

TO THE NEW-TO-PANDAS-PANS FAMILY & PRACTITIONER

Understanding the Impact of Symptoms, A Psychologists View

By Dr. Lisa Scholder, LP

Definition: Abrupt Onset of OCD or restrictive food intake, and, 2 or more of the following symptoms:

Anxiety, developmental regression, deterioration in school performance, emotional lability/depression, oppositional issues, motor (tic) or sensory issues, sleep disturbances or enuresis.

What is happening with these families? Imagine—a capable, confident, verbal child—your child—turning into what appears to be a mentally ill, non-functional person you cannot recognize nearly overnight! The trauma to the PANDAS/PANS child and their family is profound and life changing. This is a family diagnosis that can tear entire families apart! PANDAS/PANS is an insidious disorder, in which the sufferers' brain is, in essence, hijacked by confused antibodies. The antibodies attack the child's brain, rather than the bacteria that released them. Researchers believe there is both a genetic and infectious trigger. It often takes everything and everyone to wrestle the child back from the attacking antibodies! My own family experienced PANDAS and we, with the help of others, healed our children—this is what we learned.

Symptom & Impact Reality Guide – The Difficult Road to Recovery

SYMPTOM: OCD and Motor Abnormalities (tics—sooo not the whole story! OCD in a child with PANDAS/PANS may take many forms. Some children may have extremely lengthy eating or sleeping rituals that have to be repeated, sometimes for many hours, before they can eat or sleep! Sometimes, the rituals compel a parent to participate for hours, otherwise the child might scream and/or rage into the next day. My child developed self injurious compulsions that she would beg me to help her stop. Tics might range from simple facial grimaces and eye blinks to more complex and disabling choreiform movements.

IMPACT: PANDAS/PANS OCD can challenge the highest functioning of families. The intensity of rules and rituals can be disturbing to horrifying for parents and siblings to witness. It can rob parents of time and energy for other children in the home, not to mention the trauma of watching your previously functional child, decompensating into a non-functioning, “stranger.” The tics and/or movements can range from embarrassing to the child to causing difficulty walking.

SYMPTOM: Anxiety, Separation Anxiety, Sleep Issues—“me and my constant small shadow!” PANDAS/PANS anxiety may be subtle and as the flare continues, becomes crippling to the child and engulfing for the parent. The child needs to be in the same room with the mother or father at all times, may refuse to go to school, and even insist on following the parent to the bathroom. This symptom may be so severe that even at the thought of separation; the child might rage or become hysterical. Some children even require physical contact with a parent at all times! The child may be afraid of people, places, and situations that previously caused no upset. Perseveration, asking the same questions and/or repeating the same phrases, may become the new focus of conversation with the child. Again, the child's movement and emotional center of the brain is under new management and is likely inflamed creating multiple symptoms that all make sleep difficult to impossible. For some kids, falling asleep and staying asleep is difficult. Nightmares often occur.

IMPACT: Imagine being a parent of a child engaging in bizarre OCD rituals, unusual, and often disturbing tics or body movements, and now you can't get a physical break from this constant stress! If the child is a "tween" the embarrassment and confusion regarding this new separation anxiety can be profound. School avoidance and refusal is a daily struggle. Parents often feel frustrated, exhausted, confounded, and like... failures. Siblings, especially younger ones, might feel frightened, lost and alone. Marriages become strained beyond belief as the PANDAS/PANS child now requires one or both parents to sleep with, and engage in, sleep rituals. *Isolation becomes the family norm* as "adult only" interactions become impossible. Playdates for siblings are overwhelming for parents already stretched beyond their limits. Parents are often told to "just discipline" their child. Even many in the medical community invalidate families, or worse yet, blame the parents for their inability to manage or assume parents are exaggerating normal developmental glitches.

SYMPTOM: Enuresis, anorexia—disruptive physical symptoms!

Often the symptom picture includes one or both of the above neurological symptoms. Urinary frequency (enuresis) is having to urinate multiple times each day and can also include urinating in underwear during the day and/or night while sleeping. Anorexia is an inability to eat. Weight loss in young children must be taken seriously because it can quickly become life threatening. Often children will complain of not being able to swallow. My child would expel food when trying to swallow. She wanted to eat what was served, but could not get most of the food down. She dropped to the third percentile for weight and was doing feeding OT before we understood this was a symptom of PANDAS/PANS! These symptoms are likely caused by neurological disruption of basic functioning. These children are not "doing it on purpose." The eating dysfunction is not to be taken lightly and is not caused by social pressure to be thin or as an anger response as in non-PANDAS/PANS/anorexia/nervosa. Standard eating disorder treatment will often fail for the PANDAS/PANS anorexia due to its complex etiology.

IMPACT: Please remember, many of these symptoms, in varying degrees of severity, are present simultaneously. For example: if the OCD includes cleanliness compulsions, this can lead to constant showers, which might require a new bar of soap and towel each time, plus a parent accompanying him/her, all while everyone is sleep deprived, and the child may now be malnourished! A similar scenario is found in many PANDAS/PANS families! Parents often carry a deep and profound feeling of failure as they are unable to complete a basic parenting responsibility. Again, invalidation from friends, family, and even some in the medical community contribute to parents' suffering. Many parents can understandably fit the criteria for clinical depression, anxiety disorders, and/ or post traumatic stress disorder. I want to emphasize, there is no shame in this, as parents of a PANDAS/PANS sufferer often become emotionally, physically, and spiritually depleted. They are, in essence, fighting a war for their children. Also, a child can have multiple flares, over many months or years, without proper treatment.

SYMPTOM: Oppositional Behaviors—rage, rage, and more rage!

Many families report a "walking on eggshells" feeling around their ill child. New research is showing that severe PANDAS/PANS is an inflammatory attack on the brain and mood disinhibition is a common feature of brain inflammation. Loud and sometimes dangerous episodes are an extremely disruptive and heartbreaking symptom to members of the family. The child often feels "outside of themselves" and regrets the outbursts later. Breaking things, shouting and swearing at family members, throwing things, often without cause, can be a daily experience. The eruptions are not usually caused by any identifiable trigger. This lack of

IMPACT: The pain of witnessing and being the target of your previously loving child is deeply upsetting and frightening. Siblings must be ever vigilant to protect themselves. Grief and loss for the loving "family member of yesterday" can be profound. Parents often argue and become divided as to how to manage this symptom. Schools often become involved much to the families' embarrassment. Please remember, all of these reactions are normal responses to an abnormal situation. For the most part, parents who are doing heroic jobs in handling these horrible symptoms are alone and unprepared!

SYMPTOM: Overactivity, sensory sensitivity, school and developmental regression—the whirling dirvish! In the age of information overload and push button, instant gratification, hyperactivity is somewhat the new childhood norm. However, PANDAS/PANS hyperactivity is riddled with angst for the child and family. Most children with true ADHD can focus in on enjoyable activities, such as watching a favorite show, playing at a park, or even an art project. PANDAS/PANS hyperactivity looks more like mania with extreme physical restlessness. It cannot be focused on anything productive. As one can imagine, this overactivity makes school performance and behavior challenging. Sitting in a chair for school or for meals may also become an ordeal. Aggressiveness is frequently present as well. Yelling, screaming, and speaking very loudly may also accompany physical hyperactivity.

Multiple senses can become overly sensitive to sound, touch, tastes, textures, sights. So now, picture a child that cannot walk on carpeted floor (possible OCD symptom), got two hours of sleep due to anxiety, is hyperactive and bed wets, broke sister's doll so sister is shrieking, cannot eat anything but chicken broth for breakfast, cries and screams about not wanting to go to school, and now-refuses to wear jeans ... and, she doesn't refuse quietly. Reactions to these sensitivities can be explosive and extreme. Again, contributing to the chaos and confusion for families, not to mention what may happen during the school day. Regression, behaving like a much younger child, can also be present during a flare. Returning to thumb sucking, crawling, or baby talk can be present for some PANDAS/PANS children, as well. A previous A or B student can become a disruptive, crying, failing student almost overnight once in a PANDAS flare.

IMPACT: Overactivity, sensory sensitivities, and regression all contributes to the household confusion. Parents wrack their exhausted brains to come up with creative ways to help their children function at home and school. A PANDAS/PANS child my become reactive while riding in a car shrieking and/or threatening to jump out is not uncommon. All of the parents resources are required just to get through the day. Feeling angry at the PANDAS/PANS child may become the new family norm. School personnel may be just as confused and lost as the family. It is common for the school to blame the floundering parents when adjustments do not help the child improve. Siblings become constantly nervous and vigilant, acutely uncomfortable in their homes. Peers avoid the PANDAS/PANS child and stop including him/her for play dates. Families usually have no skills or experience to manage these symptoms since they often show up overnight! Families are left bewildered, frightened, and heart broken as anger and tears replace conversation and laughter. Schools are left frustrated and confounded.

Note to Parents – Seek Support

The above symptoms are some of the most common symptoms of PANDAS/PANS, however, your child may only have one or two of them, or may have additional symptoms. Your mental and physical health is your armor to stand up and conquer flares! It is NORMAL to feel crazy in a crazy environment. Your reactions and feelings may range from annoyance and resentment, to heartbreak and clinical depression. You may develop symptoms of post traumatic stress disorder and insomnia. Again, this is NOT a weakness, but a normal reaction to the suffering PANDAS/PANS can create! There is help for **your** symptoms. You are your child's advocate and you need sustenance. See a psychologist, find a support group, talk to your physician about antidepressants or sleep aides, get family therapy, and/or marriage counseling. Study PANDAS/PANS with your spouse so you can stand together against it. Educate family members, your child's school, neighbors, and health care providers through reliable sources such as the NIMH, IOCDF and PANDASnetwork.org. Take time for yourself, even a few minutes. Begin or continue exercising, try and plan a date with your partner. Remember your other children and the joy they seek in their lives. And, most importantly, remember that your child is in there fighting also! Continue to love and praise your child for any functional behavior you observe. Have faith your family can laugh again one day!

Note to Providers – These Families Need Your Support and Creativity

Providers, please remember why you chose this profession. This is your chance to make a big difference and deeply impact children and families. It is scientifically difficult to imagine PANDAS/PANS when observing a child for twenty minutes in your office. But, please remember, no one believed in ADHD years ago either! My child, who has a diagnosis of PANDAS could present as a "normal," non-symptomatic child for our twenty minute doctor visits for years making me appear like the crazy, overreacting one! Ask families to video tape their child and forward the footage to you. You will likely be shocked at what you witness. Most parents need to take time from work or other responsibilities to come to you. They may have had to endure screaming and OCD symptoms and sensory symptoms just to get their child to you. If a parent describes overnight symptom appearance, consider a thorough strep swab and/or even a strep blood test. If the child has been symptomatic for years, their PANDAS/PANS could have been triggered by non-strep illness, or strep could be living in sinuses. Even with a negative swab, consider a trial of antibiotics. Also, PANDAS/PANS symptoms are not caused by bacteria, but the antibodies. This translates into symptoms often persisting for many weeks until the antibodies die off. In severe cases, consider parents' requests for prophylactic antibiotics or more aggressive treatments. Educate yourselves on PANDAS/PANS and best practice treatment options at the medical professionals site, www.pandasppn.org. Above all else, do not treat parents as crazy or overreacting. You are often their only hope in what can feel like a desperate situation. Lastly, please refer responsibly if your practice makes educating and treating PANDAS/PANS not possible. **Let's fight this together!**

Dr. Lisa Scholder, clinical psychologist, CEO Whole Wellness Psychology.
Lisa does parent training and support for PANDAS and other diagnoses in her holistic psychology practice. She is co-director of the Minnesota PANDAS Network.org Chapter Support Group. She is the mother of children with PANDAS.