

PANDAS/PANS

Frequently Asked Questions (FAQs)

HOW ARE PANS AND PANDAS DEFINED?¹

PANS (Pediatric Acute-onset Neuropsychiatric Syndrome) is a clinical diagnosis given to children who have an abrupt, dramatic onset of neuropsychiatric symptoms including obsessive-compulsive symptoms and/or eating restrictions. These primary symptoms are accompanied by a variety of behavioral, emotional, cognitive, neurological and physical symptoms, which include separation anxiety, irritability, excessive mood swings, depression (sometimes to the point of suicidality), impulsivity, hyperactivity and developmental regression (acting younger than their age). The children may also develop difficulties with sleep and urinary symptoms, such as urgency, frequency and daytime accidents or bed-wetting. When the symptoms of PANS are triggered by a strep infection (such as strep throat or scarlet fever), then the syndrome can be classified as PANDAS (for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal infections). Emerging research suggests that PANDAS is a post infectious autoimmune process.

The cause of the remaining PANS cases is unknown, but likely involves neuroinflammation brought on by a variety of infectious and metabolic factors.

Onset of the illness can be acute and dramatic or episodic. There can also be a pattern of waxing and waning or relapsing and remitting exacerbations of symptoms where at times the symptoms seem to “explode” in severity. Tics can worsen when there is an infection and incapacitate the child to the point of not being able to go to school and/or requiring a visit to the emergency room.

WHAT ARE SOME SIGNS AND SYMPTOMS OF PANS/ PANDAS OTHER THAN OCD AND TICS?²

Diagnostic criteria for PANS:

1. An abrupt, acute, dramatic onset of obsessive-compulsive disorder or severely restricted food intake.
2. Concurrent presence of additional neuropsychiatric symptoms with similarly severe and acute onset from at least 2 of the following categories:
 - anxiety
 - Emotional Lability and/or Depression
 - Irritability, Aggression, and/or Severe Oppositional Behaviors
 - Behavioral (Developmental) Regression
 - Sudden Deterioration in School Performance
 - Motor or Sensory Abnormalities
 - Somatic Signs and Symptoms, including Sleep Disturbances, Enuresis, or Urinary Frequency (such as urgency, frequency and daytime accidents or bed-wetting)
3. Symptoms are not better explained by a known neurologic or medical disorder

Diagnostic Criteria for PANDAS:

1. Presence of OCD and/or tics, particularly multiple, complex or unusual tics
2. Age Requirement (Symptoms of the disorder first become evident between 3 years of age and puberty)
3. Acute onset and episodic (relapsing-remitting) course
4. Association with Group A Streptococcal (GAS) infection
5. Association with Neurological Abnormalities, such as tics, choreiform movements, motoric hyperactivity, and sleep disturbances

WHAT ARE SOME COMMON OCD PRESENTATIONS IN PANDAS/PANS?³

As with other forms of obsessive compulsive disorder (OCD), individuals with PANDAS/ PANS have intrusive thoughts surrounding obsessions and compulsions. These can be about fears of contamination, losing control, concern with exactness or perfection, religious compulsion, unwanted sexual thoughts.

Compulsiveness can be around washing and cleaning, checking things, repeatedly drawing or writing the same things over and over. OCD is diagnosed when obsessions and compulsions interfere with daily functioning and cause distress requiring a visit to the emergency room.

HOW DO CHILDREN GET PANS/PANDAS? IS PANDAS CONTAGIOUS? HOW DO I AVOID GETTING PANDAS?⁴

“The current belief is that children who develop PANS or PANDAS have a genetic predisposition for these syndromes, which are triggered by an environmental stressor, often an infection. With PANS, that trigger is unknown. PANDAS is thought to be triggered by a Streptococcal infection. Blood tests conducted on children with PANS may show signs of inflammation.”

“PANS isn’t contagious, so kids can’t catch it from a classmate. If a contagious infection (like strep throat) triggered someone’s PANS, that illness can be passed from one person to another. But in general, you don’t have to worry about your child developing PANS. Almost all school-age kids get infections and almost all recover with no complications.”

HOW IS A CHILD DIAGNOSED WITH PANS/PANDAS?⁵

As a clinical syndrome, PANS is a diagnosis that describes a set of symptoms which frequently appear together. A clinical diagnosis means that it is based on the signs, symptoms, and medical history of the patient rather than on laboratory tests or medical imaging. Thus, the diagnosis can be made on the basis of the child’s symptom presentation. However, that does not determine the cause of the symptoms, nor does it determine an appropriate course of treatment. To do that, clinicians must perform a physical examination and order laboratory studies to rule-out other known causes of neuropsychiatric symptoms.

To make a diagnosis of PANDAS, it is necessary to document a close exposure to/or infection with Group A streptococcal bacteria (the bacteria that causes strep throat and scarlet fever.) This can be done by obtaining a throat swab and sending it for overnight culture and/or by a blood test which will demonstrate a rise in anti-streptococcal titers (ASO and anti-DNase B). Rapid strep tests can be inconclusive, ask for a strep culture if the rapid strep is negative. Because the strep that causes PANDAS often is “silent” and produces few or no symptoms of a sore throat, ask for a throat culture. Perianal culture may also be appropriate. Additional tests will be determined by the child’s presenting symptoms (for example, if a child has a persistent cough, tests for mycoplasma pneumonia might be done.) Guidelines to the complete PANS/PANDAS work-up can be found in the Journal of Child and Adolescent Psychopharmacology Jan/Feb 2015.

If the rapid strep is negative, ask for a strep culture. If any of these tests are positive, the child needs to be put on antibiotics for strep. If strep is negative, the child should have blood tests for strep. If the child has had or been exposed to an illness with prolonged coughing, then your pediatrician may consider testing for a bacteria called mycoplasma.”

WHAT TREATMENTS ARE COMMONLY USED FOR PANS/PANDAS?⁶

Treatment of PANS/PANDAS is three-fold:

- Remove the SOURCE of the symptoms by using antibiotics to eradicate infection
- Return the immune SYSTEM to normal functioning with immunomodulatory therapies, such as non-steroidal anti-inflammatory medications (e.g., ibuprofen, naproxen), steroids, IVIG or in extremely severe cases, plasmapheresis
- Reduce the child's SYMPTOMS with standard psychological treatments, such as antidepressants, anti-anxiety medications or SSRIs and behavioral therapy for OCD symptoms

The choice of treatments depends on the severity of the child's symptom and the degree of dysfunction the child is experiencing. The PANDA Physicians Network provides summary guidelines for treatment of "mild", "moderate" and "severe" illness. Ideally, these treatments would be administered by a multi-disciplinary team with experience in management of inflammatory brain diseases.

PANS/PANDAS treatment is so complex it often requires collaboration with a multi-disciplinary team.

HOW DOES PANS AND PANDAS AFFECT A CHILD'S SCHOOL PERFORMANCE?⁷

If you suspect or have a diagnosis of PANS/PANDAS, begin to gather samples of handwriting and school performance with dates cross-referenced to dates of illness. You may see a decline in math and/or reading skills, handwriting regression, school refusal, executive function problems, processing delays, and short-term memory issues. If a decline in school performance is a problem, then you may need to consider an Individualized Education Plan ("IEP") or a "504 plan" to ensure your child is provided necessary accommodations so that they can access an appropriate education. Both plans are provided under Federal US Department of education regulations, 34 C.F.R. Part 104. For these accommodations, you will need to approach your child's teacher and school administration to request a meeting to discuss educational accommodations for your child in the classroom setting.

It is possible to have a decline in cognitive function – specifically writing and mathematics and changes in processing speed. Keeping dated handwriting samples often is important. While symptomatic, it is difficult for a child to focus or improve their work in these areas. Reducing the required homework in these fields during symptomatic times is important while knowing that the parent/teacher can work to make up the lost time/education once symptoms have reduced.

HOW DO I ADJUST MY EXPECTATIONS OF MY CHILD'S BEHAVIORS/SCHOOL PERFORMANCE?⁸

A. Medical and Longer-Term Expectations:

1. PANS OCD has a relapsing remitting course. Most children will experience at least one recurrence of symptom onset due to a PANS trigger. Parents need to understand there is no "quick fix".
2. With PANS OCD, the course is relapsing-remitting, with dramatic, abrupt exacerbations of OCD and ancillary PANS symptoms.
3. Unlike traditional OCD, some studies have shown improvement in neuropsychiatric symptoms in patients with PANDAS after 2–6 weeks of antibiotic treatment. It is unclear if these improvements are from treatment of a latent infection or from some other non-microbial effects.
4. Residual OCD may persist despite any treatment of infection, inflammation, CBT, or medications. In the 1999 study using aggressive immunomodulatory treatment, patients improved on average 45%. Cognitive-behavior therapy (specifically exposure with response prevention) can be helpful in eradicating symptoms of PANS. Anti-obsessional medications can also be used in combination with CBT but studies indicate to "start low and go slow."

B. Home and School Expectations:

1. PANS OCD is OCD. Family education and support is critical, particularly in the early stages of illness. Providing material on treating and managing childhood OCD is an important step.
2. Communication with the school will help alleviate stress and establish a better understanding between faculty and student. Parents may request to be informed of documented strep within the classroom and ensure that teachers are following good hygiene practices. Clinicians and parents might also volunteer to provide an

informative lecture to class, parents, and teachers, and/or request a 504 Plan, IEP, or Student Success Team (“SST”).

C. Suggestions for parents:

1. Build a team of medical professionals for your child that you trust. It is common for a symptomatic child to need collaboration from a pediatrician, immunologist, neurologist, and child psychiatrist/child psychologist to manage symptoms. The treatment options and guidelines for care are evolving; research to find specialists through Pandas Network/PPN or through online support groups if necessary.
2. Find a support group, along with accepting help from family and friends. There are many online support groups across the country for families and caregivers.
3. Make a medical journal for your child. Document each and every appointment. Ask for copies of the doctor notes and test results. If possible, go back and request all medical records for your child, including growth charts and dental procedures, since birth. It can help to document any past illnesses /procedures. Build a timeline for your child and note every major illness or milestone. Bring your journal to every appointment.
4. Be careful and diligent of germs, especially when traveling or going to the dentist. Avoid water fountains, when possible. If your child is having a dental procedure (other than a regular cleaning), request an antibiotic prior to the procedure. Strep is known as a common trigger, but it is not the only illness that will cause symptoms to re-occur.
5. Be transparent regarding your concerns with your doctor’s, school personnel and your employer. Consider reassessing expectations and be patient with your child (and yourself) during this period.

SOURCES:

¹ PANDAS Physicians Network Diagnostic Guidelines

<https://www.pandasppn.org/ppn-pandas-diagnostic-guidelines/>

<https://www.pandasppn.org/ppn-pans-diagnostic-guidelines/>

Stanford Medicine

<https://med.stanford.edu/pans.html>

Stanford Children’s Health

<https://healthier.stanfordchildrens.org/en/q-sudden-symptoms-first-sign-pans-pandas/>

Southeastern PANS/PANDAS Association

www.sepans.org

<https://www.sepans.org/education-packets>

² PANDAS Physicians Network

<https://www.pandasppn.org/ppn-pans-diagnostic-guidelines/>

<https://www.pandasppn.org/ppn-pandas-diagnostic-guidelines/>

³ International OCD Foundation

<https://iocdf.org/about-ocd/>

Beyond OCD

<http://beyondocd.org/information-for-parents>

<http://beyondocd.org/ocd-facts/what-is-ocd>

⁴ Stanford Children’s Health

<https://healthier.stanfordchildrens.org/en/q-sudden-symptoms-first-sign-pans-pandas/>

KidsHealth from Nemours

<https://kidshealth.org/en/parents/pandas.html>

⁵ Susan E. Swedo, M.D., Scientist Emerita, National Institute of Mental Health, National Institutes of Health Intramural Research Program

Clinical Evaluation of Youth with Pediatric Acute Onset Neuropsychiatric Syndrome (PANS): Recommendations from the 2013 PANS Consensus Conference

<https://www.liebertpub.com/doi/full/10.1089/cap.2014.0084>

⁶ Susan E. Swedo, M.D., Scientist Emerita, National Institute of Mental Health, National Institutes of Health Intramural Research Program

Overview of Treatment of Pediatric Acute-Onset Neuropsychiatric Syndrome

<https://www.liebertpub.com/doi/full/10.1089/cap.2017.0042>

Clinical Management of PANS: Part I—Psychiatric and Behavioral Interventions

<https://www.liebertpub.com/doi/full/10.1089/cap.2016.0145>

Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part II—Use of Immunomodulatory Therapies

<https://www.liebertpub.com/doi/full/10.1089/cap.2016.0148>

Clinical Management of Pediatric Acute-Onset Neuropsychiatric Syndrome: Part III—Treatment and Prevention of Infections

<https://www.liebertpub.com/doi/full/10.1089/cap.2016.0151>

⁷ Wright’s Law Special Education Advocacy Site

<https://www.wrightslaw.com/>

Immune Deficiency Foundation

<https://primaryimmune.org/wp-content/uploads/2015/01/IDF-School-Guide-3rd-Edition-2015-FINAL.pdf>

⁸ PANDAS Physicians Network

<https://www.pandasppn.org/seeingyourfirstchild/>

For additional information, please reference the following resources:

PANDAS/PANS Parent Handout

PANDAS/PANS School Systems Handout