The Sick Children's Trust gave us a 'Home from Home' for over eight weeks whilst Oscar was in hospital. When we were going through hell they provided us with some sense of normality.

Wednesday 6 June, 2018

Just two days after we found ourselves in an unfamiliar hospital, over an hour from home, where our son lay where our son lay in a bed on the neurology ward surrounded surrounded by doctors, The Sick Children's Trust came to our aid and supported us in a way we could never have thought possible. Having somewhere to stay, first at Magnolia House and then at Treetop House, totally free of charge and just two minutes from Oscar's side, helped us to stay sane and therefore meant we could be the best Mum and Dad to our son.

Oscar was diagnosed with autism in August last year. It took a long time to get this diagnosis, so, although it was traumatic to find out that our three year old son had a developmental disability that would impact him throughout life, it also came as a relief because it meant we had the help of local specialists to come up with the best possible educational care plan for Oscar. It also meant my husband, Craig, and I knew where we stood in terms of his wellbeing. Or so we thought.

Although Oscar had suffered from three seizures during the first four years of his life these had all happened when he had been under the weather and run down and he wasn't diagnosed with epilepsy. However, in February this year, that all changed when Oscar had his worst seizure to date. As soon as we realised what was happening we gave him his rescue medication, which was sadly ineffective and he continued to fit. It wasn't long before the paramedics arrived and Oscar was rushed to Doncaster Royal Infirmary for emergency treatment on the high dependency unit.

We spent ten days in Doncaster. Oscar had an ECG and CT scan, both of which showed inclusive results. He also had a lumbar puncture, where a sample of his spinal fluid was tested. With no infection being flagged up, doctors thought he was getting better, but we knew our son and we knew something more sinister was at play. He wasn't himself and kept flinching, as if in serious pain. Craig and I decided he needed to be examined and diagnosed by a consultant who was familiar with him and his normal behaviour so took him into Scunthorpe General Hospital as soon as we could, where he had been cared for up until this point.

As soon as he was seen in Scunthorpe, an electroencephalogram (EEG) was arranged for early the next morning. This is a test used to find problems related to activity of the brain and showed that Oscar was suffering from encephalitis, an uncommon but serious condition in which the brain becomes inflamed. His consultant broke the news to us that encephalitis is a life-threatening condition, which had led to Oscar's symptoms and seizures, but it meant he also needed lifesaving treatment at a specialist hospital far away from home.

Before we knew it we were at Sheffield Children's Hospital with just an overnight bag between the three of us. Oscar was admitted onto the neurology ward and, already heavily sedated, was put onto a course of antibiotics to try to calm the agitation in his body. For two nights Craig and I stayed on the ward, trying to get a few hours' sleep here and there but with poor results. Then, out of the blue, a nurse mentioned The Sick Children's Trust and that there was a room for us at a place called Magnolia House. We hadn't heard of the charity before this and would never have expected to be given free accommodation, not least just moments from where Oscar was receiving lifesaving treatment.

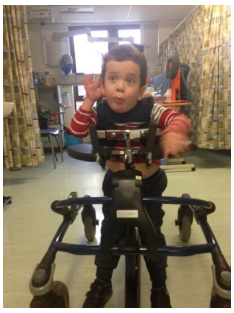
Ann, the manager at both Magnolia and Treetop Houses, showed us around and it was amazing. When you are sleeping on the ward you can't switch off, but there we had a warm and comfortable private room, with access to a great bathroom and even facilities where we could cook and prepare meals. It made an immediate difference to my state of mind – suddenly we had somewhere we could get our heads down and escape to for some emotional support and comfort. After three days at Magnolia House we moved over to Treetop House, just a lift ride away from where Oscar was being treated.

Oscar was very poorly and the antibiotics hadn't worked so he was put onto a course of strong steroids for a couple of weeks. He was still heavily sedated, which was terrifying to see, but we were hopeful that once the swelling on his brain went down, he could move into the rehabilitation stage. After two weeks Craig had to go back to work, which was difficult for us both, but he continued to return to Treetop House every evening and I could make him dinner in the kitchen there and we could fill each other in on the

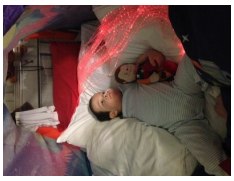
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day's happenings whilst being there for Oscar. We also spoke to other families, who were going through a similar experience and, like us, struggling to process very complicated traumatic emotions. The emotional support we gave each other in Treetop House was mutual and we are still in touch with families who continue to be supported by The Sick Children's Trust.

It was a very long eight weeks before we got to take Oscar home. He still wasn't himself and the day we left Sheffield was the first day he walked since his initial hospital admission. Since then he has been having 10-15 seizures each day, been diagnosed with epilepsy and we are still working on getting him the correct medication. Some of the medication used to treat his condition can cause terrible side effects and Oscar has been very angry and frustrated at times, but we think we are over the worst of it. Because he is non-verbal it is so hard to know what he is thinking, but he recently started St. Luke's specialist school in Scunthorpe and after half-term will progress to being there fulltime. Looking back we couldn't be more grateful to The Sick Children's Trust. At a time of such uncertainty and worry they offered us a practical way out of our predicament, not to mention deep emotional support and comfort.

Emma Sutton, Oscar's Mum.

About The Sick Children's Trust

The Sick Children's Trust is 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.

We believe keeping families together significantly improves the recovery of seriously ill children. We provide free, high-quality 'Home from Home' accommodation, as well as emotional and practical support, to families with sick children in hospital in the UK.

The Sick Children's Trust was founded in 1982 by two paediatric specialists Dr Jon Pritchard and Professor James Malpas. Today we have ten 'Homes from Home' at major hospitals around the country where families can stay free of charge, for as long as they need whilst their child is undergoing treatment.

We support around 4,000 families every year, and there is a growing demand for our 'Homes from Home' as children must increasingly travel long distances to get the specialist treatment they need.
www.sickchildrenstrust.org

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