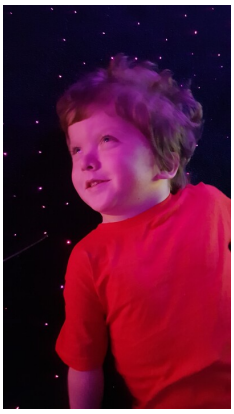
Treetop and Magnolia Houses have been our lifeline during our darkest times, without them we don't know how we could have coped

Monday 18 December, 2017

Media:



My son, Zac, arrived 11 weeks early at only 29 weeks on 30 January 2013 at Bassetlaw District General Hospital (BDGH) and I knew immediately that something was very wrong. I had needed an emergency caesarean and I had a couple of minutes with my baby before he was whisked away. Zac was born with hydrocephalus, caused by an excess of cerebral spinal fluid (CSF) on his brain, and was soon diagnosed with cerebral palsy (CP).

Stuck in a hospital bed, it was my husband, Andy, who comforted me and told me Zac had been transferred to the Jessop Wing in Sheffield's Royal Hallamshire Hospital and that we could follow him there as soon as I could be moved.

The next day the doctors agreed to transfer me to Jessops too, so I could be close to Zac. My blood pressure was all over the place and I wasn't discharged for a week, but that's when everything became a nightmare of car journeys to and from Worksop, and family tension as I couldn't drive after surgery. Over the next two months my husband would arrive home from his night shifts exhausted and wanting to sleep and I would need to be driven straight to Sheffield to be with my baby. Looking back I don't know how we really coped and with all the upset and stress of worrying about Zac. It was horrible being so far away from him. I felt like he could sense when I wasn't there, but fortunately when he was just over nine weeks old he was stable enough to come back to BDGH, which is within walking distance of our home.

A week later doctors became concerned as Zac's head began to swell and he was deteriorating fast. We had thought he was going to be discharged and were just waiting for oxygen to become available to take home, so it was another horrible shock when he took a turn for the worse. Unable to support him any longer at BDGH, the EMBRACE team arranged to collect my baby and take him to Sheffield Children's Hospital. Whilst we were waiting for them to arrive, Andy and I were told about The Sick Children's Trust. A nurse told us that whilst Zac was being treated on the high dependency unit (HDU) we could stay in free accommodation provided by the charity, just minutes from our baby boy. Honestly, I can't tell you how much The Sick Children's Trust helped our family – I think it saved my marriage, because we were no longer stressed about travel to and from the hospital and taking our fear and anger out on each other. Andy could stop at the 'Home from Home' when he wasn't at work, without worrying about driving miles and miles to see Zac.

We stayed at Treetop House for two months before we got to take Zac home for the first time. Being able to stay at Treetop House meant that an unbearable situation was made more bearable. It was a safe haven in a time of huge stress and allowed for us to be close to our son, but also have somewhere to retreat for some quiet time together. It also meant that close friends and family could visit, making a very lonely time slightly less so. But it also put us amongst other families who were going through a similar situation. This enabled us to share our days with each other, the good and the bad. We have stayed in touch with some of the other families we met there having bonded through our shared experience.

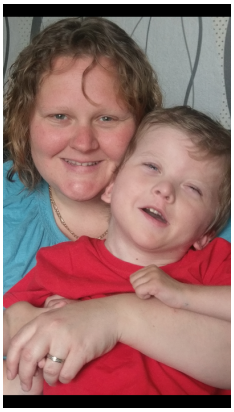
After Zac was discharged he continued to be monitored closely at Sheffield Children's Hospital as an outpatient and it wasn't until earlier this year that we relied on the generosity of The Sick Children's Trust once again. We had seen Magnolia House four years earlier, and knew it was even closer to the wards so when the pressure built up in Zac's brain at the end of February and he was admitted to the hospital, The Sick Children's Trust offered us a room there. It is awful when the pressure builds up on his brain due to excess CSF as Zac begins to make unusual movements, as though he is having a seizure and then becomes so sleepy and can't keep down any of his feeds. Zac will always need to be tube fed.

2017 has been a tough year for Zac. He had to be put into a medically induced coma in February and even though it was only for a few days, it felt like years. Being close by in Magnolia House meant I felt comfortable to leave his side for a quick shower or to make some food, knowing I could be back in under a minute. We have stayed with The Sick Children's Trust three times this year and Zac has had surgery twice for a shunt, which relieved the pressure on his brain. He is an amazing, brave little boy and I can't believe he is almost five years old. Zac suffers from other complex conditions and will never walk, talk coherently or be able to see anything but shadows, but most of the time he is a happy little boy who amazes us with his playful nature and chattering.

Although we don't know what the future holds for Zac, the doctors are impressed by how well he has

recovered since his last operation in September. We have stopped asking about his prognosis or making plans for the future because what is important to my family is the here and now so we take every day as it comes and are grateful for every moment we have with Zac.

Becky Keith, Zac's mum



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