Those two weeks that Quinn was in hospital were very long and very tough, but having a room in Eckersley House made all the difference

Thursday 11 October, 2018

Paige Lewis, 19, from Bingley, was supported by The Sick Children's Trust, a charity that supports families with seriously ill children in the country's leading paediatric hospitals. She was given free 'Home from Home' accommodation for two weeks at Eckersley House when Quinn was rushed back into hospital shortly after being born and required an emergency transfer to Leeds Children's Hospital from Bradford Royal Infirmary. **Here she tells her story:**

My gorgeous son Quinn was born weighing a healthy 7lb 7oz. I felt like the luckiest girl in the world as I took him home later that day. However, by the evening I was a little concerned as Quinn still hadn't passed any meconium, his first faeces, and so the next morning I mentioned this to the midwife who recommended that we went straight back to Bradford Royal Infirmary to check that he didn't have an intestinal obstruction.

It was horrible being back in hospital just a day after bringing my son home. Walking out the door 24 hours earlier, I felt so positive and was excited to introduce Quinn to my friends and family. But I found myself back in hospital, and I knew it was going to end in tears. Quinn had to stay in hospital, my heart broke as he refused to breast feed and struggled to swallow even the smallest droplets of milk. More worrying was the yellow bile he kept throwing up.

The doctors in Bradford rang the neonatal specialists at Leeds Children's Hospital to explain what was going on and before I knew it Quinn and I were rushed across to Leeds in an ambulance. He was admitted onto the neonatal intensive care unit (NICU) and a further contrast x-ray resulted in him passing his first faeces. Although relieved to find out Quinn had passed meconium, I knew we were not yet out of the woods as Quinn underwent further tests. A day after our arrival in Leeds a nurse mentioned that there was a charity called The Sick Children's Trust and that they gave parents, like me, a place to stay when their child was seriously ill. It was located just moments from the hospital. Shortly after going onto the waiting list, a room became available and I moved in. It was such a relief because I could never have left my boy in Leeds and travelled back to Bradford without him. I would have slept out on the street if I had to.

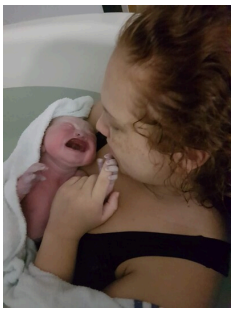
Even as a single Mum I was never alone. My parents were fantastic and both of them took turns to stay with me in Eckersley House whilst Quinn was in hospital. They couldn't believe such a charity existed either. Knowing I was in Eckersley House gave them comfort because they knew how hard I was finding it all and that having a 'Home from Home' at the hospital was alleviating a part of my pain. I really can't thank the staff at Eckersley House enough. They were so kind. I was the youngest Mum there and the staff knew I was finding things hard and they were amazing. After a bad day on the ward it was such a comfort to go back to Eckersley House and be around people who understood what it was like to think of nothing but your baby.

A biopsy of Quinn's bowel wall revealed he was suffering from a rare condition called Hirschsprung's disease. This causes faeces to become stuck in the bowel because the nerves that control bowel movements are missing from a section at the end. To hear that your baby has a disease is overwhelming. Even though the specialist tried to reassure me that when Quinn was a few months old they would treat his condition with surgery and there would be a high chance of complete recovery, I was still devastated.

From then on it was so important that my parents and I could stay close to Quinn, which we could do by having Eckersley House. I needed my family there with me to help me as we had to be all hands on deck over on the ward to learn how to care for my son's needs. Quinn had to have daily rectal washouts, a type of colonic irrigation, which we found tricky to get to grips with, but by being at Eckersley House we could be on the ward, learning from the nurses, as much as possible. The washouts also require more than one person to be involved, which is why having two beds in my room at Eckersley House was so important. It also helped me bond with my baby. I felt like Quinn knew I was doing as much as I could to get him home quicker.

After staying at Eckersley House for two weeks, the day came when the specialist agreed we were competent enough with Quinn's care to take him home. And this is where we are now. Back home. I

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have written a blog about my experience, which helped me process some of the emotion around what has happened. Quinn has an outpatient appointment at the end of the month and we will then get a date for the operation to remove the part of his bowel that isn't working. Hopefully The Sick Children's Trust will be able to support me in Eckersley House again so our story, 'My Boy & I', can continue.

Paige Lewis, Mum to Quinn

Notes to Editors:

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.

We support 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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