
Individual Health Care Plans for PANS or PANDAS

A guide for parents and carers

PANS AND PANDAS

What are PANS and PANDAS?

PANS Paediatric Acute-onset Neuropsychiatric Syndrome

PANDAS Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections

PANS and **PANDAS** are post infectious autoimmune and/or neuroinflammatory medical conditions that affect both physical and mental health. They can be triggered by common infections (for example strep throat, chickenpox, or influenza). An exacerbation of symptoms is known colloquially as a flare. For more information please visit PANS PANDAS UK!

Charity Number: England - 1178484 | Scotland - SC053206

Contact Us

 www.panspandasuk.org

 info@panspandasuk.org



How do the conditions of PANS and PANDAS affect children and young people?

Children* with PANS and PANDAS can abruptly go from doing well in school to experiencing a range of difficulties. These can include developing obsessive thoughts and compulsions, urinary issues, tics, anxiety, a regression in skills, distressed behaviours, eating issues and problems sleeping. Sometimes children also have sensory issues, hallucinations and thoughts of harming themselves. These issues can fluctuate with symptoms changing a lot over time. Any child with these symptoms should receive a full medical evaluation.

Some children with PANS or 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 and 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** or other 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.

An IHCP is not the same as an Educational, Health and Care Plan (EHCP).

An EHCP is put in place to provide support for special educational needs, whereas the IHCP focuses 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, Health and 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 and PANDAS does have an EHCP, then the requirement for an individual health care plan should be included in their EHCP.

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

**'Schools/educational settings' will hereafter be referred to as schools.

Does my child with PANS and 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. 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 and PANDAS.

A well-written IHCP can provide a clear explanation of the condition of PANS and 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 and PANDAS in a number of ways. A well-written IHCP can provide a clear explanation of the condition of PANS and 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 include a plan for when behaviours and symptoms change in type, duration, or frequency. Providing reassurance for parents/caregivers, the child and school staff as well as ensuring 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 and 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:

- Diagnosis and details of the professional team supporting the child. Individual triggers (as known)
- Signs and symptoms including the impact on education, any social and emotional needs, and the potential impact on attendance.
- Plans that need to be implemented for school trips (including overnight as applicable) and any other extracurricular school activities, outside the usual timetable.
- Awareness that the support required is likely to change over time, and that the IHCP will need to be updated accordingly. At the very minimum the plan should be reviewed once a year, but it is very likely in the case of PANS and 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.
- 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

- Inform the school 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.
- 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.
- 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 professional³ has been included.
- Identify whether there are any school staff training requirements. Has the school accessed any training on the conditions of PANS and PANDAS? If not then please refer them to the PANS PANDAS UK website for further health and education resources.^{4/5}
- Implement the IHCP and circulate to all relevant staff members.
- 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 and PANDAS?

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

What follows is a sample IHCP, designed to provide insight into what a complete IHCP for a child with PANS and 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

Review date

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Additional information

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Diagnosis (or working diagnosis)

Owen has a diagnosis of PANS (Paediatric Autoimmune Neuropsychiatric Disorder) - Diagnosed on 2/02/24 by Dr Blue, Paediatric Neurologist at Edgeway Children's hospital.

PANS is a brain condition which follows a relapsing and remitting course. Owen 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 following an illness or infection. It can then take months of treatment for Owen to return to baseline. Even then residual OCD, memory issues and handwriting issues remain.

Medical professionals and services

Owen is currently under the care of Dr Redmond (Consultant Paediatric Neurologist), Professor Black (Consultant Immunologist), Dr Brown (Paediatrician, and Mauve Green (Child Psychologist at CAMHS)

Triggers

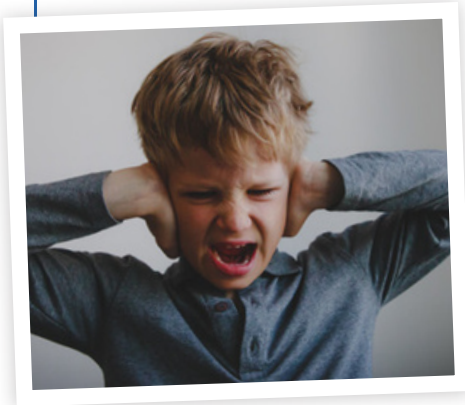
Not all of Owen's triggers are known, however his triggers do include infections and allergies (in particular streptococcal infections) and grass and tree pollen. Parents/carers would like to be notified about the presence of infections (particularly streptococcal infections) within his class/year group 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 |
|---|---|
| <p>Obsessive thoughts and compulsions - these include repetitive thoughts of harm coming to family members, and tapping and counting compulsions. Owen cannot listen and follow instructions in class whilst managing his OCD</p> | <ul style="list-style-type: none"> • All staff to be aware of Owen's obsessive thoughts and compulsions • Report changes to parents/ caregivers • Management of OCD to be guided by health input |
| <p>Inattention and hyperactivity - Owen may display difficulties with focus and concentration. This may present as excessive fidgeting, concentration difficulties and a struggle to remain seated</p> | <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 |
| <p>Separation anxiety - particularly marked from Mum</p> | <ul style="list-style-type: none"> • Flexible starting times • Supported transition periods • Pastoral and Nurture support • Accommodations and adjustments during a flare |
| <p>Sleep disturbance - this can be severe - Owen will appear tired and may well be late for school. Tiredness is known to exacerbate the symptoms of Owen's PANS</p> | <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 • Pastoral support |
| <p>Rapid mood changes, irritability or despair leading to distressed behaviours. Changes in mood state can occur suddenly and without an obvious trigger. Owen is very remorseful and upset following these incidents</p> | <ul style="list-style-type: none"> • Pass to leave the classroom when Owen 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 |
|--|--|
| <p>Urinary frequency including toileting accidents in school. This is often an early warning sign of a PANS flare for Owen. He struggles to inform staff following a toileting accident due to embarrassment</p> | <ul style="list-style-type: none"> • All staff to be aware of Owen's obsessive thoughts and compulsions • Report changes to parents/ caregivers • Management of OCD guided by health input |
| <p>Marked deterioration in handwriting or maths skills</p> <p>This can be an early indicator of a flare</p> | <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 |
| <p>Misophonia- when in a flare. Owen becomes acutely sensitive to sounds. This can include classmates chewing or breathing, or simply the multiple sounds of a busy classroom. Owen 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</p> | <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 Owen uses to mitigate the stress • Understanding from staff that Owen cannot respond to instructions/tasks whilst managing misophonia • 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 Owen

- List all medications or therapies with a brief overview of their function. Include whether the medications are administered at home or at school. with additional details if medications are to be given within a school setting.
- Parents/carers should be aware of their responsibility to update the school/educational setting as required.

What to expect

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

- At baseline, Owen 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 Owen. Outbreaks of illness at school should be reported to parents/carers by telephone.
- When in a severe flare, Owen experiences such debilitating symptoms of OCD that he is often unable to leave the house. He struggles 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 Owen's prescribed medication.
- Any significant changes for Owen regarding handwriting, memory skills and the onset of toileting accidents may signal an impending relapse and should be reported to parents/carers immediately.

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What support is required?

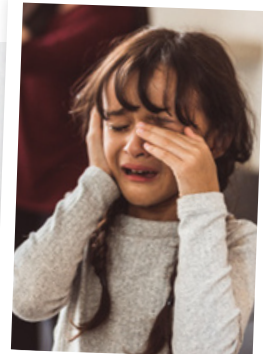
- Support needs to be flexible and responsive to Owen's symptoms.
- When well, Owen requires little additional support and dislikes being seen as different to his peers. He does, however, struggle with attention and organisational skills, sustained difficulties with handwriting and residual OCD which may not be obvious. Staff should therefore be aware that he may require extra prompts and support.
- When in a relapse, Owen is likely to require significant pastoral support. He experiences severe separation anxiety, OCD and mood lability (including distressed outbursts). He also experiences issues with sleep disturbance and sound sensitivity and may well have toileting accidents in school.
- During periods of remission, Owen is also likely to benefit from pastoral 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 Owen 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, Owen may also struggle with his working memory, visual processing, and executive function skills. It is key that staff are aware that his academic progress may fluctuate.

Early warning signs and plan of action

Following exposure to an infection or other trigger, Owen can very rapidly develop multiple symptoms. Some of the early warning signs include toileting accidents, a marked increase in separation anxiety (particularly from Mum) and distressed behaviours. Parents/carers should be promptly informed within the school day.

Summary and 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, Health and 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. www.panspandasuk.org
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. 'Evidence from clinician could include evidence taken from a clinic letter'
4. www.panspandasuk.org/for-educators
5. www.panspandasuk.org/for-medical-professionals

Whilst some of the content may also be relevant across Scotland, Wales and Northern Ireland, this information is based on the Education system for England

Contact Us

-  www.panspandasuk.org
-  info@panspandasuk.org

