

Individual Health Care plans

PANS and PANDAS: A guide for Parents/Carers

PANS AND PANDAS

What are PANS and PANDAS?

PANS (Paediatric Acute-onset Neuropsychiatric Syndrome)

This is a neuropsychiatric condition triggered by a misdirected immune response which results in inflammation of a child's brain.

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. This results in neuroinflammation.

Both conditions cause a wide range of physical, cognitive, and behavioural symptoms and can only be diagnosed by a medical professional. For further information please go to the PANS PANDAS UK website.¹

*By Tina Coope on behalf of the PANS/PANDAS UK charity.
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How do the conditions of PANS/PANDAS affect children and young people*?

Children with PANS/PANDAS often experience the abrupt onset of unexplained changes in lots of different areas. These can include new issues with learning, physical problems, social skills, behaviours, and emotions. In PANS these changes can be triggered by a range of infections, environmental triggers (such as allergies), or even psychological triggers such as extreme stress. In children with PANDAS, these changes follow a streptococcal infection. The symptoms experienced are often relapsing and remitting, and very distressing for the child and their families.

The broad constellation of neuropsychiatric symptoms linked to PANS/PANDAS can cause severe difficulties with learning, attending school and being able to participate in age-appropriate activities. Many children with PANS/PANDAS develop Special Educational Needs (SEN) and will require additional support for both their health condition and their learning needs.

This information sheet specifically discusses the issue of Individual Health Care Plans and PANS and PANDAS relating to the Government guidance for England.²

IHCPs and PANS/PANDAS

What is an Individual Health Care Plan? (IHCP)

An IHCP is a plan that clearly sets out a child's **medical** needs in school/ educational settings*. It is designed to support both physical and mental health conditions and should involve all staff that support the pupil in school. It must also include guidance from medical professionals and school health services.

The IHCP is not the same as an Educational and Health Care Plan (EHCP). An EHCP is put in place to provide support for special educational needs, whereas the IHCP focusses on ensuring children's medical needs are properly supported in educational settings. Some children may have both types of plan, and others may only have one type in place.

If a child has SEN but does not have an Education and Health Care Plan, then their SEN needs should be included in their health care plan and linked to their SEN Support Plan (sometimes known as an Individual Education Plan/IEP or Pupil Profile). If a child with PANS/PANDAS does have an EHCP, then the requirement for an individual health care plan should be included in their EHCP.

Does my child with PANS/PANDAS need an IHCP?

There is no specific guidance regarding which medical conditions require an IHCP, and it is open to the school's discretion. Government guidance suggests that they will often be essential in conditions that fluctuate, for those children with continuing health needs, or where there is a high risk of the need for emergency intervention. They are also likely to be helpful for medical conditions that are long term and complex.³ The requirement is therefore based upon the impact of the condition, and so in practice, whilst one child with a particular disorder may require an IHCP, another child with the same condition may not.

In summary, if your child has a medical condition that requires specialist management, then a healthcare plan is likely to be essential. This includes conditions such as PANS/PANDAS.

A well-written IHCP can provide a clear explanation of the condition of PANS/PANDAS and can specify the particular symptoms experienced by your child (both observable and non-observable).

What are the benefits of getting an IHCP for my child?

Individual health care plans can be beneficial for children with PANS/PANDAS in a number of ways. A well-written IHCP can provide a clear explanation of the condition of PANS/PANDAS and can specify the particular symptoms experienced by your child (both observable and non-observable). **It also ensures accurate observation and understanding of the symptoms and can ensure a plan is in place for when behaviours and symptoms change in type, duration, or frequency.** It provides reassurance for parents/caregivers, the child and school staff. It also ensures that all relevant parties are informed and sharing a consistent approach. The plan also helps to identify any potential training requirements for educators and health professionals.



How to apply for, and create, an IHCP

What should the IHCP include?

Schools each have their own templates, and the level of detail included will depend on the complexity of the condition. They should all be specific, clear and contain the key details. Any information about a child's medical condition must be managed sensitively, and in accordance with the school's data protection and safeguarding processes.

Alongside the generic requirements for information, there are some particular recommendations for the conditions of PANS/PANDAS. This is not an exhaustive list, and the plan might also include other aspects of a pupil's care.

As an overview, the IHCP should include:

- The diagnosis and details of the professional team supporting the child.
- Individual triggers (as known)
- The signs and symptoms including the impact on education, any social and emotional needs, and the potential impact on attendance.
- The plans that need to be implemented for school trips (including overnight as applicable) and any other extracurricular school activities, outside the usual timetable.
- An awareness that the support required is likely to change over time, and that the IHCP will need to be updated in response to this. At the very minimum the plan should be reviewed once a year, but it is very likely in the case of PANS/PANDAS that it will need to be reviewed more regularly. The IHCP should therefore also include:
 - When it will be reviewed
 - Details of who is allowed to alter the plan and which sections they are permitted to change.
 - Details of the review meeting.
- A clear definition about what constitutes an emergency and a plan to ensure that all relevant staff follow the correct procedures.



Next Steps: Developing an IHCP

- 1** Inform the school/educational setting that the child has a new or suspected diagnosis, that their needs have changed, and that you would like to request an IHCP. Parents/Caregivers, healthcare professionals or educators can initiate the process.
- 2** The school will then arrange a meeting to discuss the pupil's medical needs. Parents/caregivers should share the relevant supporting information. This could include clinic letters, a list of triggers, symptoms, impacts, medications, and professionals involved.
- 3** Ensure that all relevant school staff, the child, the parents/caregivers, relevant health care professionals and other clinicians as appropriate have the opportunity to contribute. Develop the IHCP as a team and ensure that input from a health care professional has been included. ⁴
- 4** Identify whether there are any school staff training requirements. Has the school accessed any training on the conditions of PANS/PANDAS? If not then please refer then to the PANS PANDAS UK website for further health and educational resources. ^{5,6}
- 5** Implement the IHCP and circulate to all relevant staff members.
- 6** Review the IHCP annually or as required when the health care needs change. Ensure that Parents/caregivers are aware of their responsibility to inform the school about medication changes and that it is clear how changes in the pupil's presentation are to be communicated.

Has the school accessed any training on the conditions of PANS/PANDAS?

What might an IHCP for a child with PANS/PANDAS look like?

What follows is a sample IHCP, designed to provide insight into what a complete IHCP for a child with PANS/PANDAS might include. Please remember that each child is different, and therefore the impact of the condition and level of detail required in the health care plan will also vary. **The following suggestions are not intended to be definitive, and the level of detail is given with the intention of being illustrative of various possibilities of how an IHCP might be written.**

Sample Individual Health Care Plan

Name of school/setting

Child's name

Group/class/form

Date of birth

Child's address

Medical diagnosis or condition

Date

Review date

Additional information

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Diagnosis (or working diagnosis)

X has a diagnosis of PANS (Paediatric Autoimmune Neuropsychiatric Disorder) - Diagnosed on 2/02/21 by Dr Blue, Paediatric Neurologist at Edgeway Children's hospital.

PANS is a complex immune-mediated inflammatory brain condition which follows a relapsing and remitting course. X can go from being very well, and relatively symptom-free, to severely affected by any combination of his symptoms within a short space of time (hours) following any illness or infection. It can then take months of treatment for X to return to baseline. Even then residual OCD, memory issues and handwriting issues remain.

Medical professionals and services

X is currently under the care of Professor Red (Consultant Paediatric Neurologist at OPSS), Professor Grey (Consultant Immunologist) at Hereford Children's Hospital, Dr Brown (Paediatrician at Southwold General) and Dr Green (Child Psychologist at the specialist National OCD clinic in South Birmingham). Dr Black and Dr Mauve (CAMHS) at the Children's Assessment Centre, Bagnall are also involved in X's care.

Triggers

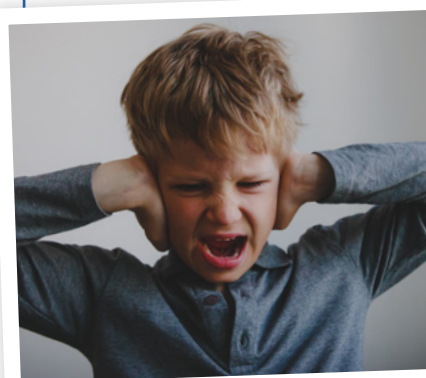
Not all of X's triggers are known, however his triggers do include infections and allergies (in particular streptococcal infections) and grass and tree pollen. Parents/Carers would like to be notified about the presence of infections (particularly streptococcal infections) within his class/year group via telephone call or email.

Summary of signs and symptoms

This should include the impact on learning, behaviour and classroom performance alongside any additional provision/adjustments required.

Signs and Symptoms	Additional provision and reasonable adjustments
Obsessive thoughts and compulsions – these include repetitive thoughts of harm coming to family members, and tapping and counting compulsions. X cannot listen and follow instructions in class whilst managing his OCD	<ul style="list-style-type: none"> All staff to be aware of X's obsessive thoughts and compulsions. Report changes to Parents/ Caregivers. Management of OCD to be guided by health input
Inattention and hyperactivity – X may display difficulties with focus and concentration. This may present as excessive fidgeting, concentration difficulties and a struggle to remain seated.	<ul style="list-style-type: none"> Fidget toys, wobble seat, Regular movement breaks, Reduced expectations in a 'flare'. Pass to leave the classroom as required. Instructions broken down into small steps
Separation anxiety – particularly marked from Mum	<ul style="list-style-type: none"> Flexible starting times Supported transition periods. Pastoral and Nurture support. Accommodations and adjustments during a 'flare'
Sleep disturbance – this can be severe – X will appear tired and may well be late for school. Tiredness is known to exacerbate the symptoms of X's PANS	<ul style="list-style-type: none"> Flexibility with regards to starting times and attendance Regular breaks A safe and comfortable space to relax/sleep such as the sofa in the Nurture room. Reduced expectations. SEMH support
Rapid mood changes, anger, irritability or despair leading to oppositional and occasionally aggressive behaviour. Changes in mood state can occur suddenly and without an obvious trigger. X is very remorseful and upset following these incidents	<ul style="list-style-type: none"> Pass to leave the classroom when X is feeling overwhelmed. Safe Nurture space and pastoral support Agreed strategies for supportive management within the context of PANS

Signs and Symptoms	Additional provision and reasonable adjustments
Urinary frequency including toileting accidents in school. This is often an early warning sign of a PANS flare for X. He struggles to inform staff following a toileting accident due to embarrassment	<ul style="list-style-type: none"> Discreet access to a change of clothes. Pass to leave the classroom. Pastoral support to recognise that this is a symptom of his condition.
Marked deterioration in handwriting or maths skills. Again, this can be an early indicator of a flare	<ul style="list-style-type: none"> Adjustment and compensation during 'flares' Reduced expectations. Instructions broken down into small steps Alternative forms of recording Regular movement breaks Focus on effort rather than outcomes Communicate the deterioration to parents
Misophonia- when in a 'flare' X becomes acutely sensitive to sounds. This can include classmates chewing or breathing, or simply the multiple sounds of a busy classroom. X will place his hands over his ears and may become rapidly distressed. He may also pinch his legs hard to try and mitigate the stress of his misophonia	<ul style="list-style-type: none"> Ear defenders or 'in ear' discreet ear plugs Regular breaks A calm classroom environment Giving space and time Pass to leave the classroom. Prior warning of loud noises/ for example fire alarms or a noisy activity. Pastoral and Nurture support Awareness by staff of the strategies X uses to mitigate the stress. Understanding from staff that X cannot respond to instructions/tasks whilst managing misophonia. Creating a low arousal classroom environment where possible Recognising that the levels of misophonia are likely to vary from day to day.



Medication and treatment required for X

- Treatment for X's PANS includes anti-inflammatory agents and immune modulators, such as antibiotics, non-steroidal anti-inflammatories, and corticosteroids.
- Cognitive behavioural therapy (CBT) is used to resolve lingering OCD symptoms once inflammation has resolved.
- Currently X takes prophylactic antibiotics (Amoxicillin), an SSRI (Sertraline), Propranolol, and Ibuprofen.
- The antibiotics prevent infection, the Sertraline and Propranolol help reduce anxiety and OCD, and the ibuprofen reduces inflammation.
- These are all currently administered at home.
- Parents/carers are aware of their responsibility to update the school/educational setting as required.

What to expect

X's condition is relapsing and remitting; therefore, his symptoms and requirements fluctuate accordingly.

- At baseline, X requires little additional support. He experiences residual OCD, working memory issues and some minor difficulties with his handwriting.
- Triggers for a relapse may vary from throat infections, ear infections, flu, colds, gastroenteritis etc. Effectively, any illness which provokes an immune response has the potential to result in neuropsychiatric symptoms in X. Outbreaks of illness at school should be reported to parents/caregivers by telephone.
- Following an infection, X's immune system creates antibodies which cause inflammation in the basal ganglia. This causes a very sudden and dramatic change in X's physical, emotional and mental status.
- When in a severe 'flare', X experiences such severe OCD that he is often unable to leave the house. He regresses cognitively, and can also experience issues with fine motor control, sensory sensitivities, attention skills and emotional lability.
- 'Flares' such as these are treated promptly with antibiotics and, if required, short bursts of corticosteroids to reduce inflammation.
- Any marked regression for X in handwriting, memory skills and the onset of toileting accidents may signal an impending relapse and should be reported to parents immediately.

What support is required?

- Support needs to be flexible and responsive according to the trajectory of X's illness.
- When well, X requires little additional support and dislikes being seen as 'different' to his peers. He does, however, struggle with attention and organisational skills, sustained difficulties with handwriting and residual OCD which may not be obvious. Staff should therefore be aware that he may require extra prompts and support.
- When in a relapse, X is likely to require robust Social, Emotional and Mental Health (SEMH) support. He experiences severe separation anxiety, OCD and mood lability (including aggressive outbursts). He also experiences issues with sleep disturbance and misophonia and may well have toileting accidents in school.
- During periods of remission, X is also likely to benefit from SEMH support. This is to support his understanding of his unpredictable condition.
- When in a relapse, it is very likely that attendance will be impacted, and X may be late or unable to attend school at all. His health needs should be prioritised. School and education/health professionals should ensure that they are adopting a collaborative and health informed approach.
- When in a relapse, X may also struggle with his working memory, visual processing, and executive function skills. It is key that staff are aware that his academic trajectory is likely to be atypical, with significant regressions in relapse and huge gains when in remission.

Early warning signs and plan of action

Following illness/trigger, X can very rapidly (within hours) develop multiple symptoms. Some of these early warning signs include toileting accidents, a marked increase in separation anxiety (particularly from Mum) and new onset emotional lability with aggressive/emotional outbursts. Parents/Carers should be promptly informed within the school day.

Summary/Key points

- Inform the school about the child's condition
- Meet to discuss the child's medical support needs
- Agree on the need for an IHCP, and ensure that input from a health professional is included
- Identify School Staff Training needs
- Implement the IHCP and circulate to all relevant parties
- Review the IHCP at least annually or more often as required



Glossary

EHCP- Education and Health Care plan- a plan for children and young people up to 25 who require more support than is available through special educational needs support. EHC plans identify educational, health and social needs and set out additional support to meet those needs.

IHCP- Individual Healthcare Plan- A plan for children with medical conditions to describe the child's care needs and how their needs will be met at school.

SEN- Special Educational needs- used to describe learning difficulties or disabilities that make it harder for a child to learn than most children of the same age

SEN support plan- when an education setting has identified a child with SEN they are required to create a SEN support plan. This might also be called an Individual Education plan or similar.

References

- 1 <https://www.panspandasuk.org/> (accessed 21/07/21)
- 2 Department for Education (2015) Supporting Children at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England.
- 3 Department for Education (2015) Supporting Children at school with medical conditions: Statutory guidance for governing bodies of maintained schools and proprietors of academies in England. (p.10)
- 4 'Evidence from clinician could include evidence taken from a clinic letter'
- 5 <https://www.panspandasuk.org/for-educators> (accessed 21/07/21)
- 6 <https://www.panspandasuk.org/for-medical-professionals> (accessed 21/07/21)
- 7 *'Children/Young people' will thereafter be referred to as 'child/children'
- 8 *'Schools/educational settings' will hereafter be referred to as 'schools'

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