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Oliver's Story

If a child 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.

Read Oliver's story to find out more about one family's struggle to get diagnosis and treatment.

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“ He went from being a perfect, normal kid... to falling from the highest cliff, and he is still stuck at the bottom. ”

Ben hasn't seen his son's face for four and a half years. 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.

“When I visit my son, he hides from me. He'll hide from everyone. It is like having a ghost in the house. We can hear him, but never see him. He's lost everybody he knew, everything he loved. It has all been replaced by terror.”

At nine years old, Oliver was on top of the world. Progressing towards a black belt in his beloved Mixed Martial Arts, Oliver's energy and bravery expanded into all areas of life. He was adventurous, creative and outgoing, entertaining his friends and family with funny videos and practical jokes. Oliver thrived at school, described by teachers as confident, independent and eager to learn. Then, after a simple ear infection, Oliver's life changed unimaginably.

“Two days after finishing his antibiotics, 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.”

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Oliver, 9, living with PANS for five years

Oliver was immediately admitted to hospital, where was diagnosed with at autistic breakdown. He didn't respond to treatment and his quality of life continued to deteriorate. After nine months of constant decline, the family discovered PANS PANDAS UK and recognised Oliver's symptoms. They fought for more tests and, a further six months later, Oliver was diagnosed with probable PANS PANDAS. He was treated with anti-inflammatories and antibiotics and showed an immediate positive response. Finally, there was hope for the family, but it was short-lived.

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 PANS and PANDAS



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3 Oliver could have been helped at the start if the medical professionals had just listened to us, if they were more aware of PANS and PANDAS. I truly believe that two weeks of the right medication, at the right time, could have changed Oliver's life.”

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Being so ill for nearly two years had taken a huge toll on Oliver's mental health and soon he was admitted to hospital again. Here, all medication was stopped, despite him showing improvements, because the hospital team disagreed with the diagnosis. Oliver immediately returned to rock bottom.

“Nobody believed us, or believed in PANS or PANDAS. Neurology and Psychiatry were arguing about his condition while Oliver lay curled up on the floor of his hospital room. He was there for 10 days; refusing food, clothes or bedding until we took him home without treatment. Oliver was extremely distressed and had lost a lot of weight; we were back to square one.”

Traumatised by this experience, Oliver quickly lost trust in medical professionals and treatment options. Two years later, Oliver is still too frightened to engage in any kind of intervention. The CAMHS psychiatrist, who supported the probable PANS/PANDAS diagnosis, maintains that Oliver's mental distress and symptoms have a physical cause. There is hope for treatment now, but no-one can reach Oliver at the moment. The longer the delay, the harder it will be to bring him back.

“Oliver could have been helped at the start if the medical professionals had just listened to us, if they were more aware of PANS and PANDAS. I truly believe that two weeks of the right medication, at the right time, could have changed Oliver's life.”

Recently, Oliver's anxiety levels have lowered, although he is yet to leave the house. He reads books about what's happening in the world and has started asking questions about family members, demonstrating a new level of awareness. Ben writes letters to Oliver and often sends books to support his new-found interests, but he hasn't yet been able to speak to his son.

“Sometimes, it feels like a bereavement; the strongest relationship in my life has gone. I've lost my son, but he has lost everything. So, I'll never give up hope, I'll keep fighting for Oliver.”

Oliver's family have drawn tremendous support from engaging with the PANS PANDAS UK community. Speaking to other families, talking to the team and learning more about the conditions has been a huge source of hope, education and inspiration. Ben wanted to share Oliver's story to reach out to researchers and medical professionals.

“I know from other families that if a child gets to see a medical professional who is aware of PANS and PANDAS, they can go back to normal very quickly. But, if they are treated by someone who isn't aware, the child might become trapped like Oliver for many years. That's why I want to raise awareness and support PANS PANDAS UK.”

PANS PANDAS UK hope that by spreading awareness now, we will soon be sharing more stories of success and recovery. Learning from Oliver's experience can ensure that no other child, adult or parent, faces such a tough journey home.



Scan here to find out more about PANS and PANDAS



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“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.”

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

Contact Us

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