



Parents Guide to PANS and PANDAS

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PANS and PANDAS are severe forms of obsessive-compulsive disorder (OCD) that appear suddenly (acute onset) in young children, accompanied by other confusing and distressing symptoms. This guide explains how to recognize PANS and PANDAS, how they're diagnosed and what the recommended treatments are.



What Is Acute Onset OCD?

For most children with OCD, symptoms come on gradually. At first a child is often able to hide both his fears and the rituals he develops to calm them. Eventually the fears become too overwhelming, and the rituals too time consuming, to conceal from parents.

But there is another kind of OCD in which full-blown symptoms come on virtually overnight, accompanied by other symptoms including tics, eating restriction, rage, depression and even suicidality — in children as young as three or four.

“Parents, with great reluctance, talk about their child being possessed, either by a demon or by aliens,” says Dr. Susan Swedo, a pediatrician who has been studying the syndrome for decades.

What Are PANS and PANDAS?

When children suddenly develop full-blown OCD and these associated symptoms, it may be what's called PANS — pediatric acute-onset neuropsychiatric syndrome. It's called “acute onset” because the behavior changes come on suddenly, reaching full-scale intensity within 24 to 48 hours. It's a syndrome because there are quite a few other symptoms that appear alongside the intense anxiety.

If the onset of these symptoms is linked to a strep infection, it's called PANDAS — pediatric autoimmune neuropsychiatric disorder associated with streptococcal infections — which is a subgroup of PANS. Some 86 percent of acute onset OCD cases are linked to strep. Children especially at risk are those who have what doctors call “occult” or hidden strep infections — that is, children who can be “carriers” of the infection but don't get symptoms themselves, and hence don't get treatment.

PANS cases have also been linked to other infections, including Lyme disease, mononucleosis, mycoplasma (walking pneumonia) and the flu (such as H1N1).

PANS and PANDAS are episodic disorders. Symptoms may disappear for extended periods then reappear, stimulated by a later exposure to strep or some other bacteria or virus. Symptoms may get increasingly severe with multiple recurrences.

Controversy Over Causes

While this syndrome has been recognized for decades, the link between the symptoms and an infection has been the subject of intense controversy, with some researchers and clinicians claiming insufficient evidence, and denying children treatment to fight the sometimes elusive infection.

But the medical community has coalesced around a clearer description of the symptoms, their causes and how they should be treated. This should make it easier for parents to get care for severely affected children.

Dr. Swedo, who heads the pediatrics and developmental neuroscience branch of the National Institute of Mental Health, first identified PANDAS in 1998, and has been in the vanguard of research and advocacy ever since. The larger category, PANS, was added in 2010 to account for cases that could not be linked definitively to strep infections.

There is now broad acceptance that PANDAS is, like rheumatic fever, a misdirected immune response to the strep bacteria, which mimics human heart or brain tissue. The immune system attacks the heart (in the case of rheumatic fever) or brain (in the case of PANDAS), causing this array of mental health symptoms.

What Does PANS Look Like in Children?

“What this is *not* is garden variety OCD, Tourette’s, ADHD, conduct disorder — anything else,” explains Dr. Swedo. “We’re talking about a six-year-old, seven-year-old, maybe as young as three or four, who undergoes an *acute* behavioral change, a very, very dramatic onset.”

Acute onset OCD might take the form of a child suddenly asking for constant reassurance, or engaging in endless handwashing. Many children with PANS become obsessive about food, severely restricting what they will eat because of acute fears of contamination, choking or vomiting. This can develop into anorexia, and can result in extreme weight loss, necessitating hospitalization and the use of a feeding tube.

Separation anxiety can also appear suddenly, sometimes so overwhelming that a 10-year-old, or even a 14-year-old suddenly has to start sleeping with his mother. And panic attacks are common. “In those first few days, the child is in a state of near-constant panic,” Dr. Swedo adds. “These changes are not subtle.”



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What Are the Criteria for a PANS Diagnosis?

All children with the disorder have acute onset of OCD symptoms or eating restrictions. But they also have a debilitating and baffling set of other neurological symptoms with similarly sudden onset. To be diagnosed with PANS they must have two of the following seven criteria:

- Separation anxiety, panic, other forms of anxiety
- Behavioral regression: Kids suddenly acting much younger than they should for their age, such as reverting to baby talk
- Emotional lability: These children can be severely depressed, even suicidal
- Irritability, aggression and severely oppositional behaviors
- Deterioration in school performance: Sudden decline in math and reading competence, memory and concentration; increase in hyperactivity
- Motor or sensory abnormalities: Their handwriting and drawing deteriorates dramatically (also linked to regression), and they may be distressed by noise or light
- Somatic symptoms: These include sleep disturbances, bedwetting and other changes in urinary frequency or intensity



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What Should You Do if You Think Your Child Has PANS?

Parents' first stop when they experience such a dramatic behavior change is usually the pediatrician, or in extreme cases, the emergency room, Dr. Swedo notes. She recommends that you refrain from insisting to the doctor that your child has PANS, and bringing along articles on the disorder as backup, since medical professionals tend to be skeptical of a parental rush to diagnosis.

The best way to present this, she says, is: "I'm really worried about my child's brain. There's been an abrupt change in his behavior. This is what I've seen at home. It's completely out of character." The goal, as she puts it, is to partner with the doctor in terms of *let's figure it out together*. PANS is one possible explanation for the sudden changes in behavior, but your physician will want to consider others as well.

In the past, pediatricians and other doctors have often dismissed families describing acute onset OCD, Dr. Swedo said, assuming that parents must have missed earlier, less severe symptoms. But PANS and PANDAS should now be much more widely recognized.

It's also good to check with your child's teacher or school to see if strep has been going around. A child doesn't have to have symptoms of strep to have an infection — some kids never get symptomatic.

What Should You Expect Your Doctor to Do?

If a child has urinary symptoms, Dr. Swedo recommends urinalysis and urine culture. She recommends a throat culture to look for strep, and an exam to see if an occult, or hidden, strep infection is observable.

If the rapid strep test is positive, she recommends a three-week course of antibiotics, to aggressively treat a possible sinus infection. Sinusitis is the trigger of symptoms for many kids, she says.

And Dr. Swedo also recommends that the pediatrician schedule a follow-up visit for three days later, to check in with the family. “The family stress is through the roof with this syndrome — by some measures higher than kids who’ve been diagnosed with leukemia,” she notes. “So a physician treating the medical causes should also make a referral, immediately, to a psychologist or psychiatrist — whatever is available in your area.”

Many children respond within the first week of the antibiotic treatment. The longer the symptoms have been active before the child starts treatment, the longer the response may take. If the symptoms disappear, you finish the course of antibiotics and then practice what Dr. Swedo calls “watchful waiting.” Some kids, however, don’t respond to the antibiotic treatment alone. And many will have later episodes when symptoms recur, triggered by another infection.

What Is the Treatment for Subsequent Episodes?

Treatment for recurrences of PANDAS involves targeting what Dr. Swedo calls the three S’s: “the symptoms, the source and the system.”

- The treatment for the symptoms — OCD and other forms of severe anxiety — is cognitive behavioral therapy (specifically, exposure and response prevention) and anti-depressant (also called anti-obsessional) medication, a selective serotonin reuptake inhibitor or SSRI. These treatments have been shown to be effective in reducing the symptoms, but they do not target the source of the problem.
- The treatment for the source — the infection — is another course of antibiotics.
- The system refers to the immune system, which is attacking the brain and generating these neuropsychiatric symptoms. The first-line treatment for the misfiring immune system is with IVIG, or intravenous immunoglobulin. IVIG is made from healthy blood plasma and is thought to balance the immune system. IVIG is recommended only for severe cases in which repeated courses of antibiotics combined with CBT and SSRIs were not successful in stopping the flare-up of symptoms.

— If IVIG, in turn, is not successful, children are treated with plasmapheresis (the removal, filtering and return of blood plasma). A review of 40 patients treated with plasmapheresis, published last year, showed an average improvement of 65% at 6 months following treatment, and 78% at longer-term follow-up.

Additional Resource:

- childmind.org/parents-guide-getting-good-care

Dr. Swedo notes that these three targets for treatment — symptoms, source and system — are exactly the same as if you were treating a child with asthmatic childhood pneumonia. “You treat the source — this is the pneumonia part — with antibiotics. You treat the symptoms with cough syrup — you don’t ask the child to cough for the next month, until the pneumonia resolves. And you treat the immune system with the inhaled steroid, the Singulair and all the rest.”

Long-term Antibiotics to Prevent Recurrence

Children who have had a recurrence of PANDAS are often given antibiotics for an extended period as a form of prevention, or prophylaxis, for recurring strep infections. Strep is so common in the school population that it is now recommended that prophylaxis continue until patients are about 21, Dr. Swedo says. “You want to get them through college, boot camp — places where they’re going to have high exposure to things like mono and strep.” Research shows that antibiotic prophylaxis can reduce significantly the number of episodes of PANDAS symptoms a child experiences.

Unfortunately, even the strep prophylaxis won’t prevent *all* later episodes of PANDAS symptoms because the immune system, once primed, continues to react dangerously to other kinds of infections as well, misidentifying the brain as foreign, and generating symptoms.

“But by preventing the strep,” Dr. Swedo notes, “you prevent over three quarters of those episodes, and you get them down to the point where the symptoms can be controlled with traditional anti-depressant medications and CBT.”



The Child Mind Institute is an independent nonprofit dedicated to transforming the lives of children and families struggling with mental health and learning disorders. Our teams work every day to deliver the highest standards of care, advance the science of the developing brain, and empower parents, professionals and policymakers to support children when and where they need it most. Together with our supporters, we’re helping children reach their full potential in school and in life. We share all of our resources freely and do not accept any funding from the pharmaceutical industry. Learn more at childmind.org.