

PANDAS/PANS School Systems Handout

WHAT ARE PANDAS AND PANS?

PANDAS is an abbreviation for Pediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. The term was first used in 1998 to describe a subset of children and adolescents who have obsessive compulsive disorder (OCD - worries or intrusive, illogical thoughts and/or repetitive behaviors) and/or tic disorders, and in whom symptoms worsen following strep infections such as strep throat or scarlet fever. The PANDAS subgroup is part of a larger cohort of children whose symptom onset is unusually abrupt and dramatic, or Pediatric Acute-onset Neuropsychiatric Syndrome (PANS). PANS is characterized by an unusually abrupt onset of OCD or eating restrictions.

SYMPTOMS:

Children diagnosed with PANDAS/PANS can have significantly different symptoms – making diagnosis difficult and specialized treatment common. PANS may occur in children with neurodevelopmental disorders, including autism, and would have similarly abrupt onset. These children will have a combination of some of these symptoms:

1. Anxiety (especially worries about being separated from familiar people or places)
2. Developmental regression (acting much younger than actual age or losing milestones)
3. Extreme mood swings and/or depression (sometimes to the point of suicidal thoughts or attempts)
4. Personality changes, including irritability, aggression or oppositional behaviors
5. Deterioration in school performance due to ADHD-like symptoms of impulsivity, hyperactivity and concentration difficulties; new onset of difficulties with math or reading, deterioration of handwriting or drawing skills, and poor memory
6. Abnormal movements (motor tics, such as eye-blinking, shoulder shrugs, or vocalizations), sensory abnormalities (including new sensitivities to light, sound or textures)
7. Other signs and symptoms, including sleep disturbances, urinary urgency or frequency or new onset of bed-wetting and daytime accidents

As each child's symptoms can vary greatly, it is important to give specific focus to each individual child's needs. A meeting with the parents/guardians and all teachers, advisors, and school personnel that are able to attend is imperative prior to the school year or as soon as symptoms appear/re-occur. Make a specialized plan (IEP/504) to meet the child's changing academic needs, understanding the child's most common symptoms as described below:

1. **Presence of OCD or tics (motor and verbal):** A child may be scared of vomit/germs/illness. Be cognizant when selecting classmates at the beginning of the school year. Allow students with these symptoms to keep their own water bottle/supplies, if needed. Tics are common; helping these children to find an ideal/safe spot in the classroom is important.
2. **Acute onset and episodic (relapsing/remitting) course:** Be wary of any significant changes in a student and make sure to communicate with the parent/guardian of any noticeable changes in the classroom/school. Children can go through long periods of time with little to no symptoms – but re-occurrence is common and symptoms can appear quickly.
3. **Restrictive eating:** Children who drastically reduce their food intake may need to be watched carefully at lunch and snack times. Since some children will only eat certain foods, it is important to allow that some of these be brought to school when necessary. Do not force a child to eat but do let the parents know what you are observing.

4. **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, knowing that the parent/teacher can work to make up the lost time/education once symptoms have reduced.
5. **Anxiety, separation anxiety, sleep disturbances, bed wetting, daytime wetting, depression:** Many children have anxiety focused on getting to and staying in school. Their home is usually their 'safe' space and leaving their home/parent to go to school – where many of their fears/symptoms are evident – is overwhelming. Creating a 'safe' space in the school is important. Allow the child to leave the classroom when necessary/safe to do so.

FURTHER SUGGESTIONS:

Making as many individualized preparations as possible will aid in the care of these children while at school, allowing them to stay in school and further their education. Here are further suggestions:

- ▶ For the child scared to stay in school, have them make their own daily plan – along with a teacher - to guide themselves through the day and cut the day into smaller increments. Allow them a reward at each increment – a call to a parent at a specific time, a spot next to the teacher, a trip to a safe space, etc., to help them make it to the next milestone.
- ▶ A 'safe' space can be created, away from the nurse, (fear of illness can be heightened in the nurse's area where other sick children may be) within the school. This space will allow a child in the midst of their symptoms a space where other students cannot witness their actions.
- ▶ A parent/guardian can make a reward box (stickers, notes from home, pictures, art supplies, etc.) to place in a safe space. Depending on the age of the child, they may use the stickers/rewards as an incentive to return to class to pass out the stickers or the teacher can use them to help keep a child in class.
- ▶ Reduce the homework load for a child who is symptomatic. If a child can stay at school, their behavior/temperament once they get home can decline rapidly. Homebound instruction may need to be considered.
- ▶ The necessary doctor's appointments and therapy appointments can be frequent with times that usually are not flexible in regards to the school day. Work with the parent/guardian on the missed lessons/ schoolwork – usually they, too, are missing work to get their child the care they need.
- ▶ When possible, place a sympathetic friend in the child's class. Having a friend nearby to assist the child/teacher/ school personnel is positive and helps to keep the child in school and avoid setbacks.
- ▶ Provide extra clothing.

RECOMMENDED EDUCATION BOOKS:

PANDAS and PANS in School Settings: A Handbook for Educators by Patricia Rice Doran

PANS, CANS, and Automobiles: A Comprehensive Reference Guide for Helping Students with PANDAS and PANS by Jamie Candelaria Greene

For additional information, please reference the following resources:

PANDAS/PANS Parent Handout

PANDAS/PANS Frequently Asked Questions (FAQs)