

A close-up photograph of a woman and a young girl sitting in a car. The woman is on the left, smiling warmly, and the girl is on the right, smiling broadly with her mouth open. They are both looking towards the camera. The background shows the interior of the car, including the window and door panel.

# Evie's Story

I imagine people think that if I was braver, tougher, stronger.. then I wouldn't have suffered all these years. Like it's my fault that I am not getting well, that I've caused this."

- Evie

## Introducing Evie

At six years old, Evie loved to dance, especially tackling the quick step which saw her whirling across the floor, full of energy and beaming with confidence.

But, returning to class after a bout of Strep throat, Evie suddenly began to find the steps much harder. She felt **exhausted**, became **uncoordinated** and would often feel too **dizzy** to dance. She had no idea what was happening, or why her favourite activity was suddenly so much harder to do.

Evie developed **severe anxiety** and found it challenging to be apart from her parents for any length of time. Where previously she had loved school and was always excited to attend, it was impossible to walk through the school gates.

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It was like I was different person. I was suddenly so nervous but couldn't explain why, I was just scared of everything.

I had this feeling I'd never experienced before, thinking 'what is going on, why do I feel this way'?

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“ I just remember not wanting my parents to leave me at school, but I didn't know why. I liked school, I'm a hard worker and I wanted to be with my friends, but I also didn't want my parents to leave. I was only seven, but I remember it clearly and I still can't explain it.

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With support from her parents, Evie was initially able to continue her schooling, but found the experience exhausting as she battled with **anxiety** and **frequent panic attacks**. This became much harder after contracting Strep again a few years later. Evie developed **sensory difficulties, restrictive eating, insomnia** and began to experience **terrifying hallucinations**. Physically and mentally exhausted, Evie was **unable to leave her bedroom for six months**.

## Living with PANDAS

At 12 years old, Evie was diagnosed with PANDAS and given a course of antibiotics. Her **symptoms reduced**, enabling her to begin home-schooling and manage her condition. Now, Evie experiences these symptoms as flares, **ranging in duration** from days to weeks, with some gaps in between.

Now 15, her life has improved slightly, but Evie still finds it difficult to leave the house, or to have visitors, because she can't predict when these flares will happen.

Sadly, one of Evie's biggest battles is helping the people in her life to understand what her condition is, and how it affects her. Evie often finds herself having to change plans last minute because of **sudden exhaustion** or **anxiety**. This has led to some people in her life questioning whether she is really ill, or struggling to understand the **constant changes in her behaviour**.

When I'm not believed, I start to doubt myself. I imagine people think that if I was braver, tougher, stronger.. then I wouldn't have suffered all these years. Like it's my fault that I am not getting well, that I've caused this.

Shockingly, some of the people who have questioned Evie's experience have been medical professionals. Over the years, many doctors didn't believe what Evie and her parents described, because they were unable to see the symptoms first-hand.

Even after her diagnosis, some doctors remained sceptical. On more than one occasion, Evie's parents were accused of being overprotective and indulging their daughter by letting her stay at home. Something that upsets and angers Evie:



My parents are amazing, they have never blamed me or suggested I was doing this for attention or to skip school. They have always trusted that I wouldn't want to do that to myself or to my family. No matter what people have said to us, we know in our hearts what is true, and we know that we are trying our best.

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There are two sides of me; when I am 'me', and when I have got PANDAS.

In some ways I think people might believe me more if they saw me during a flare, but I don't want to be associated with that version.

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Whilst managing her recovery, Evie and her family have drawn immense support from the **PANS PANDAS UK community**. They have developed friendships with other families affected by PANS or PANDAS, and Evie regularly contributes to our **Youth Advisory Board**.



I'm so grateful for the amazing opportunities to speak out about PANS and PANDAS. Not only is it nice to see that people are trying to raise awareness, I'm actually seeing first-hand that it is happening.

It's an exciting and hopeful time, and that makes me feel positive about the future.




## 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

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