



Our son Harrison was just four weeks old when he was suddenly taken ill and subsequently rushed to Great Ormond Street Hospital (GOSH).

After various tests he was found positive for Group B Strep which had led to meningitis. This was an incredibly stressful time for us and there were moments when we thought we'd lose him. He stayed there for a total of 12 days before being transferred to a neurological ward for another week.

During this time we stayed at Rainbow House and were extremely grateful to The Sick Children's Trust for supporting us as it gave us the opportunity to be as close as we could to our son.

We would have not been able to travel backwards and forwards to GOSH as we lived in Essex, which was a round trip of three hours; undertaking this daily would have wiped out any energy my husband and I had left and we needed to save all our strength to get Harrison through this horrible time. We looked into the possibility of staying in a hotel but this wasn't financially feasible for us the only other option was sleeping on the sofa in the family room, something I know that GOSH would have preferred we didn't do but wild horses wouldn't have made us leave our son. As a mother I needed to be as close to him as possibly to bond with.

When we heard about Rainbow House it was like our prayers had been answered. It allowed us to catch some sleep and re-charge our batteries for each day which was what we desperately needed after some of the dreadful days we had with Harrison. The house gave us a sense of normality. We brought a couple of meals into the kitchen to heat up and it was a godsend. The kitchen was so well equipped with your own storage space if needed and it was good for our first cup of tea in the morning to wake us up!

It also gave us privacy for much needed discussions, tears and just moments of desperation that we didn't want to share our sadness with the other families going through their own traumas.

After a week in the hospital we were told some news that left us having to face the decision of turning off our son's life support. As you can imagine this was the most desperate situation we could have ever faced. Having just one family room at the Paediatric Intensive Care Unit (PICU) meant that you would go off into corridors or find quiet spots to break down, discuss and relay information. They gave us a private room on the worst day to talk with our families but myself and Richard needed time to be alone with our thoughts and to discuss our feelings and options. Coming home to the house gave us that much needed release to really break down and have a "proper" melt down. It got me through the day knowing that I would have privacy at Rainbow House at the end of very hard days.

Staying at the house was not only a relief for my husband and I but also took the pressure away from our families worrying about whether we were getting any rest

and sleep whilst away from us, where we were sleeping and that we had somewhere to keep the mountains of belongings gradually being brought up to us. It also kept our family unit together as we were allowed to have our other son stay with us if we wanted to, this helped reassure him that we were there for him too as we were missing him desperately but Harrison was so unwell that we daredn't go back to Essex.

Even though Harrison was so young that he didn't know what was going on, I am sure he knew that we were there as much as possible. When he was conscious it meant that we were there when he went to sleep and there when he woke up. It also meant that we were getting the rest we needed to be at our best for him when he needed us the most. The staff at GOSH encourage you to go to sleep at night rather than keep vigil by his bed, so that we could build up our energy for the day that he would eventually wake up. This was sound advice, something we passed on to many new families arriving at GOSH PICU while we were there. The situation that we were dealing with was enough to take all of your stored up energy. We would have fallen apart without the rest that we got of a night at Rainbow House.

Harrison is home now and so far is doing well. We know that he has permanent brain damage but what that means for him in the future we don't know. But he is here and we have him home. He is our little miracle when we think of where we were at one point. Our family is doing well and we have fantastic support from lots of healthcare professionals monitoring him and brilliant families around us. We can't thank The Sick Children's Trust enough for being there for us during this extremely stressful and frightening time, they made it just that little bit easier to cope.

**Kelly Grahame, Harrison's mum.**