

# Communicate, Collaborate & Advocate

## Communicate and Collaborate with the Family

- **Regular Updates:** Keep an open line of communication with the family, providing regular updates on the child's progress and any concerns that arise.
- **Collaborate on Strategies:** Work together with the family to implement strategies that are effective at home and in school. Consistency between home and school can be beneficial.
- **Involve the Family in Decision-Making:** Involve parents or caregivers in meetings and decisions regarding the child's educational plan and accommodations.

## Advocate for the Child

- **Promote Inclusion:** Encourage inclusive practices that allow the child to participate in all school activities to the fullest extent possible.
- **Support the Family's Advocacy Efforts:** Help the family navigate the school system and advocate for the necessary services and accommodations.

By implementing these strategies, schools can create a nurturing environment that supports both the child with PANS/PANDAS and their family, helping them manage the challenges while promoting academic and emotional growth.



## Plan for Transitions

- **Prepare for Changes:** Help the child prepare for transitions, such as moving from one grade to another, by providing clear expectations and gradual introductions to new environments or teachers.
- **Develop a Transition Plan:** For significant changes, such as moving to a new school, create a transition plan that includes visits to the new setting, meetings with new staff, and discussions on how to continue support.

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## PANS/PANDAS Information for Educators

**PANDAS** Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

**PANS** Pediatric Acute-onset Neuropsychiatric Syndrome

### What are PANS and PANDAS?

In PANDAS, the immune system mistakenly attacks the brain after a Strep infection. PANS is a broader term that includes cases triggered not just by Strep but also by other infections, toxins, or stress.

### Diagnostic Criteria for PANS

PANDAS: OCD and/or tics

PANS: OCD and/or eating restrictions

Includes at least two of the following symptoms:

- Anxiety or separation anxiety
- Emotional lability or depression
- Irritability, aggression, or severe oppositional behaviors
- Behavioural regression or developmental setbacks
- Decline in school performance
- Motor or sensory abnormalities
- Somatic symptoms such as sleep disturbances, enuresis, or frequent urination

### Age of Onset

Originally, PANDAS was thought to start between ages 3 and 13, but we now know that PANS and PANDAS can also begin in older teens and adults. The average age of onset is 7.5 years, with boys being twice as likely to be affected as girls.

PANS and PANDAS are complex. Learn about the condition and share information with colleagues.

### Sudden Onset (Sometimes Gradual)

Surveys of parents and physicians show that 88% of cases have a sudden onset, with symptoms escalating within three days. In some cases, the onset is more gradual.

### Relapsing & Remitting

Offer flexible accommodations that support the child through all phases of the condition—when they're acutely ill, during recovery, and once they're well.

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# Spotting the Early Signs

Spotting early signs of PANS or PANDAS in a school setting involves being aware of sudden and significant changes in a student's behaviour, emotions, or academic performance. Here are key indicators:

## Behavioural and Emotional Changes

- **Sudden Onset of OCD or Anxiety:** Look for new, intense obsessive-compulsive behaviours or extreme anxiety that seems to appear overnight.
- **Mood Swings:** Rapid, uncharacteristic shifts in mood, including irritability, aggression, or emotional outbursts.
- **Separation Anxiety:** A previously independent child may suddenly become fearful of being away from parents or caregivers.
- **Cognitive challenges:** Impulsivity, forgetfulness, and confusion.
- **Sensory issues:** Sensitivity to clothing, sound, and light can be significant.

## Academic Performance

- **Decline in Schoolwork:** A noticeable drop in grades, difficulty concentrating, and worsening handwriting, spelling, or math skills, which can happen abruptly.
- **Behavioural Regression:** Reverting to behaviours typical of a younger age, such as baby talk, clinginess, or fear of previously manageable situations.

## Physical Symptoms

- **Tics or Motor Abnormalities:** Sudden onset of tics, unusual movements, or changes in handwriting.
- **Somatic Complaints:** Frequent headaches, stomachaches, or other unexplained physical symptoms.

## Social Interaction

- **Withdrawal or Isolation:** A child who was previously social may begin to withdraw from friends or avoid social situations.

## Classroom Behaviour

- **Oppositional Behaviours:** Increased defiance, refusal to follow instructions, or difficulty managing emotions in the classroom setting.



If these signs appear suddenly and are out of character for the student, it's important to communicate with the child's parents or caregivers and suggest they seek a medical evaluation. Early identification and intervention are crucial for managing PANS PANDAS.

# Supporting the Child and Family

Supporting a child with PANS or PANDAS and their family in the school setting requires a collaborative approach that addresses both the educational and emotional needs of the student. Here are some strategies:

## Create a Supportive Environment

- **Foster Understanding and Awareness:** Educate teachers, staff, and classmates about PANS PANDAS to reduce stigma and build empathy. Understanding that these conditions can cause sudden behavioural changes can help create a more supportive atmosphere.
- **Build a Team:** Assemble a team that includes teachers, school counsellors, administrators, the school nurse, and the family to regularly discuss the student's needs and progress.
- **Designate a Safe Space:** Provide a designated quiet area or "safe space" where the child can go when feeling overwhelmed or needing a break from sensory or emotional stressors.

Build a relationship with the child so they feel safe to communicate.

## Address Emotional and Behavioural Needs

- **Implement Behavioural Supports:** Use positive reinforcement strategies and consistent routines to help manage behaviour. Avoid punitive measures for behaviours that are symptomatic of PANS PANDAS.
- **Provide Counselling Services:** Offer access to school counselling services to help the child cope with anxiety, OCD, or emotional challenges.
- **Peer Support and Social Skills Training:** Facilitate peer support groups or social skills training to help the child maintain friendships and social interactions.



## Tailor Educational Plans

- **Develop an IEP Individualized Education Plan (SEP, IPP, SSP, ISSP depending on the province or territory):** Work with the family to create a plan that outlines specific accommodations such as extended time on tests, reduced homework load, or modified classroom expectations.
- **Flexible Attendance and Deadlines:** Allow flexibility with attendance, deadlines, and workload during flare-ups. Consider offering remote learning options if the child is unable to attend school.
- **Adjust Classroom Demands:** Simplify tasks, provide clear instructions, and offer additional support as needed. Consider reducing sensory stimuli in the classroom, such as bright lights or loud noises.