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Pediatric Acute Onset Neuropsychiatric Syndrome (PANS) and Pediatric and Neurologic Disorders Associated with Streptococcus (PANDAS): Information for Families



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Summary: Paediatric acute-onset neuropsychiatric syndrome (PANS) is a condition marked by the sudden and dramatic onset of symptoms such as obsessive-compulsive disorder (OCD), and restricted eating. Other symptoms may include problems with mood, anxiety, concentration, tics, and loss of the ability to function at home or school.

Pediatric and neurologic disorders associated with streptococcus (PANDAS) is a similar condition where following a strep infection, children and youth may develop sudden onset of OCD symptoms.

What are PANS and PANDAS?

PANS and PANDAS are conditions where people can have sudden, dramatic onset of the following

Classic symptoms:

• Obsessive-compulsive disorder (OCD)	• Obsessions: Distressing worries, e.g. worries about being contaminated. • Compulsions: Repetitive habits, e.g. having to wash repeatedly.
• Severely restricted food intake	• Losing interest in food or drink to the point of losing weight, needing reminders to eat.

Other associated symptoms may include at least 2 of the following:

• Mood	• Anxiety, including separation anxiety; fears about food, eating or choking, or selective mutism (talking much less). • Depression, moodiness and mood swings (e.g. switching between laughing or crying out loud.) • Irritability, temper tantrums.
• Cognitive	• Troubles with school or work due to troubles with memory, reading, or math.
• Sensory sensitivities	• New or worsening sensitivity to light, sound or touch (e.g. troubles with wearing certain clothing textures).
• Motor coordination troubles	• Troubles with fine motor (such as losing their ability to write) or gross motor (becoming clumsy).
• Sleep problems	• Troubles falling asleep or staying asleep.
• Urinary problems	• Needing to urinate more often (aka urinary frequency) • Bedwetting (aka enuresis)
• Psychosis	• Seeing things that others do not see or hearing things that others do not hear.
• Behaviour	• Aggression, or strongly oppositional behaviour • ADHD symptoms (problems with being inattentive, hyperactive, distractible, fidgety) • Regression (development), e.g. talking like a younger child, becoming more clingy, more fears at bedtime, separation fears, bedwetting.

Symptoms gradually improve but can come back suddenly.

What is Sudden?

The symptoms of PANS or PANDAS appear extremely quickly within 2-3 days. In some cases, parents describe that their child went to bed their usual self and woke up completely changed -- “it was like someone replaced my child.”

What Causes PANS and PANDAS?

PANS can occur at any age. The cause is unclear. Some experts believe it to be due to an autoimmune reaction following an infection.

PANDAS is a specific type of PANS where

- The first episode of symptoms occurs in childhood, usually at age three and up.
- The auto-immune reaction is felt due to Group A Streptococcal (GAS) infection.

Is it PANS or PANDAS?

	PANS	PANDAS
What are the symptoms?	Sudden onset of • Obsessive-compulsive disorder (OCD) symptoms, or • Severely restricted food intake.	Sudden onset of • Obsessive-compulsive disorder (OCD) symptoms May also have similar symptoms as PANS.
At what age does it occur?	At any age	First episode occurs in children and youth.

What causes it?	Possibly due to inflammatory reaction as a result of infection but further research is required.	Presumed to be an Auto-immune reaction following group A streptococcal (GAS) infection.

Do You Suspect PANS or PANDAS?

Start by seeing a health professional such as your family physician or pediatrician.

How are PANS / PANDAS treated?

Treatment for PANS / PANDAS is still in its early stages.

There is still insufficient research to conclusively recommend any specific treatments apart from the usual therapies for OCD or restricted eating.

For OCD symptoms, treatments might include:

1) Cognitive behavioural therapy (CBT)

CBT is a standard treatment for OCD and appears to be helpful whether or not someone has OCD from PANDAS, or not.

Strategies used in CBT include

- Exposure, which is exposing one to the feared situation, e.g. touching something dirty.
- Response prevention, which is avoiding or delaying doing the compulsive behaviour, e.g. needing to wash one's hands after touching something.
- Exposure/response prevention is done step-by-step. One starts with simple goals, working up to harder ones. For example, if there is an urge to wash one's hands, one starts by avoiding the urge to wash one's hands for 10 seconds before giving in. The next time, the time before washing is gradually increased to longer and longer times (e.g. 20 seconds, 30 seconds, 1 minute, 5 minutes, etc.) Eventually, it gets to the point where one is delaying the urge so long, that essentially the compulsive behaviour is overcome.

2) Medications

Is there any active strep infection?

- If so, one could treat with antibiotics (e.g. Azithromycin) for 7-10 days, as one would treat a usual infection.

Are there OCD symptoms?

- If so, then one can treat with specific serotonin reuptake inhibitors (SSRIs) such as
    - Fluoxetine (Prozac),
    - Sertraline (Zoloft),
    - Citalopram (Celexa),
    - Escitalopram (Cipralex).

Various other medications have been proposed, however there is still insufficient evidence to firmly recommend any other particular treatments.

What Can Parents Do for PANS / PANDAS?

Reach out for support and help for yourself.

- It can be very challenging caring for a child with PANS/PANDAS.
- If you are overwhelmed, then take a break and get support for yourself.

Is your child stuck with an obsession or compulsion?

- Validate and empathize with them about how distressing this is for them. Obsessions are compulsions are not something they choose to have.
- If they are in the midst of a compulsion or obsession, it may be best to let them complete it.
- Do speak to a healthcare provider for specific guidance in your situation.

Is there separation anxiety?

- Accept that your child cannot function, and it is natural they feel safer when near a parent.

Is there regression, i.e. your child is acting like a much younger child?

- Accept that your child has regressed and may need more support until their brain heals.

The Good News

If symptoms are due to PANS or PANDAS, the good news is that in most cases, symptoms improve over time.

School Accommodations and Modifications for PANS/PANDAS

School accommodations and modifications are necessary for most students, as PANS/PANDAS affects all aspects of learning, behaviour and function.

Symptoms will improve and worsen. Any individualized education plan (IEP) should be written based on the worst episodes. When symptoms improve, the student may not require the same services and support.

Examples of accommodations and modifications include:

- General
    - Do accept that there may be many absences.
- Low stamina
    - Accept that the student may be more easily fatigued and exhausted; allow shorter school days, more breaks, etc.
- Restricted eating with reduced intake
    - Allow additional time for meals; provide more private space for meals; allow the child to meet parent for lunch.
- Handwriting (fine motor) difficulties:
    - Allow the usual accommodations for fine motor troubles, such as use of a keyboard; provide notes; etc.
- Coordination (gross motor) difficulties:
    - Consider excusing them from physical education class if there are severe coordination issues.
- Learning / cognitive issues
    - For math difficulties, allow use of a calculator; use of times table, working with a resource teacher or tutor.
- Troubles with inattention, hyperactivity or impulsivity
    - Give the same accommodations for students with ADHD, such as preferential seating; chunking work; short, simple instructions; limit distractions, etc.
- Cognitive difficulties
    - Do not require them to make up assignments or tests.
- Urinary problems
    - Does the child require frequent toileting breaks? If so, give permission to leave the class.
- Separation anxiety
    - Accept that there may be more separation anxiety, and strategies similar to younger children may be required.

    - Allow a parent to be nearby the classroom or school (e.g. allow parents to help out in the school so they can be close by).
- Obsessive-compulsive symptoms
    - Be creative with workarounds for obsessive-compulsive symptoms.
    - Are there perfectionistic behaviours, e.g. repeatedly writing and erasing things? If so, allow the child to type answers on a keyboard.
    - Is the child stuck reading things over and over again? If so, consider audiobooks.

For more information about school accommodations/modifications

- PANDAS and PANS in School Settings: A Handbook for Educators by Patricia Rice Doran, Ed, D.

Scientific References

Wilbur C, Bitnun A, Kronenberg S, Laxer RM, Levy DM, Logan WJ, Shouldice M, Yeh EA. PANDAS/PANS in childhood: Controversies and evidence. Paediatr Child Health. 2019 May;24(2):85-91. doi: 10.1093/pch/pxy145. Epub 2018 Dec 9. PMID: 30996598; PMCID: PMC6462125.
https://pubmed.ncbi.nlm.nih.gov/30996598/

For more information about PANS / PANDAS

PANDAS Network
https://pandasnetwork.org/
PANDAS/PANS Ontario
https://www.pandaspansontario.org/
PANDAS—Questions and Answers from the National Institute of Mental Health (NIMH)
https://www.nimh.nih.gov/health/publications/pandas

PANS information from Stanford University
https://med.stanford.edu/pans.html

OCD in Children/Youth: Information for Parents. This is a handout about ‘regular’ OCD not caused by PANS, and has more detailed information that may also be helpful for supporting your child with OCD due to PANS.
http://www.ementalhealth.ca/index.php?m=article&ID=8876

About this Document

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Disclaimer

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