

04

A word of thanks from Neil and Lucy

There is no question that This Morning and the parents who were brave enough to appear on the show and share their story have saved our son's quality of life. We are so grateful to them and to This Morning for covering the conditions on their show.

Unfortunately, there are many who are not as lucky as we have been and are left totally unaware of the condition. As few as 10% of NHS doctors have heard of the condition, meaning that many children are mis-diagnosed with mental health conditions, or simply labelled as naughty children, where really, they could receive treatment and see a significant improvement.



Many children are mis-diagnosed with mental health conditions, where really, they could receive treatment and see a significant improvement

How do I know if my child has PANS/PANDAS?

If your child has undergone a dramatic personality change, is displaying some OCD, tics or issues with food, together with a number of other symptoms (see diagnostic criteria on our website) then you may suspect PANS or PANDAS. In very young children, OCD can display as very intense anxiety or fears.

PANS and PANDAS are closely associated with infections and viruses. Both the initial onset and subsequent exacerbations are usually incited by a variety of childhood infections. The specific microbe most commonly recognised has been streptococcus (PANDAS). However, mycoplasma pneumoniae, as well as influenza, chicken pox and other common viruses have also been noted.



Symptoms may fluctuate as a child heals, but can often return or worsen if the child is exposed to another infection.



Who we are

PANS PANDAS UK are a Charity with a mission to raise awareness of these life changing conditions. PANS PANDAS UK support to families who are affected and have a good relationship with a network of doctors to encourage education in these conditions.

Contact Us

 www.panspandasuk.org
 info@panspandasuk.org

01



Jack's Story

When our son Jack was born, he was developing normally and was a happy, relaxed baby. In the summer of 2017 when he was just 18 months old, we noticed a dramatic difference in his behaviour.

Case Study: Jack Gilson

Name: Jack Gilson

Age: 3

Diagnosis: PANDAS (Paediatric Autoimmune Neuropsychiatric Disorder Associated with Streptococcal Infections)

Symptoms: Aggression, OCD, tics, anxiety, attachment issues, difficulties communicating and eating restrictions.

History: In the words of Jack's parents, Neil and Lucy:



Had developed tonsillitis and he became suddenly very aggressive. At the time we put it down to his age but after this Jack developed tonsillitis a further 10 times and his behaviour worsened each time. Not only was he aggressive but also developed OCD (especially related to his socks), and developed a tic which made it difficult for him to play with his friends. He then developed anxiety, attachment issues and had trouble wanting to communicate and eat. It got to the point where Jack didn't want to leave the house and some days, he wouldn't speak a word. He would bite his own arm as he was so anxious and we would struggle to get him dressed each day as he said the clothes hurt him. Some days when he was in this state you would look at him and it was like there was no-one there."

What the doctor said:

We took Jack to many different doctors and we could not find the answers to these changes in behaviour. The tic was put down to Tourette's or to an allergy to something and the behaviour was said to be "normal" for his age. At this point we were desperate, and it was heart-breaking to see. Not only was Jack suffering mentally, he was also physically very poorly, he lost finger nails and toe nails and had little energy. We had listened to so many different opinions and had been made to feel like we were being paranoid. Eventually we accepted that, as he got older, Jack would be officially diagnosed with Autism and the behavioural characteristics were just something we would have to learn to live with. We felt so alone, and we were so worried for Jack's future.

“
Jack was prescribed a course of antibiotics and within two weeks we had our son back
”



The Breakthrough:

It was then we saw the article on This Morning. A mother was on there talking about her son. The segment was called "Did household mould turn our son evil?" I watched it and just felt like I was watching Jack. The symptoms were very similar to our son after he had tonsillitis. The doctor who was interviewed on the show described a condition called PANS/PANDAS and described it as a "treatable condition". We contacted our own doctor and told him what we had learned. He said that he hadn't heard of it before, but he agreed that many of the symptoms Jack had matched up with symptoms of PANS/PANDAS. We then made an appointment with the doctor who featured on the show to discuss Jack's symptoms.

From this moment on, our family's lives changed for the better. Jack was prescribed a course of antibiotics and within two weeks we had our son back. The worried look in his eyes was no longer there. His tic had completely gone and his behaviour drastically improved. He started eating normally again and was able to leave the house without any anxiety. Jack was diagnosed with having PANDAS. The doctor also recommended that Jack's tonsils were removed to limit the strep infections he was regularly contracting.

Jack had his operation in early 2019 which was successful and despite a few flares of behavioural symptoms (which the doctor had warned us to expect) he is doing well and improving every day.