I can safely say that the only reason we have managed to get through these past months with our sanity intact is because our family has been able to stay at Eckersley House run by The Sick Children's Trust.

Thursday 26 April, 2018

When our third baby, Leah, was born it was very clear there was something wrong with her. She was completely yellow – even the whites of her eyes. My wife, Paige, and I knew what jaundice was, but nothing could have prepared us for what we saw. The midwife at Queens Medical Centre in Nottingham, where Leah had been born, immediately organised for blood tests to be carried out and once the results came back we were referred directly on to Leeds General Infirmary (LGI), over 80 miles from home, for an ultrasound scan.

As soon as the ultrasound results came back, doctors broke the devastating news to Paige and me that Leah had a condition called biliary atresia. Having never heard about the rare disease, which only occurs in one out of 16,700 babies, we had no idea what it even meant. We soon learnt however that biliary atresia is a disease of the liver and bile ducts whereby the bile flow from the liver to the gallbladder is blocked, causing the bile to be trapped inside the liver. We were terrified to hear that this causes damage and scarring on the liver cells (cirrhosis), and could eventually lead to liver failure. The message was loud and clear. Without treatment our baby was going to die.

I tried not to panic as doctors explained what was wrong with Leah, but it was difficult to remain calm. Paige and I have two other young children, Laurissa and Lucas, who are only three and two years old respectively. At this point we had no idea what the future might hold because biliary atresia cannot be treated with medication. Leah was monitored for a few days before it was decided we would all go home back to Nottingham and once she was a little stronger, our baby would have a Kasai procedure - an operation to re-establish bile flow from the liver into the intestine.

So that was that. We made the two hour journey home, uncertain about what the future held, but reassured that Leah would not need to be in the hospital before the Kasai procedure, which was scheduled in for the following month. At this point we had no idea about the existence of Eckersley House or the work of The Sick Children's Trust. It was on our return for Leah's procedure that a nurse told us about the 'Home from Home'. We had been really worried about what we were going to do once we got to Leeds. With two other little ones, one of whom has Down syndrome, and not much money between us, we had been certain our family would be split up. Thanks to The Sick Children's Trust, over the past six months, we have battled on together as one.

The charity offered us a room from the moment Leah was admitted to the hospital. Being able to stay as a family in a private room just minutes from her hospital cot at no cost whatsoever was incredible. Neither Paige nor I were working – I have been Lucas' full time carer since he was born in 2016, so the cost of a B&B in Leeds would have crippled us. But Eckersley House is so much more than just a room near to your seriously ill child. It is a safe haven, a place of respite – a real 'Home from Home'. The kids loved it, especially the playrooms because there were so many toys for them to choose from. And for Paige and me it was a slice of normality, away from the bright lights and flashing monitors on the ward where we could retreat, feed our kids in the well-stocked kitchen and even watch a bit of TV.

After eight days we were discharged home. Leah was to be monitored closely with regular blood tests at Queens Medical Centre, but the hope was that for the time being bile would drain from Leah's liver and her jaundice level would go down. However, this didn't happen. Leah remained yellow and became increasingly agitated. She was clearly in a lot of discomfort, was losing weight and constantly itching her skin. We returned to the centre for another blood test. Concerned by the results, the specialist who had been looking after Leah from LGI travelled over to take a look at her.

The Kasai procedure hadn't worked. Leah's only chance of survival would be a liver transplant. And until a suitable donor was found, Leah had to remain at LGI.

We headed back to Leeds later that day with Leah, Laurissa and Lucas, unsure about what to do next. We just hoped that The Sick Children's Trust would come to our rescue once again. It did. Eckersley House came to our aid in a way we could never have imagined. Within the house, alongside the family bedrooms, there's a flat, which we were offered. So since the beginning of February we have been staying somewhere that we now come to think of as home. The facilities are excellent and the flat has its

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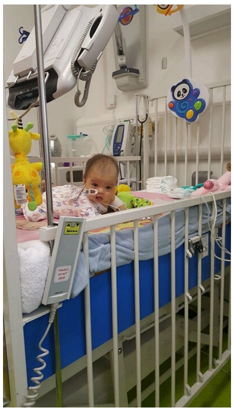

own front room, kitchen and bathroom. To both Paige and I it feels like we moved out of one home and into another! The kids love it, especially all the attention they get from the house staff for whom nothing is too much trouble. Jane and her team are incredible and knew exactly what to say to us during the long wait for a donor liver for Leah.

It was seven weeks before Leah went down for her transplant. We were in the flat at Eckersley House when the call came through. Automatically assuming, after such a rocky few months, our precious baby had taken another turn for the worse, we were elated yet petrified to be told she was going into theatre within the hour.

I am thrilled to say though that, from this point onwards, things have only improved. Over the past four weeks we have remained in the flat at Eckersley House whilst Leah recovers from her operation. And she has recovered so well. Doctors could not have predicted how well our brave baby has done. She is a completely different child and no longer yellow. Her eyes sparkle and she smiles at us all the time. Tonight is the first night we have been allowed to take her off the ward and she is spending the night with us at Eckersley House. It feels amazing to have all five of us together in our ‘Home from Home’. In a strange way, I think we will all miss Eckersley House and everything that it has given us. We will never forget the support we have received from The Sick Children’s Trust and I can’t believe we hadn’t heard of its amazing work before now.

Being so close to Leah whilst she recovers from her transplant has meant we have been instrumental in administering her care. She will need medication all her life, which is quite complicated and daunting. The nurses have had to show us how to give this to Leah. She is also tube fed so Paige has been hands on at feed times, using the pump and making sure that once home she knows exactly what to do. If we were not staying just two minutes from the ward where Leah is being treated I am certain we would not be taking her home so soon – it is quite overwhelming how many steps there are to her treatment plan, but Eckersley House has enabled us to be there by her side and the professionals at all times. Finally, Laurissa and Lucas are enjoying getting to know their baby sister and Paige and I are hopeful that Leah is going to live a great life.

Dave Lawson, Leah’s Dad.

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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