying EBSA in the case of PANS or PANDAS requires mapping the child or young person's history and understanding which phase of the condition they are in, so that support strategies are targeted and appropriate

Area	Key considerations
Working knowledge of the conditions	Ensure all stakeholders understand PANS and PANDAS, including variability and masking of symptoms.
Co-occurring conditions or neurodivergence	Identify any neurodivergence or other health factors influencing presentation and support needs
Age of onset, severity, and medical timeline	Include onset, duration, severity, and any delays between onset, diagnosis, and treatment.
Impact of past school experiences and emotional toll	Review previous school experiences and the cumulative psychological impact of living with an unpredictable condition.
Severity and symptoms of most recent flare (including triggers and patterns)	Assess intensity, scope, and known triggers or patterns of symptom escalation/remission.
Previous support strategies	Examine interventions already attempted and whether they were helpful or harmful (e.g., graded exposure during a flare).
Family context and stressors	Consider safeguarding referrals, legal pressures, and financial strain.
Peer and social connections	Explore whether friendships or social contact were maintained during absences
Educational gaps	Review missed learning and curriculum gaps to understand academic pressures during reintegration.

Support during flares

Once key information has been gathered, the next step is to consider how to respond during acute phases of the condition. Support during flares requires a **flexible, health-focused approach** that prioritises wellbeing, and recognises the severity and variability of symptoms. A child and young person will typically experience a series of flares enduring a wide breadth of often severe neuropsychiatric symptoms. Both the type and range of symptoms can be highly variable.

A young person in a flare:

- may be too unwell to be in school
- demonstrate significant regression in all areas
- develop sudden SEN

Broad support principles should include:

- Accommodations to compensate for skill decline
- Reduced expectations
- Heightened levels of flexible support

Some children and young people can still manage to attend school in flares, but will require considerable accommodations with a limited capacity for learning. Others will be too unwell to attend school at all. The physical and mental health needs of children and young people with PANS and PANDAS should be prioritised.

PANS and PANDAS are medical conditions and therefore the following will apply:

- A child or young person with PANS or PANDAS **must not be penalised for school absences** that relate to their medical condition. Their mental and physical health needs should be treated with equal importance.
- If a child or young person with PANS or PANDAS is expected to be absent for more than 15 days, consecutive or disparate, the Local Authority is responsible for ensuring that they **receive an education as close to normal** as possible during their absence.
- Appropriate educational options may include **home teaching, a hospital school, or a teaching service**. Full-time education should be provided unless part-time education better suits the child or young person's needs, particularly during severe PANS or PANDAS flare-ups.
- More information can be found in the **statutory guidance** known as Arranging education for children who cannot attend school because of health needs (Department for Education, 2023).
- For more information on **alternatives to attendance at school** please refer to Arranging Alternative Provision, a Guide for Local Authorities and Schools (Department for Education, 2025).

Long-term positive engagement with education is essential. Early detection, diagnosis, and effective treatment are crucial for achieving the best health and educational outcomes for the child or young person.

Reintegration principles

Reintegration after a PANS or PANDAS flare is a complex process that requires **sensitivity, flexibility,** and **collaboration**. For some children and young people, this challenge is compounded by extended periods of missed education and the need to reintegrate multiple times following successive flares. Health may fluctuate, emotional vulnerability can persist, and gaps in learning often widen, making a one-size-fits-all approach ineffective. The goal is to create a plan that prioritises wellbeing, rebuilds confidence, and supports educational progress at a pace that feels safe and achievable.

Whilst there are currently few studies about the long-term outcomes and duration of PANS and PANDAS, families report that in some cases, the conditions have lasted for years and persisted into adulthood. Whilst every case is different, some children and young people with PANS and PANDAS are likely to miss significant time out of their education. Their condition pattern, unique circumstances and symptom profile will all require thought, and **close collaboration with all stakeholders** who understand the complexity and have undertaken training in the conditions.

Professionals should ensure that they do not lose sight of the individual story of the child or young person.

The diagnosis or suspected diagnosis of PANS or PANDAS covers a huge spectrum and will not in itself tell you much about the individual needs of one particular child or young person.

Characteristics of physical recovery:

- Gradual reduction of severity of symptoms
- Unlikely to be linear progress
- Some symptoms may linger and become chronic necessitating ongoing support
- Timescales for recovery are hugely individual, and may vary within the same child or young person in different flares
- New flares can potentially be triggered at any point in the cycle of recovery.

> [She] joined secondary as symptoms escalated, ended up being out of school for two and a half years, parenting classes were suggested but no pressure; things changed once we got diagnosis of PANDAS and once well enough started at a new secondary.
>
> Everyone thought she was anxious and struggling with anxiety. At the worst times CAMHS crisis team wanted to put her on an adolescent's ward because of psychosis. Luckily, this didn't happen just wish everyone had listened to us sooner when we were first suggesting PANDAS.

Reintegration framework

This table summarises the core principles and practical steps for reintegration, providing a clear framework for schools and professionals to plan a safe, flexible return to education for children and young people with PANS or PANDAS.

These principles should be adapted to the individual child or young person's needs and used alongside pre-transition planning to ensure continuity and emotional security.

Principle	Practical steps
Individualised approach	Tailor reintegration to the children's or young person's unique health status and symptom profile. Avoid one-size-fits-all strategies.
Health first	Begin reintegration only when the child or young person is medically stable and emotionally ready. Prioritise health over attendance targets.
Paced and flexible	Use phased timetables, allow late starts and rest breaks. Expect non-linear progress and avoid penalties for setbacks.
Collaborative planning	Involve families, health professionals, and the child or young person in decision-making. Ensure all stakeholders understand the condition.
Trauma-informed practice	Reduce anxiety triggers, avoid pressure, and create a sense of safety. Recognise emotional impacts of flares and missed schooling.
Educational continuity	Address curriculum gaps, provide reasonable adjustments, and avoid overwhelming academic demands.
Statutory support consideration	Where needs are significant and long-term, explore whether an Education, Health and Care Plan (EHCP) assessment is appropriate to secure coordinated provision.
Ongoing review	Set flexible review points and adapt plans as health status changes. Consider external assessments if abilities have shifted.
Individual Health Care Plan	Consider the need for an individual health care plan (IHCP) to formalise medical needs and educational adjustments.
Social reconnection	Maintain or rebuild peer relationships through safe, positive activities before academic reintegration. Reintegration planning should also consider siblings, as they may need reassurance and opportunities to maintain positive relationships during and after periods of absence.

Gathering views

Following the establishment of reintegration principles, it is essential to ensure that the child or young person's voice is central to planning. Gathering their views helps shape a supportive approach that **reflects their priorities, preferences, and emotional readiness**.

The ability of a child or young person with PANS or PANDAS to share their views will vary significantly depending on their current health status and symptom severity. During acute phases, communication may be limited, and professionals should adopt a flexible, empathetic approach that prioritises wellbeing over formal consultation.

It is important to recognise that what a child or young person shares, including their priorities, preferences, and feelings will often be shaped by their current health status. For example, during a flare, they may focus on immediate comfort and safety, whereas in recovery, they may express aspirations for social reconnection or academic progress.

When gathering the views of the child or young person, consider approaches that **reduce cognitive load and make expression easier.** Strategies might include using **simple visual tools, structured prompts**, or **low-pressure formats** that allow the child or young person to communicate preferences and feelings in a way that feels safe and manageable. These could take the form of cards, diagrams, or interactive resources designed to support choice-making and emotional expression.

These methods uphold the principle of **collaborative, child or young person-centred planning** while recognising that engagement must be paced and adapted to their health status. Professionals should remain sensitive to fluctuations in capacity and avoid placing undue pressure on the children or young people during periods of distress or flare-ups.

> Her current school are very flexible and try to work within the times that she can get to school and have recently provided work set online for her to complete when possible.
>
> However, because she sometimes makes it in and when is not in a flare, is very competent, there isn't the provision to provide any home support during a flare or to fill in gaps of the education she is missing when cannot attend.

Realistic expectations

Recovery from PANS or PANDAS is rarely straightforward. Even after symptoms improve, children and young people may experience **fluctuating health, emotional exhaustion, and lingering challenges** such as obsessive thoughts or difficulties with emotional regulation. These ups and downs are typical.

Reintegration plans must **allow for flexibility**, recognising that progress may involve good days interspersed with setbacks. Support teams should reassure families and avoid placing undue pressure on the child or young person.

Starting with small, achievable steps and **gradually building engagement** is more effective than expecting rapid progress. It is easy to underestimate the level of effort required for a child or young person to manage in the classroom, so **pacing and sensitivity** are essential.

Whilst plans must be flexible and sensitive to health needs, it is equally important to maintain high aspirations for the child or young person. Reintegration should support recovery and emotional security, but also long-term goals, enabling access to opportunities that reflect their potential.

Although every case is unique, **flares are often deeply traumatic** for the child or young person and their family. Recovery tends to involve good days interspersed with more challenging periods as everyone re-adjusts. Feelings such as **frustration, distress, and residual obsessive thoughts or compulsive rituals** can significantly affect the home environment.

Children and young people are also likely to be exhausted particularly if they are not sleeping well and/or are working extremely hard to emotionally regulate throughout the school day. Sometimes their support will need to change, and they will need to take a break. This is entirely typical, and the support team should always be reassuring. It is **very easy to underestimate the level of challenges** that a child or young person with PANS or PANDAS is likely to be dealing with in the classroom.

> My son can now articulate how it feels to have a flare. He says he can feel it coming on and can't stop it. He hears a "white noise" kind of sound inside his head. He doesn't think the same way any more. He is full of hatred for himself and can't stop his anger.
>
> After a flare when he gets better he remembers what happened and is full of shame, though can't explain why he was angry.

Case study

Pearl developed PANDAS aged just eight years old. Her abrupt onset of severe symptoms, including panic attacks and extreme anxiety, made school a major trigger and led to a prolonged period of absence.

Experiences like Pearls illustrates the complexity of reintegration for children with PANS or PANDAS.

> Pearl missed around nine months of school due to her illness. School have been brilliant and I sent them all of the information from the PANS PANDAS UK website so that they could learn for themselves and understand it better.
>
> I always felt like [school] might have thought I was making a lot of it up because Pearl masked it so well if she ever did make it into school, but then her headteacher came to visit us at home and he witnessed first-hand how bad things were. Once he saw it for himself, he was so understanding and we worked together to support her once she was eventually back at school.

Initially, Pearl's difficulties with attending school were rooted in **overwhelming medical symptoms** caused by PANDAS. As treatment progressed and her health improved, she began re-engaging with school and other activities, suggesting her earlier challenges were primarily health-driven rather than persistent EBSA. This highlights the importance of understanding the interplay between physical health and EBSA.

Whilst recovery was not absolute, at age 10 Pearl's mum describes her as 'around 80% back to her normal self' although she "still struggles with certain things," indicating **residual impacts that require sensitive monitoring and support.** Her case shows how sudden-onset PANDAS symptoms, for example panic attacks and separation anxiety, can closely resemble EBSA.

If this anxiety had been misinterpreted as purely emotional rather than medically driven, Pearl might have faced **inappropriate interventions** such as attendance pressure or psychiatric-only referrals, likely worsening her distress and delaying effective treatment.

Pearl's full story, and more case studies, are available at www.panspandasuk.org

Educational Psychologists

Supporting children and young people with PANS or PANDAS and related attendance difficulties often requires coordinated input from a broad network of professionals.

Health, education, and social care teams may all play a role, alongside specialist services such as CAMHS, paediatrics, and school-based staff.

Within this multi-agency context, educational psychologists (EPs) are uniquely positioned to bridge medical and educational perspectives, ensuring that interventions are evidence-based and tailored to the child's individual needs.

Educational psychologists contribute across assessment, planning, and intervention, integrating psychological and educational considerations into a holistic approach. Their work helps schools and families understand the underlying factors affecting attendance and supports the development of strategies that promote both learning and emotional wellbeing.

By combining psychological expertise with collaborative practice, educational psychologists help create safe, supportive environments that enable children and young people with PANS or PANDAS to re-engage with learning and thrive despite the challenges posed by these conditions.

The role of educational psychologists

- **Assessment:**
  EPs undertake comprehensive assessments to understand the child or young person's cognitive, emotional, and behavioural profile. This includes identifying the impact of medical symptoms on learning and emotional regulation and considering co-occurring needs such as SEND or neurodivergence.

- **Psychological Formulation:**
  EPs develop formulations that integrate medical, psychological, and environmental factors. This helps schools and families understand the underlying reasons for attendance difficulties and informs tailored interventions.

- **Collaborative Planning:**
  EPs work closely with schools, families, and health professionals to co-produce support plans. These plans prioritise the child or young person's voice, incorporate trauma-informed approaches, and align with statutory guidance such as the SEND Code of Practice.

- **Intervention and Support:**
  EPs recommend and sometimes deliver evidence-based interventions, such as anxiety management strategies, emotional regulation techniques, and graduated reintegration plans. They also advise on reasonable adjustments and whole-school approaches to reduce attendance barriers.

- **Multi-Agency Working:**
  EPs act as a bridge between education and health services, ensuring that medical information is understood within the educational context and interventions are coordinated across agencies.

Conclusion

Supporting a child or young person with PANS or PANDAS is never just about getting them back into a classroom, it is about understanding their unique journey and finding the right way forward.

Education can take many forms. What matters most is creating an approach that feels safe, supportive, and achievable.

By listening carefully, working collaboratively, and prioritising wellbeing alongside learning, we can empower children and young people with PANS or PANDAS to have a voice in shaping their educational journey.

When they are actively involved in decisions, they can rebuild confidence, maintain meaningful connections, and access education in ways that reflect their needs, strengths, and aspirations.

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Reference list

Footnotes

[1] Additional information about the symptoms and diagnostic criteria.

[2] PANS PANDAS UK 2022 survey: 217 parents/carers reported outcomes

These themes reflect experiences shared by families and are not formal research evidence

[4] Masking in schools is when a child or young person with PANS or PANDAS hides or suppresses their symptoms for example anxiety, tics, or obsessive thoughts to appear 'fine' at school, even though they may feel unwell or overwhelmed inside

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Glossary

Chronic symptoms
Those that persist for a long duration and can significantly impact on a child or young person's quality of life

Developmental regression
Loss of previously acquired skills or abilities in a child or young person across different areas for example motor, language, and social skills.

Emotional lability
Rapid and exaggerated shifts in mood/emotions that often appear disproportionate to the situation

Enuresis
Daytime or nighttime wetting

Hidden Disabilities
A condition that is not immediately apparent to others but can significantly impact on individuals

Motor or sensory abnormalities
Disruptions to the brains ability to process and respond to sensory information impacting motor skills

Neurodivergence
A natural variation in how the brain processes information, think, feel and interact with the world.
Examples include Autism, ADHD, Dyslexia, Dyspraxia, Dyscalculia.

PANDAS
Paediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal infections

PANS
Paediatric Acute-onset Neuropsychiatric Syndrome

Residual symptoms
Symptoms that persist after other symptoms have resolved or improved

SEND register
A school's internal record that identifies children and young people who have been identified as having ongoing special educational needs with or without disabilities

Separation anxiety
Repeated and intense distress when thinking about separation. For example, being apart from loved ones or when away from home

Social, Emotional, and Mental Health needs (SEMH)
A range of difficulties or challenges that some children or young people may experience in managing emotions, mental well-being, and behaviour.

Special Educational Needs and Disabilities (SEND)
A range of learning difficulties or disabilities that can affect how a child or young person learns and develops. These needs might include challenges with learning, communication, physical development, or managing emotions and behaviour, and often require extra support in school and beyond.

Urinary frequency
Feeling the need to frequently urinate more often than would be typical.

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