

Lacey recovering on ward S2 at Sheffield Children's Hospital

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**I can't put in to words what it feels like to be told your two year old daughter has a life-threatening brain tumour. And that it's growing so deep inside her head that they might not be able to remove it all.**

The support I received from The Sick Children's Trust whilst my daughter was recovering from lifesaving surgery is something I will never forget.

When Lacey was just 18 months old, I began to think that she wasn't well. I persuaded my GP to refer us to a paediatrician at our local hospital, The Diana Princess of Wales Hospital in Grimsby. The paediatrician thought Lacey was fine, but told us to come back for a follow up appointment in 12 months' time. However, rather than improve, it seemed that over the next year Lacey got worse. She fell over a lot and her knees didn't bend properly. When we went back for the appointment, I asked that Lacey have an MRI scan and the paediatrician agreed.

After the MRI, we went back home to Louth in Lincolnshire where we live with my partner, Alex. We had to wait for the results which at some points felt like an eternity. But the call came one Saturday at the end of July and we were asked to go to the hospital immediately. All of us raced to the hospital where we were taken straight to the paediatrician's office. I clung to Alex's hand as we were told that Lacey had a brain tumour and it could be cancerous.

You expect things to move like lightening from that point, but they didn't for us. We were advised to go home and wait for a referral from Sheffield

Children's Hospital. The tumour was tiny, measuring at only 9.5mm long. But the consultants needed time to establish whether it was growing or not. Three months later Lacey had a second MRI and again we had to wait for the results, but during that time I received a call from Lacey's nursery. She had been violently sick. Concerned, I immediately rang the hospital to chase up the MRI results. This was the earth shattering moment that I found out that Lacey needed to have brain surgery. The tumour was growing.

In the blink of an eye we were in a hotel in Sheffield, over two hours from home, waiting for the hours to pass until Lacey's lifesaving operation. I was terrified, but knew I needed to be brave for my little girl. At 10am the next morning, Lacey went into surgery. I had been warned it would take all day as it was a very complicated procedure. The tumour was so deep and located on her cerebellum, which is the part of the brain that contributes to coordination, precision, and accurate timing. No wonder Lacey had kept falling over.

Lacey was in surgery for ten hours and it wasn't straightforward. Her blood kept clotting and in the end the surgeons had to stop because her condition was deteriorating. They hadn't managed to remove all of the tumour and when she finally came out of surgery her airway was very swollen and she couldn't breathe. She was taken to the high dependency unit (HDU) where for six hours I watched on helplessly as my little girl grew weaker. By 2am her airway was so blocked that even a nebuliser wasn't able to deliver the medication she needed. The decision was made to admit her onto and the paediatric intensive care unit (PICU) and ventilate her so that her little body didn't have to struggle so much. As Lacey was wheeled away on a trolley, I was left on my own with the thought that I would never see my daughter alive again.

Fortunately Lacey stabilised and the next morning a nurse on PICU told me about The Sick Children's Trust, a charity which runs free 'Home from Home' accommodation. At Sheffield Children's Hospital, there were two – Magnolia and Treetop Houses. I hadn't heard of the charity so was surprised when she said there was a room for me to stay in. Lacey was still unconscious but I just wanted to be there with her to hold her hand. However, the nurse assured me that the 'Home from Home' wasn't far and persuaded me I needed to rest. Reluctantly, I kissed my daughter goodbye and let Ann, the Magnolia and Treetop House Manager, show me around.

As I unlocked the door to my room in Magnolia House, I felt incredibly emotional. It was lovely. I decided I would just lie on the bed for just a few minutes. The bed was so comfortable that I fell asleep immediately and managed to get a few hours of much needed rest! Miraculously, when I returned to PICU, feeling a little refreshed and stronger, Lacey was off the ventilator and breathing by herself, albeit on very strong steroid medication.

Over the days that followed, Magnolia House and then Treetop House became my lifeline. Even though they are within the hospital grounds, it doesn't feel like you're in that environment. It feels like you are at home. The decoration, furniture, books and toys make it so homely and it feels like you can escape the beeping of the machines for a bit. You can get away from the trauma and the stress that comes with having a seriously ill child in hospital. Although I couldn't relax completely, I could get a little respite and the houses gave me somewhere comfortable to reflect. I was also able to make a cup of tea or some food when I wasn't on PICU with Lacey, which was important because I needed to keep my strength up for my little girl.

Home is over two hours away and I don't know how I could've managed the daily journey to Sheffield. Especially with the cost of petrol and I could not have afforded to stay in a hotel close to the hospital. It wasn't just the practicality of the 'Homes from Home' that was important, the emotional support I received from the staff was priceless. There are also other people's stories all over the walls, which gives you a sense of hope, as you can read what they've been through and the positive outcomes. You have to stay hopeful for your child, but it can be quite isolating, so reading stories and speaking to other parents in the house really helped.

Lacey went back onto HDU before being moved up to ward S2, the hospital's dedicated neurosciences ward, but shortly after being moved she went downhill. Her heart rate plummeted to just 42 beats per minute and the monitors began to beep. The doctors were concerned with her recovery – Lacey was sleeping a lot and when she was awake she was having dreadful tantrums, which was very out of character. From a CT scan they identified she was suffering from hydrocephalus, an accumulation of cerebrospinal fluid (CSF) on her brain around the cerebellum and attempted to drain it.

It was a very scary time because the increase in pressure on Lacey's brain could have caused brain damage. Eventually a neurosurgeon had to operate on Lacey and a thin tube, called a shunt, was implanted into her brain

through which the excess CSF could flow. Lacey had to have two operations, as the first shunt became blocked. I just waited for my little girl to come back to me and then finally, a day after the second shunt surgery, Lacey was herself again. Her real recovery then began.

I continued to stay each night at Treetop House. The staff were always there to comfort me. The specialist was convinced the tumour was cancerous and that Lacey would need radiotherapy and chemotherapy, but by some miracle it was benign. It was the staff in Treetop House that reassured me that everything would be OK whilst I waited for the results. And it was the staff who were there as a shoulder to cry on when it all got too much. Without The Sick Children's Trust I would have been waiting alone, so I can't thank Ann and Nichola enough for being there for me.

Finally, just two days before Christmas 2017, Lacey was discharged and we went home. Although quiet, we had a lovely time on Christmas Day. We all had so much fun opening our presents and Lacey loved playing with her new toys. I still felt in shock and numb from everything that had happened. After so long away, I couldn't quite believe we had made it home in one piece.

Lacey is growing stronger and she is having both physiotherapy and occupational therapy at home, which will help her to walk again and manage her thoughts and behaviour. She will need further appointments and in the future will be monitored closely by the hospital in case the tumour that remains grows any bigger. When we go back for her follow ups we intend to pop in and see the staff at Treetop House, to let them know how well Lacey is doing and thank them for their support.

**Dani Spence, Lacey's mum.**

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The Sick Children's Trust was founded in 1982 by two paediatric specialists Dr Jon Pritchard and Professor James Malpas. They believed that having parents on hand during hospital treatment benefited a child's recovery.

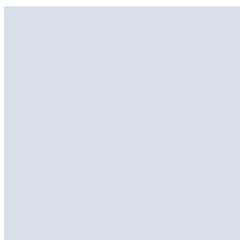
Today we have [ten 'Homes from Home'](#) at major hospitals around the country where families can stay free of charge.

Every year we help around 4,000 families, but there is a growing demand for

our 'Homes from Home' as children must increasingly travel long distances to get the specialist treatment they need.

We are working to a future where every family with a seriously ill child in hospital will be able to stay together, just minutes from their child's bed during their treatment.

## Contacts



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