



PANS PANDAS UK
awareness support education

BELLA'S STORY

I would say our daughter, Bella, has always been a sensitive child. As a little girl, she seemed to have lots of friends at school, although she would often feel 'left out'. She was funny, bright, friendly, creative and full of energy.

At 11 she started secondary school. The first two terms went really well and then she started having problems with her friendship group and became a very anxious and emotional child. By the end of the school year, we had decided to move her to another school.

We were relieved it was the summer holidays and she could have a break from the stress of school. We were having a very special holiday in Tanzania and Bella was so excited about it. On return from our holiday, Bella became very unwell with tonsillitis and a terrible tummy bug. She was so poorly that doctors decided to test her for Malaria even though she had been taking medication to prevent it.

The new school year started but Bella was still too poorly to attend. Eventually, she was well enough and so went back to school. But she was so utterly distressed at the prospect of returning and did not want to leave my side and became very emotional most days with lots of screaming and raging. I put it down to her friendship issues and assured her that I was doing all I could to get her into another school.

As part of the process to move her to another school, we had to get a psychologist to assess her and confirm that staying at her current school was affecting her

mental health. It was during her final assessment appointment with the psychologist that our world caved in. The psychologist told me that Bella had disclosed that she was planning to kill herself. She also said that Bella was hearing voices. It was devastating and I was terrified for my little girl.

I immediately took her out of school while awaiting the results of our appeal. I also took her straight to our GP who did an emergency referral to CAMHS. We later received a letter from CAMHS telling us our appointment was in 3 months time. I could not believe they could leave a suicidal child without help for so long.

Within a few days of her disclosure of her plans to kill herself, she began to have episodes of huge distress at the violent and often very sexual intrusive thoughts that were plaguing her constantly. She wasn't able to sleep and stayed awake late into the night. When eventually she did sleep, she would wake several times screaming from terrifying nightmares.

We had to keep our windows locked as Bella kept trying to jump out. On one occasion she was trying to get out her bedroom window but had been spotted by her 8 year old brother. He ran over to her and grabbed her feet to stop her and screamed out for us. I have never felt so heartbroken and devastated than seeing my 12 year old daughter in such distress she was trying to kill herself and her little brother hanging on to her trying to save her.

Other more subtle changes had happened too. She said she couldn't read anymore because the letters kept jumping around. Her concentration span was non-existent and all her senses seemed to be turned up to extra high.

A week had passed since the disclosure to the psychologist and so much had happened and Bella's state of mind had deteriorated so dramatically. Just when I thought things couldn't get any worse, they did. We were in the living room and Bella started screaming and pointing to something in the room. We couldn't see what it was. Hysterical, Bella said there was a gollum-like creature and he was coming to get her. She screamed and screamed and tried to run out of the house

to get away from 'it'. She would have done it too if she hadn't suddenly dropped to the floor having a violent seizure. It was so terrifying, I can't even explain to you how awful that moment was.

We took her to A&E where, after hearing about her experience at school, said that the seizure was an extreme panic attack and anxiety. Not a single test was done. Bella told them she was going to kill herself and so she was admitted on the children's ward to await an assessment from the Crisis Mental Health Team. We waited three days on the ward before they came. During this time Bella was hallucinating, having seizures, screaming and trying to attack herself, clawing at her face and ripping her hair out. This was all on a ward filled with other children and their families. The staff on the ward completely ignored us with the excuse that they were not mental health nurses and therefore they could not treat her.

At the end of the third day on the ward, the crisis team turned up. Having had a discussion with Bella separately and then with us, they concluded that she was suffering from extreme anxiety and sent us home with an appointment in a week's time. I was so angry. During the car ride home, Bella tried to jump out of the car onto the motorway.

Bella was now having up to 30 seizure type episodes a day, hardly sleeping, extreme mood swings, hallucinating and being driven demented by horrific intrusive thoughts. We were having to hold her down to stop her from hurting herself.

It was like we had lost our little girl. At one point I became convinced she had been possessed and got a priest in to bless the house. When that didn't help I even paid for a woman to come in and perform cleansing rituals. I couldn't comprehend how catastrophically Bella had changed from being a generally happy pre-teen to a suicidal, hallucinating and raging child who was having multiple seizures a day.

We finally got to see a key worker at CAMHS a week later. Again, they did not want to do any tests on Bella to check there was not something else going on. They put it all down to the friendship issues she was having at school. I conceded that this certainly played a part but it didn't seem to explain all her symptoms and how she had got so bad so quickly. During the session Bella fell to the floor having a seizure. I went down beside her to hold her hand and comfort her. The CAMHS worker said, 'don't do that mum, you need to imagine she is a little toddler again and just wanting attention'. I could have slapped that woman across the face.

We left.

My husband's job provided health insurance and so having decided CAMHS was not good enough to help us, we went to a private psychiatrist. She was horrified that her seizures had not been investigated and immediately sent her for an MRI and a 24hr EEG. They came back clear.

Bella was continuing to try and kill herself and we had to be with her 24 hours a day and never leave her side. She was also self harming. I was so stressed I couldn't sleep and was unable to eat. Bella was hardly sleeping and struggling with the continuing intrusive thoughts.

The psychiatrist decided that Bella was a danger to herself and as frightened, shell shocked parents, we very reluctantly agreed for Bella to be admitted to a psychiatric hospital. Bella was keen to go as she was desperate to feel better.

It was a very traumatic time for us all. Poor Bella, at only 12, was the youngest there. The other patients were very poorly too and the things she saw and heard in the 6 weeks she was there will never leave her.

She was diagnosed with OCD and given medication for anxiety as well as antipsychotics and came home. It was now three months since she had become ill.

Bella was accepted into a new school and wanted to go and be 'normal'. It proved impossible though. We often couldn't get her into school in the mornings as she kept having seizures or becoming overwhelmed with anxiety or having the most massive rage episodes that left her exhausted. The school was very understanding and she was able to have a reduced timetable. We were supported by the SEND team and the School Family Worker who could not have been more kind and accommodating.

Bella's little brother was starting to suffer under the stress of what was happening at home. He fretted at school, worrying his sister would be dead by the time he got home. He felt very responsible for her. His primary school were fabulous and referred him to young carers where he received therapy and learning skills on how to cope with his worries.

In the meantime, Bella was being put on medication after medication in an attempt to find one that would help her symptoms. But nothing seemed to work.

In June, 8 months into this crisis, I had to give up my job to look after Bella. She was not able to attend school at all by now and my mother, who had been looking after her while I was at work, could not cope with the enormous and stressful job of managing her in my absence.

Then, in July, my husband was made redundant. As well as being a blow financially, it was also the end of our private health insurance and we were left with no choice but to go back to CAMHS.

Our lives continued in a new normal. It was hell. My days were spent on my laptop researching and reading and researching and reading trying to find

something that could help me understand what was going with Bella and what I could do to help her. I was struggling to believe that this was all OCD and anxiety from school.

In the beginning of August, just as the holidays began, we all got summer colds. At the same time, Bella's mental health deteriorated even more. She would have episodes where she didn't think we were her real parents and hid under the bed screaming for her brother to run away before we got him. She started having ticks which made her neck snap back and her arms flap up and down. She had verbal ticks too, whooping and whistling. She became very suicidal and tried to take pills but we thankfully got them out of her mouth before she swallowed them. We hid all the knives as she was determined to cut her wrists.

CAMHS wanted to admit her for her own safety. Exhausted and terrified, we agreed. This was worse than the first admission. Another teen on the ward had smuggled in razor blades and handed them out to the other patients. Thankfully Bella said no thanks but plenty took up the offer. In front of Bella, the other kids took out their blades and sliced their arms and legs. There was blood on the floor and walls. Bella and another child were shut in a room with glass walls called the fish bowl while the staff dealt with the incident.

We were horrified when we learnt of what had happened and what she had witnessed. I wanted to take her out and bring her home. But we were told that if we did, she would be sectioned as they believed she was still a danger to herself. I couldn't risk her being sectioned as we would lose control altogether.

This time she was diagnosed with OCD, major depression and conversion disorder.

Two months later she came out. She had actually improved despite only having a small increase in her meds. Her voices and hallucinations had all but gone. She was going days without seizures and her rages were rarely seen. The summer

holidays ended and she was looking forward to going back to school. We couldn't believe how much better she was.

Two weeks into starting school, Bella developed a sore throat and had a few days at home. One evening she was sobbing in her room and I came in to see what was wrong. She cried, 'my voices are back'! Then like a tidal wave, all the symptoms came back...hallucinations, intrusive thoughts, seizures, ticks. It was devastating. It almost felt worse than the first time she became ill as this time we knew what was ahead.

Again she was not able to attend school.

She would have episodes that would last for minutes to hours and even days where she would be completely paralysed from the waist down. You could literally stick pins in her legs and she couldn't feel a thing. To make matters worse, she would also lose her sight or hearing. Then, it would return after a few minutes. Again, we took her to A&E and again, we were told by the crisis team that it was anxiety due to her friendship issues.

After a conversation with my aunt in New Zealand, she asked if I had ever heard of PANDAS. Admitting I had not, she explained that it was an auto-immune illness and triggered by a strep infection. I got on to google and started reading. I cried. With the exception of urination issues, it described Bella's experience exactly. I went on to Facebook and found a group PANS/PANDAS UK. I joined and read avidly through all the posts. I had joined many Facebook groups trying to find one where I felt I could connect with what members were experiencing with their children. I joined one for childhood schizophrenia and another for OCD but whilst I could identify with some of the posts, most did not sound like my daughter's experiences. But the PANDAS group was like a lightbulb going off.

It took a long time to find the right professionals to help but eventually we settled on a private Neurologist and a private Immunologist. Two weeks into antibiotics and Bella's seizures reduced to 2 or 3 a month. Over time they got even less.

Ticks disappeared and her rages reduced dramatically. Bella's blood results showed high strep titres of nearly 800. She had high protein count in her cerebral fluid indicating inflammation in her brain. At last there was proof that it wasn't all about mental health illness and friendship problems at school.

We still have a very long way to go. Flare ups happen and when they do, everything comes back with a vengeance. She self-harms and has attempted suicided several times. The psychiatric symptoms are still very much around. There have been several visits to A&E and an overdose. But we now have amazing professional support. Our GP is wonderful and supportive, our private Neurologist and Immunologist are brilliant. And although CAMHS was total rubbish, they did one good thing, and that was refer us to the Dialectical Behaviour Therapy team where they have worked so hard with Bella in helping her mental health. They are on board about PANDAS and even read up about it so they could better support her.

It took us 2.5 years to get to the point of having the right team around us. I had to fight tooth and nail to get the help Bella so desperately needed. She missed out on 3 years of school and the chance of having a happy teenage life. I'm angry that nobody thought to investigate her symptoms further when she first presented at her most poorly. I'm angry that she had to endure seizures for so long when all she needed was antibiotics to make them go away.

Bella is the bravest and most incredible human I have ever met. What she deals with everyday is beyond comprehension. But she tries and tries and pushes herself. I love you Bell xxxx