PANS/PANDAS Relapse Explained: Why Symptoms Keep Returning Transcript

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Introduction to PANS and PANDAS

If you're a parent of a child with PANS If you're a parent of a child with PANS or PANDAS, or a young adult living with or PANDAS, or a young adult living with this yourself, there's one mistake I see this yourself, there's one mistake I see over and over again. PANS stands for over and over again. PANS stands for Pediatric Acute onset Neuropsychiatric Pediatric Acute onset Neuropsychiatric Syndrome, and PANDAS stands for Syndrome, and PANDAS stands for Pediatric Autoimmune Neuropsychiatric Pediatric Autoimmune Neuropsychiatric Disorders Associated with Streptococcal Disorders Associated with Streptococcal Infections. In both conditions, children Infections.

Why Symptoms Can Change Suddenly

In both conditions, children can change suddenly. Intense anxiety, can change suddenly. Intense anxiety, obsessive-compulsive behaviors, rage, obsessive-compulsive behaviors, rage, tics, regression, tics, regression, and personality shifts, sometimes and personality shifts, sometimes literally overnight. And here's the literally overnight.

The Cost of Focusing on the Wrong Symptom

And here's the mistake I see repeatedly, treating the mistake I see repeatedly, treating the most dramatic symptom as if it's the most dramatic symptom as if it's the main problem. What usually follows is main problem. What usually follows is painfully familiar. Symptoms improve painfully familiar. Symptoms improve briefly, then plateau, and then flare briefly, then plateau, and then flare again. I've seen this exact pattern again. I've seen this exact pattern repeat for years in PANS and PANDAS repeat for years in PANS and PANDAS cases, both in families who are brand cases, both in families who are brand new to this, and in those who have been new to this, and in those who have been struggling for a long time. And the cost struggling for a long time. And the cost of this mistake isn't just medical. It of this mistake isn't just medical.

Dr. Fred Bloom and the Channel's Approach

It costs time, childhood, family stability, costs time, childhood, family stability, and trust. If this feels familiar, stay and trust. If this feels familiar, stay with me, because this mistake is subtle, with me, because this mistake is subtle, extremely common, and often missed. For extremely common, and often missed. For those of you who don't know me, I'm Dr.

those of you who don't know me, I'm Dr. Fred Bloom. I'm an integrative and Fred Bloom. I'm an integrative and holistic physician, and I work with holistic physician, and I work with complex chronic cases, especially complex chronic cases, especially children with immune-mediated children with immune-mediated neuropsychiatric conditions like PANS neuropsychiatric conditions like PANS and PANDAS.

and PANDAS. If this content is helpful, I invite you If this content is helpful, I invite you to like this video, subscribe, and share to like this video, subscribe, and share it with other families who may be it with other families who may be struggling. This channel is about making struggling. This channel is about making complex cases make sense, without blame, complex cases make sense, without blame, and without oversimplifying.

and without oversimplifying.

The Core Mistake in PANS and PANDAS Care

Now, let's talk about the mistake Now, let's talk about the mistake itself. The mistake is this, confusing itself. The

mistake is this, confusing the most visible neuropsychiatric the most visible neuropsychiatric symptom with the root cause.

symptom with the root cause. In PANS and PANDAS, that often looks In PANS and PANDAS, that often looks like treating OCD as a primary like treating OCD as a primary psychiatric disorder, treating anxiety psychiatric disorder, treating anxiety as a brain chemistry issue, treating as a brain chemistry issue, treating rage as a behavioral problem, and rage as a behavioral problem, and treating tics as a neurological treating tics as a neurological endpoint. And I understand why this endpoint. And I understand why this happens. These symptoms are severe, happens. These symptoms are severe, frightening, and deeply disruptive to frightening, and deeply disruptive to families. So, everything naturally families. So, everything naturally focuses on stopping that.

focuses on stopping that. But in PANS and PANDAS, the loudest But in PANS and PANDAS, the loudest symptom is very rarely where the problem symptom is very rarely where the problem started. This mistake happens for started. This mistake happens for understandable reasons.

understandable reasons.

Why This Mistake Happens

First, crisis-driven care. PANS often First, crisis-driven care. PANS often begins abruptly. Families are in begins abruptly. Families are in survival mode, and the immediate goal survival mode, and the immediate goal becomes symptom control.

becomes symptom control. Second, psychiatric framing. Because Second, psychiatric framing. Because symptoms are emotional and behavioral, symptoms are emotional and behavioral, care quickly shifts into psychiatric care quickly shifts into psychiatric models, even when immune activation and models, even when immune activation and inflammation are driving the process.

inflammation are driving the process. Third, Third, Third, single-trigger thinking. A strep single-trigger thinking. A strep infection, mycoplasma, COVID, or another infection, mycoplasma, COVID, or another illness is identified, and the entire illness is identified, and the entire case becomes built around that one case becomes built around that one factor. And finally, the desire to calm factor. And finally, the desire to calm the storm. When a child is suffering, the storm. When a child is suffering, everyone wants relief now, and that's everyone wants relief now, and that's human.

human. human. The problem isn't symptom management. The problem isn't symptom management.

What Happens When Treatment Stays Symptom-Focused

The problem is when symptom management The problem is when symptom management becomes the entire plan. In real PANS becomes the entire plan. In real PANS and PANDAS cases, this mistake creates a and PANDAS cases, this mistake creates a very familiar pattern.

very familiar pattern. Parents often say, "The medication Parents often say, "The medication helped, but only temporarily. helped, but only temporarily.

Antibiotics worked, but every flare Antibiotics worked, but every flare comes back. Each flare looks different, comes back. Each flare looks different, and we're always chasing the next and we're always chasing the next symptom." symptom." symptom." Clinically, you see partial improvement Clinically, you see partial improvement without full stabilization, symptom without full stabilization, symptom shifting, OCD improves, rage worsens, shifting, OCD improves, rage worsens, increasing medication sensitivity, and increasing medication sensitivity, and flares triggered by stress, illness, or flares triggered by stress, illness, or growth spurts.

growth spurts. And this needs to be said clearly. These And this needs to be said clearly. These families are not failing. Most are doing families are not failing. Most are doing everything they're told. Many are everything they're

told. Many are exhausted, and some feel blamed or exhausted, and some feel blamed or dismissed.

dismissed. dismissed.

Shifting to a Systems-Based Approach

The issue is not effort. It's approach. The issue is not effort. It's approach. Earlier in my career, I focused heavily Earlier in my career, I focused heavily on what was most disruptive.

on what was most disruptive. If OCD was severe, that became the If OCD was severe, that became the focus. If rage was dangerous, that focus. If rage was dangerous, that dictated the plan. If anxiety dominated, dictated the plan. If anxiety dominated, we chased anxiety.

we chased anxiety. At the time, that made sense. What I At the time, that made sense. What I didn't fully appreciate back then was didn't fully appreciate back then was this.

this. this. In PANS and PANDAS, neuropsychiatric In PANS and PANDAS, neuropsychiatric symptoms are often downstream signals, symptoms are often downstream signals, not the primary dysfunction.

not the primary dysfunction. With experience, I began to see that With experience, I began to see that when treatment focused only on when treatment focused only on suppressing symptoms, families stayed suppressing symptoms, families stayed stuck in cycles.

stuck in cycles. When I shifted toward understanding When I shifted toward understanding immune load, inflammatory thresholds, immune load, inflammatory thresholds, nervous system regulation, and proper nervous system regulation, and proper sequencing, cases began to stabilize.

sequencing, cases began to stabilize. That shift changed how I practice. What That shift changed how I practice. What works better is systems-based thinking.

works better is systems-based thinking. In PANS and PANDAS, recovery depends on In PANS and PANDAS, recovery depends on recognizing immune activation versus recognizing immune activation versus immune exhaustion, understanding when immune exhaustion, understanding when the nervous system is stuck in survival the nervous system is stuck in survival mode, and respecting the order in which mode, and respecting the order in which systems can safely be addressed. When systems can safely be addressed.

Who This Applies To Most

When care is sequenced properly, care is sequenced properly, flares become less intense, baseline flares become less intense, baseline gradually improves, windows of stability gradually improves, windows of stability widen, and families regain widen, and families regain predictability.

predictability. predictability. This isn't about ignoring psychiatric This isn't about ignoring psychiatric symptoms. It's about understanding why symptoms. It's about understanding why they're happening now. This applies most they're happening now. This applies most to children with relapsing or waxing and to children with relapsing or waxing and waning PANS symptoms, kids who improve waning PANS symptoms, kids who improve but never fully stabilize, and families but never fully stabilize, and families stuck between antibiotics, psych meds, stuck between antibiotics, psych meds, and uncertainty. It applies less to and uncertainty. It applies less to single, self-limited post-infectious single, self-limited post-infectious episodes, and short-lived flares with episodes, and short-lived flares with full recovery. PANS and PANDAS are not full recovery.

Questions for Families and Closing Thoughts

PANS and PANDAS are not uniform conditions, and individualized uniform conditions, and individualized thinking

isn't optional. It's essential. thinking isn't optional. It's essential.

If your child improved but never fully If your child improved but never fully stabilized, if every flare feels like stabilized, if every flare feels like starting over, and if you've been told, starting over, and if you've been told, "This is just how it is," that doesn't "This is just how it is," that doesn't mean you missed something. It may mean mean you missed something. It may mean the wrong thing was treated first.

the wrong thing was treated first. This mistake is common, understandable, This mistake is common, understandable, and often correctable. and often correctable.

I'll leave you with a few questions. I'll leave you with a few questions. Have symptoms been treated repeatedly Have symptoms been treated repeatedly without lasting stability?

without lasting stability? Were you told one symptom was the main Were you told one symptom was the main problem, but progress stalled? problem, but progress stalled?

And does this help explain the pattern And does this help explain the pattern you've been living with? you've been living with? If this resonates, share your experience If this resonates, share your experience in the comments. Your child's case in the comments. Your child's case likely makes more sense than you've been likely makes more sense than you've been