

Paediatric Acute-Onset Neurologic Syndrome (PANS) (aka PANDAS): Information for Families



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Summary: Paediatric acute-onset neurologic syndrome (PANS) describes a small group of children that develop a series of symptoms following a streptococcal infection. Affected children can develop various symptoms such as anxiety, mood problems, obsessions, compulsions, inattention, hyperactivity and have behavioural problems such as regression (i.e. behaving like a younger child). Treatment can include antibiotics to treat the underlying streptococcal infection, as well as other treatments to help with the symptoms such as obsessions, compulsions, etc.

What is PANS?

Paediatric acute-onset neurologic syndrome (PANS) describes a small group of children that develop a relatively rapid onset of various symptoms following a streptococcal infection. Symptoms include anxiety, mood problems, obsessions, compulsions, inattention, hyperactivity, tics and behavioural problems such as regression (i.e. behaving like a younger child).

Who Gets PANS?

PANS occurs in childhood (age 3 to puberty).

What Happens In PANS?

The following steps are felt to occur:

- The person develops a strep infection
- The person's body produces antibodies against the strep bacteria
- The antibodies end up reacting with the person's own brain
- As a result, the person develops the various symptoms seen in PANS.

What Symptoms Are Seen In PANS?

Patients can have symptoms such as:

- Anxiety
- Emotional lability and/or depression
- Irritability, aggression and/or severely oppositional behaviours
- Behavioural (developmental) regression
- Deterioration in school performance
- Sensory or motor abnormalities
- Somatic signs and symptoms, including sleep disturbances, enuresis or urinary frequency

Because PANS is not a common condition, and because the symptoms seen in PANS can be seen in other conditions, it can be challenging for doctors to make a diagnosis.

When To See a Doctor

If you suspect PANS, see a health professional such as your family physician or paediatrician. Your physician may order certain blood tests.

How is PANS Treated?

OCD symptoms

OCD symptoms from PANS are typically treated the same way that one might treat OCD symptoms from any other cause.

First choice of treatment (“first-line”) includes:

Cognitive behavioural therapy (CBT) is usually the first treatment to start with, and consists of seeing a counselor/therapist (e.g. psychologist, social worker, or certified counselor) to learn a variety of specific strategies to deal with the OCD such as:

- Exposure, which is exposing one to the feared situation, e.g. touching something dirty.
- Response prevention, which is trying to avoid the compulsive behavior, e.g. washing one’s hands after touching something dirty.
- Exposure / response prevention is done in a graduated hierarchy, which means that one starts step-by-step with simple challenges, and works up to more complicated challenges
 - E.g. when 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 behavior is overcome

Second choice of treatment (“second-line”) includes:

Medications such as specific serotonin reuptake inhibitors (SSRIs) if non-medication strategies are not effective. Examples include Fluoxetine (Prozac), Sertraline (Zoloft), Citalopram (Celexa), Escitalopram (Ciprallex).

Experimental treatments

When OCD is felt due to PANS, there are experimental treatments being tested such as intravenous immunoglobulin (IVIG) at specialized research centres. However, for the average person with PANS, there is insufficient evidence to recommend any experimental treatments at this point.

What Can Parents Do About PANS?

OCD Symptoms

When a child has obsessions and compulsions due to PANS, provide your child with empathy and support. At times, you may be tempted to feel frustrated and angry at your child, but avoid doing so. Your child is unwell, and needs to feel loved and cared for by nurturing adults. Anger and frustration will make your child feel unsafe, and not be helpful.

Start with empathy, acceptance

- Child is washing his hands obsessively.
- Parent: "How hard this must be for you!" ((Empathizing with the child)
- Parent: "The OCD wants you to wash your hands over and over again. That's the OCD speaking."
(Externalizing the OCD, which is a way of talking about the OCD to help people understand that the OCD is the problem, not the child)
- Parent: "We'll just accept that the OCD wants you to wash your hands... (Acceptance)
- Parent: "Let's do something else. Let's go for a walk together..." (Using distraction)

A health care professional might recommend more specific strategies as well. Fortunately, OCD due to PANS will tend to improve over time.

Separation anxiety

While your child is experiencing these symptoms, your child may have problems separating from you. This is completely natural, and the best way is to simply accept that during this period, your child will need to spend much more 1:1 time with you. It makes sense; at a fundamental level, your child knows that s/he is ill, and it is natural that children seek out parents when they are ill, as a way of coping and survival.

Regression

You may notice that your child loses his/her ability to function at home or school. You may need to keep your child at home, and your child may need much more close supervision. The good news is that this is usually temporary, and will resolve as the PANS resolves.

For More Information

PANDAS: Frequently Asked Questions about Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Infections

Retrieved Mar 4, 2014 from <http://www.nimh.nih.gov/health/publications/pandas/index.shtml>

For More Information about OCD

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

Written by the health professionals at the Children's Hospital of Eastern Ontario (CHEO). Special acknowledgements to Dr. Asif Doja, neurologist.

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