

LOOK at pictures of Jack Gilson today and you see a happy, healthy ten-year-old boy. He is, says his father Neil, proudly: 'Doing amazingly at school, he's bright and sociable. And he's really good at sport.'

He gets on well with his older sister Lily, 12, and younger sister Ruby, three, and has lots of friends. Yet not long ago, his parents, Neil and Lucie, both 40, feared he would never lead a normal life.

Because following a bout of tonsillitis when he was 18 months old, Jack changed almost overnight from a 'happy, sunny, relaxed toddler' - to a child who was too anxious to leave the house and who 'screamed in pain when we were putting his clothes on,' says Neil.

What's more, Jack 'developed aggressive behaviour - mainly towards himself', which meant he would bite his own arm - and he refused to eat and developed a tic, which involved him rubbing his ears on his shoulders. Neil recalls 'some very bleak times'.

'Some days he'd get really upset, then suddenly stop and stare,' he says. 'It was freaky, like there was something in the room, he'd have a completely blank expression.'

By ANNABEL VENNING

Neil says Jack also developed a hatred of having the straps on his pushchair on: 'Once, he had a tantrum, fell out and cut his face so badly he had to go to hospital.'

When Neil and Lucie, who run a hotel in north Devon, sought medical advice regarding Jack's apparent personality change, it was suggested he may be autistic.

But the couple were convinced something else was at play.

'We knew what normal toddler behaviour was - we already had Lily,' says Neil. 'It didn't sit right with us that he was fine one day and then totally different.'

It was while searching for answers that Lucie stumbled upon a TV show featuring parents talking about their toddler, who had displayed sudden symptoms just like Jack's.

Alongside the parents was Dr Tim Ubhi, a consultant paediatrician

who explained that such symptoms can result from two little known conditions - known collectively as PANS-PANDAS - that stem from disruption to the normal signals coming from the brain, leading to the sudden onset of obsessive behaviours and tics.

Both PANS (paediatric acute-onset neuropsychiatric syndrome) and PANDAS (paediatric autoimmune neuropsychiatric disorders associated with streptococcal infections) are triggered by minor everyday infections.

PANS can be brought on by infections such as flu, Covid, a

Immune system 'misfires' to launch attack on brain

tummy bug, possibly even exposure to mould, chemicals or trauma, whereas PANDAS is linked to infection by Group A Streptococcus bacteria, which causes sore throats, tonsillitis and scarlet fever.

For some reason, the immune system 'misfires' and launches an attack on the body, specifically the brain, rather than on the incoming bug that caused the infection.

'The immune system appears to mount an exaggerated response, attacking the body - specifically the brain - instead of limiting its activity to the original trigger [which is usually an infection],' explains Professor Rajat Gupta, a consultant in paediatric neurology at Birmingham Children's Hospital and one of only a handful of NHS consultant specialists.

'Through several immune pathways, this over-activation leads to inflammation within the brain, which disrupts normal signalling involved in movement, behaviour, emotions, and sensory processing,' he adds.

'This disruption is what then gives rise to the symptoms associated with PANS and PANDAS (see box), which may include tics, obsessive-compulsive behaviours, restrictive eating and sensory sensitivities - which may cause the child to become unusually distressed by certain textures, making it difficult for them to tolerate particular clothing or get dressed.'

There is currently no official data or government statistics on exactly how many people have PANS-PANDAS in the UK - but figures from the US conservatively estimate that it could affect one in 200 children, according to the charity PANS PANDAS UK.

Watching the clip about PANS-PANDAS was 'a light-bulb moment,' says Lucie.

Almost immediately they booked an appointment with Dr Ubhi, one of the world's leading specialists on PANS-PANDAS, who worked for more than 30 years as an NHS doctor before setting up Children's e-Hospital and The London PANS Clinic in 2024.

After a blood test revealed Strep A infection, Dr Ubhi diagnosed Jack with PANDAS, and started him on a two-week course of antibiotics to clear the original infection.

This, along with ibuprofen or steroids, which reduce the brain inflammation, are the standard treatment offered for PANS-PANDAS. The results were almost immediate for

Jack: 'We started to get our boy back,' Neil recalls.

They were lucky to get a diagnosis - and treatment - so quickly.

Awareness of PANS-PANDAS remains low, even among doctors - and many children get wrongly diagnosed, says Professor Gupta. 'Often the child is regarded as badly behaved.'

'In the worst scenarios, social services become involved and parents are accused of not being able to provide the appropriate care for their child, or of fabricating or inducing illness because children can often mask their symptoms to some extent at school.'

Because the symptoms often appear similar to a psychiatric illness, many children are wrongly referred to Child and Adolescent Mental Health Services (CAMHS) and some may even be sectioned.

Vicky Burford's son Gregory, now 22, was on the verge of being sectioned after he began suffering from hallucinations, OCD and severe eating restrictions aged 12. He was prescribed antipsychotics, antidepressants and sleeping tablets - which did nothing.

Eventually he saw a doctor who knew about PANS-PANDAS, who prescribed him a long-term course of the antibiotic, amoxicillin. Within a week he was better - and is now a happy, healthy adult.

Yet with PANS, even after the initial trigger has been treated, the immune system may remain heightened in its reactivity,' explains Professor Gupta.

'Consequently, when the child encounters a new trigger, such as another viral or bacterial infection, the immune system may again respond disproportionately, resulting in a temporary flare in symptoms.'

This is what happened to Jack. Within two weeks of starting antibiotics, the tics had gone, he became less anxious and returned to the bright-eyed, happy boy he had previously been.

But tonsillitis, caused by a Streptococcal infection, kept recurring - 11 times, in fact -

Many wrongly sent to mental health services

and each time it did, his symptoms would return.

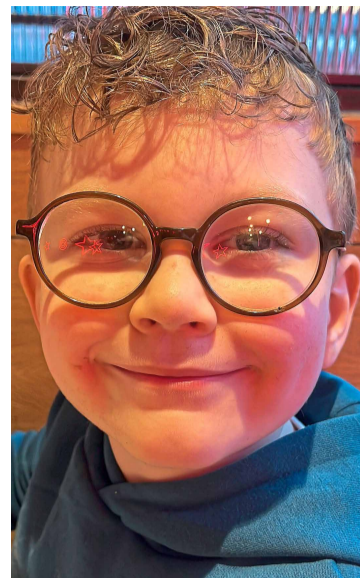
His consultant suggested he have surgery to remove his tonsils to stop this, and Jack was prescribed a further lower-dose course of antibiotics. Thankfully, his symptoms receded still further.

Eight years on, the only lasting effects are some residual shyness. And whenever he catches another bug, the tic returns, before clearing in a month or two.

'Because we know that it's PANDAS and not a psychiatric illness, it's OK,' says Neil.

PANS-PANDAS was identified in 1998 by Dr Sue Swedo, a paediatrician at the Developmental Neuroscience Branch of the National Institute for Mental Health in the US.

(More rarely, it can affect adults - sometimes the onset occurs in adulthood, but in other cases PANS-PANDAS



Extreme meltdowns: Ronan Begley changed overnight

symptoms that began in childhood persist into adulthood.)

Yet there is still no official UK guidance on the diagnosis and treatment of these conditions.

'We know of more than 8,500 families across the UK who are experiencing symptoms of PANS or PANDAS, and only a handful of them are able to access treatment via the NHS,' says Vicky Burford, who is now CEO of PANS PANDAS UK.

'The impact of these conditions in the family goes beyond just having a poorly child. We have seen so many family units broken, children unable to attend school, parents losing their jobs and even their homes. All for the want of NHS care.'

When Mhairi Begley went to ask a GP for antibiotics, saying she believed her son had PANS, one doctor told her, 'I would not give antibiotics for a child's behaviour.'

Ronan, a bright, articulate two-year-old in the summer of 2023, changed overnight into an anxious, clingy child, who had frequent, alarming meltdowns.

'People said, "It's his age and stage",' says Mhairi, 40, a secondary school teacher, who lives near Glasgow with her husband, Martin, 42, who works for the Home Office, and their sons, Ronan, now five, and Conrad, three.

'But we know the difference between a normal toddler tantrum and a meltdown - and these were extreme,' she says.

'Ronan also developed severe separation anxiety and became violent towards myself and Martin, and hurt himself.'

'He would scratch his face badly - scratches so deep they would last months - and he'd bang his head against things and bite himself. He also had disturbed sleep and went off his food. It was heartbreaking.'

Symptoms would improve, then flare up again whenever he caught a bug.

After two-and-a-half years of this, Mhairi managed to get Ronan in front of a 'brilliant' NHS neurologist who identified Ronan's symptoms as PANS.

Ronan is currently being treated with daily low doses of ibuprofen and antihistamines, with antibiotics whenever there is a flare-up in his symptoms.

'If we forget to give him a dose, it's noticeable,' says Mhairi. 'Our neurologist has

GOOD HEALTH

Jack's parents were told he was autistic - in fact, he had a little known condition that can be 'cured' with antibiotics

Triggered by everyday infections, PANS-PANDAS can make a child suddenly exhibit obsessive behaviour. But with many misdiagnosed, it's vital doctors are trained to spot the signs



Recovery: Jack Gilson is happy and loves playing sport

advised our GP to give Ronan antibiotics as soon as he gets an infection.'

Dr Ubhi says greater awareness and acceptance of PANS-PANDAS by GPs and paediatricians would spare children and families months, or years, of distress - and save the NHS untold sums spent treating the symptoms, such as anxiety and aggression, rather than identifying the root cause.

'The treatment [i.e. antibiotics]

is cheap and we have incredible stories of success,' says Dr Ubhi.

Indeed, according to a regular clinical audit at The London PANS Clinic, 71 per cent of patients have an 'excellent' response to treatment within two weeks of starting, he adds.

Yet many health professionals are reluctant to prescribe antibiotics, as Mhairi and other parents have found, when children are not exhibiting the typical symptoms of an infection (e.g. fever).

Doctors also feel anxious

prescribing two-weeks' worth of medication (seven days is the norm for antibiotics).

Dr Ubhi set up The London PANS Clinic because of his despair at the lack of NHS help for patients with PANS-PANDAS. The clinic has now treated nearly 2,000 patients and works with researchers at Stanford and Yale universities in the US to develop better understanding, diagnosis and treatment of the conditions.

For instance, the PANS-PANDAS

team at Stanford University are currently studying the mechanism by which the antibodies generated by a Group A Strep infection breach the blood-brain barrier, then cross-react with proteins in the brain, causing behavioural changes.

PANS PANDAS UK, meanwhile, is collaborating with the Royal College of Paediatrics and Child Health (RCPC) to produce a set of treatment guidelines, which will then be reviewed by NICE (the National Institute for Health and Care Excellence). These should be published by the end of this year.

And it is hoped that a study planned by the Royal College of Psychiatrists and the RCPC, to learn more about the conditions' prevalence and to better identify the symptoms associated with PANS or PANDAS will be given the go ahead. This should mean faster diagnosis and treatment.

PANS PANDAS UK is also calling for mandatory training for all medical professionals in recognising the condition.

Improved awareness cannot

come soon enough, believes Professor Gupta. He points out that, despite a statement outlining that NHS England recognises the conditions, 'NHS resources for PANS-PANDAS are still extremely limited.'

'There is still a lack of awareness and understanding about PANS-PANDAS - unfortunately the condition is not universally accepted within the NHS.'

But with the correct treatment the recovery can be dramatic, says Professor Gupta: 'We often hear parents say, "We feel we've got our child back" - that's so lovely to hear. That really keeps me going to try and make a positive difference for these children, young people (and adults) and their families.'

■ JACK'S father Neil aims to become the first person to swim Switzerland's ten largest lakes starting on June 14 in support of PANS PANDAS UK. Visit [givewheel.com/fundraising/8194/](https://www.givewheel.com/fundraising/8194/)

■ FOR more information, visit [panspandasuk.org](https://www.panspandasuk.org).

SYMPTOMS TO WATCH OUT FOR

ASK your GP if it could be PANS-PANDAS if your child develops a sudden onset of obsessive-compulsive disorder (OCD), tics or severely restricted food intake combined with two or more of the following:

- ANXIETY, including separation anxiety, irrational fears and panic episodes.
- SUDDEN mood changes and/or depression.
- IRRITABILITY, aggression and/or severe defiant behaviour.

■ SUDDEN deterioration in school performance, including hyperactivity.

■ INVOLUNTARY movement and/or sensory abnormalities (e.g. finding textures unbearable).

■ REGRESSION - a loss of behavioural and/or developmental skills.

■ INSOMNIA and/or sleep problems.

■ INVOLUNTARY urination/bed-wetting and/or a need to urinate frequently.