

Supporting & Accommodating PANS/PANDAS at School

Student needs and performance can vary widely from week to week and even day-to-day

What is PANS/PANDAS?

PANS/PANDAS is an impairing medical condition that occurs after exposure to a trigger such as strep, Lyme or mold when the body creates a misdirected immune response that inflames the child's brain. PANS/PANDAS creates impairing consequences for an estimated 1 in 250 children in the United States and can include severe forms of obsessive-compulsive disorder, anxiety, rage/aggression, learning impairment, and suicide. PANS/PANDAS is treated with antibiotics, immune therapies, and Cognitive Behavioral Therapy once medical symptoms have stabilized. The long-term prognosis is not fully understood, but in acute cases with encephalitic reaction symptoms can last for at least several years.

Symptoms at School

Children with PANS/PANDAS are often very sick and school is highly challenging. Parents report some, but not all, of the biggest challenges:

Academic

- 70% experience reading or writing regression
- 41% experience math regression
- 25% are unable to complete standardized testing from start-to-finish

Neuropsychiatric

- 79% have OCD that interferes with the ability function in one or more areas
- 66% experience debilitating anxiety
- 59% suffer from extreme sensory sensitivity

Interventional

- 40% have episodes of rage/aggression that require sequestration
- 28% have harmed themselves or others at school

Attendance

- 58% are unable to attend school at all and/or are home schooled
- 28% attend school with material interruptions in attendance
- 14% attend school full time with no unusual lapses in attendance

Supports & Accommodations

There are no set guidelines for supports or accommodations of PANS/PANDAS. Parents report some, but not all, of the resources their children have in place and find helpful:

Resource level

- 52% have an IEP
- 42% have a 504
- 6% have no formal resourcing in place

Helpful supports & accommodations

- Ability to take breaks
- Excused absences
- Provision of tutors and specialists (e.g., occupational, physical, vision therapy)
- Testing and homework accommodations
- Plan for acute symptom exacerbations, including the use of "safe spaces"
- Academic accommodations (e.g., keyboard, recording device, calculator)

Helpful Tips

- Symptoms are medical, not behavioral
- A flexible approach and open-mind are keys to success
- Effective team and parent communication can make or break a child's success at school
- Children often lose skills during symptom exacerbation which can be addressed by adaptation during the flare, followed by remediation during remission
- Caregiver burden can be overwhelming. Many PANS/PANDAS families are in crisis with high levels of emotional and financial strain. Siblings are commonly impacted by these stresses and may benefit from school guidance services.

For more information contact
PRAkids.org or
contact@praikids.org

Sources:

Swedo S, Leckman J, and Rose, N: From research subgroup to clinical syndrome: Modifying the PANDAS criteria to describe PANS (Pediatric Acute-Onset Neuropsychiatric Syndrome). *Pediatrics and Therapeutics* 2, 2012. doi: 10.4172/2161-0665.1000113; AND PRAI informal online survey of parents and caregivers of children with PANS/PANDAS, 2019.