

Both PANS and PANDAS are closely associated with infections and viruses, particularly those experienced in childhood. These stories explain what can happen if the conditions are not recognised, and treatment is delayed.

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Oliver, 9, living with PANS for five years

“Two days after finishing a course of antibiotics for an ear infection, Oliver became terrified of everything and everyone. He wouldn’t eat or drink, he was scared to sleep. He tried to harm himself and told us he wanted to die.”

Seeking refuge under a blanket, Oliver lives in his bedroom, unable to communicate with anyone except his mum and little sister. With each year that passes, his fears grow and his world gets smaller. Around him, lives have moved on, but Oliver’s life remains frozen.



“I truly believe that two weeks of the right medication, at the right time, could have changed Oliver’s life.”
Oliver’s father.

Annie, 12, living with PANDAS for three years

Shortly after contracting Strep A, Annie began to demonstrate obsessive-compulsive behaviours. Her self-confidence disappeared, causing her to avoid mirrors because she couldn’t tolerate her reflection. Soon, she withdrew from everyone around her.

Annie spends much of her time crouched on the floor, refusing to be touched or dressed. She experiences constant physical and verbal tics, and uses compulsive repetitive behaviours and rituals to cope with extreme anxiety.

“There’s so much research, so much proof, but we are told the condition doesn’t exist. We’re getting nowhere, and our daughter is getting worse. But I’ll keep fighting for her.”
Annie’s father.

Who we are

PANS PANDAS UK is a charity with a mission to raise awareness of these life changing conditions.

PANS PANDAS UK supports patients and families living with PANS and PANDAS and work with health, education and social care professionals and parliamentarians to ensure effective, equitable and efficient treatment.

Contact Us

 www.panspandasuk.org

 info@panspandasuk.org



Scan here to find out more about Oliver and Annie’s stories



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Do you understand PANS & PANDAS?

If your patient has undergone a **dramatic personality change**, is displaying **OCD behaviours**, **tics** and/or **restricted eating**, particularly **following an infection or virus**, then they may be experiencing PANS or PANDAS.

In most cases, patients respond well to early treatment. However, many children in the UK are currently experiencing prolonged, devastating symptoms affecting every aspect of their lives due to a lack of awareness.

The following stories explain the difference that early treatment can make.

Meet Rose:

Name: Rose
Age: 11
Diagnosis: PANDAS

Symptoms: Anxiety, obsessive-compulsive behaviours, tics, hyperactivity, exhaustion and separation anxiety
History: Throat infection

In 2021, Rose was a confident eleven-year-old enjoying her first experiences of secondary school. She made friends quickly, took part in clubs and activities and was living a healthy, full life. Her only difficulty was developing a sore throat, which lasted about ten days and was treated at home with paracetamol. Rose and her parents had no idea that this was the beginning of a nightmare.

“One day after school, Rose suddenly experienced a panic attack. She began hyperventilating, started thumping her head and was hysterically screaming. She was terrified by the sight of knives in our kitchen, she was convinced she would stab her own chest. Rose had never experienced any thoughts of self-harm, anxiety or panic before this day.”

What followed was an exhausting, debilitating and terrifying three weeks of intense symptoms for Rose. She experienced intrusive thoughts and separation anxiety, terrified something would happen to her or her loved ones. Rose’s behaviour regressed significantly, reverting to toddler-appropriate picture books and toys and losing the ability to write. She developed tics, memory loss, and began to experience periods of manic hyperactivity followed by severe exhaustion.

“As parents, we felt completely lost. The symptoms came on so quickly and there were so many of them. Rose hadn’t experienced any trauma, and nothing had happened at school. There was no explanation... until we found the list of symptoms for PANDAS. Rose had nearly every single one.”

What the doctor said:

Although the family GP hadn’t heard of the condition, she listened to the parent’s experience of Rose’s symptoms, and discussed their research with them.

“We were nervous that her GP would insist this was a mental health problem, and might not listen to us or believe in PANDAS. But she heard our concerns, she understood that this was very unusual for Rose and how suddenly her symptoms had appeared.”

Rose was referred for tests which revealed an incredibly high level of Antistreptolysin (Strep infection). She was prescribed a standard short course of penicillin which saw her symptoms reduce dramatically, returning as soon as the course was completed. This was all the evidence that her GP needed.

Rose soon began an extended seven-week course of penicillin to reverse the damage caused by inflammation which, combined with talking therapy to help process the subsequent symptomatology, brought Rose back from the brink.

“Rose is one very lucky girl. She is now living her normal, confident teenage life. We could easily have had a different meeting with our GP, or been dismissed and taken down another road of treatment. I dread to think what condition Rose would be in now.”
Rose’s father

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In one day, we lost the girl we had watched grow up for the past 11 years

What are PANS and PANDAS?

PANDAS is short for Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections. It describes when subtle inflammation in the brain, due to an autoimmune response to strep, is affecting a patient’s physical and mental health.

Primary symptoms of PANDAS:

- OCD behaviours
- Tics

In both PANS and PANDAS, primary symptoms are often accompanied by multiple secondary symptoms amongst which are anxiety, motor or sensory abnormalities, urinary symptoms and a sudden deterioration in school performance.

To read the full diagnostic criteria, visit www.panspandasuk.org.

PANS is short for Paediatric Acute-onset Neuropsychiatric Syndrome. PANS and PANDAS are often grouped together because they share lots of symptoms in common. Both conditions can begin quite suddenly, and symptoms may come and go over time.

Primary symptoms of PANS:

- OCD behaviours
- Restricted eating

Currently, many children are not as fortunate as Rose. See overleaf to understand what can happen if symptoms are misinterpreted or treatment is delayed.