Little boy diagnosed with leukaemia back home in time to celebrate Christmas

Thursday 21 December, 2017

Henry Fethon was diagnosed with leukaemia in September 2017 and rushed to Leeds General Infirmary. The Sick Children's Trust has supported his family at Eckersley House whilst Henry has been receiving lifesaving treatment in hospital. Fortunately, Henry has made it home in time for Christmas and, as a thank you, Henry and his family have joined in The Sick Children's Trust's first ever Christmas appeal! Dad, John Fethon, tells their story:

"Henry didn't have the easiest start when he was born three years ago at Hull Royal Infirmary. His head was very misshapen after delivery and the doctors soon detected a hole in his left lung after assessing him on the neonatal intensive care unit (NICU). Henry's mum, Alex, and I were really worried, but we were discharged a week later and took Henry home to settle him in and introduce him to his older brother, Harry.

We kept taking Henry back to Hull for those first few months. I think you always know when something isn't right with your baby. Despite the doctors sending us home and reassuring us that our son was fine, we couldn't shake the feeling that there was something wrong. His breathing just didn't seem right and Alex was especially concerned. Finally when Henry was six months old, an appointment was made for us to see a specialist at Leeds General Infirmary (LGI).

Henry had an x-ray, which showed a narrowing of the windpipe when he breathed in and after a few more tests, the specialist diagnosed him with something called tracheomalacia. We had been right to worry all along. And although it was a relief to be taken seriously, it was also incredibly scary to hear that Henry did have something wrong with him. We discovered that tracheomalacia occurs when the cartilage in the windpipe has not developed properly and so, rather than being rigid, the walls of the trachea are floppy and cause breathing problems.

The decision was made to monitor and keep an eye on Henry. The consultants were hopeful. If Henry's oxygen levels didn't dip significantly, we were told that his condition should improve as he got older and stronger so that by the time he was two years old it should've gone altogether. The specialist reassured Alex and I that surgery was rarely needed, but if Henry caught a respiratory infection he would need to be monitored even more closely and a decision would be made

LGI referred us back to Hull and over the next couple of years Henry was looked after by an amazing consultant, Dr. Mary Barraclough. As his tracheomalacia improved, we relaxed and settled into life as parents to two young boys, both with very different, but equally happy personalities. Although, Alex and I sadly separated, we made sure we remained the best possible Mum and Dad to our boys.

But then, at the beginning of summer this year, Alex began to notice that Henry wasn't himself. He was short of breath, complaining of belly ache and seemed to be consistently under the weather. Alex took Henry to see three different GPs around the local area, all who told her the same thing, Henry had a viral infection and it would clear up of its own accord. I work at sea as a fisherman, seven weeks on and seven weeks off, so wasn't around at the time. Alex was at her wit's end and in a state of panic rang Dr. Barraclough, begging her for an appointment. By this point, Henry was getting paler by the day and began to bruise really easily – Alex even asked at nursery whether Henry was being really clumsy – they said he wasn't.

Dr. Barraclough saw Henry as soon as she could. And Alex could tell she was concerned. Henry's platelet count was very low and she carried out an immediate blood test. All Alex and I could do was wait for the result.

That same day I returned home from sea and the boys came to stay with me that night. By 9pm the boys were tucked up in bed, sound asleep. 15 minutes later my phone started ringing. As soon as I saw Alex's name flash on the screen, I knew something was seriously wrong. She could barely get the words out as she said she was on her way round and we needed to get Henry to Hull. I just had time to call my Mum to ask her to look after Harry before Alex arrived. We raced Henry back to hospital and Dr. Barraclough was there to meet us at the door. The blood test results were back and showed an abnormally high white blood cell count. Henry had leukaemia. We handed our son over to the doctors in complete shock. Alex crumpled to the floor next to me and was completely beside herself. She was so traumatised by this devastating news that she just froze, she couldn't move. I told Alex I would be back to comfort her, but

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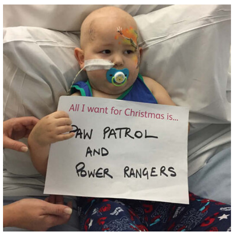
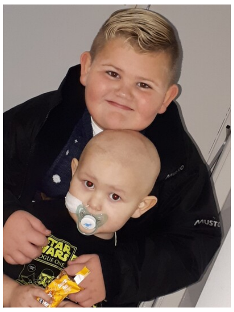
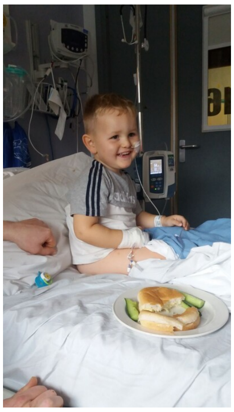
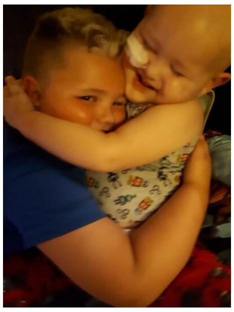
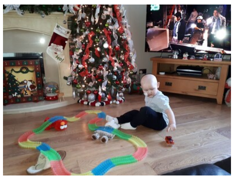










needed to go with Henry to hold his hand, as he was terrified.

Early the next morning Henry was transferred to LGI by ambulance, with Alex and I there beside him not knowing what his or our future held. For five days we were allowed to stay with Henry on the ward whilst he was monitored closely and a treatment plan was drawn up. The doctors very kindly made an exception and let us both stay there because of the circumstances, but we knew this was not a long term option. This is when I heard about Eckersley House, run by The Sick Children's Trust. The nurses on the ward told me that this was a place where I could stay, totally free of charge, only minutes from Henry and Alex.

I didn't know that a charity like The Sick Children's Trust existed and I couldn't believe it when Jane, the House Manager, showed me around. I ended up staying there for well over a month and it meant so much to our family, that both Alex and I could be right there for Henry at all times. I had to take time off work, so travelling to and from Hull every day would have meant huge petrol costs, and we couldn't afford a hotel in Leeds. Eckersley House was a total lifesaver.

Because we were supported by The Sick Children's Trust, we were able to be together as a family. Harry was incredibly upset with everything that was going on, but what helped was that during the weekends he could come and stay as the staff put up a comfy camp bed for him in my room. Being in Eckersley House gave us some sense of normality when there was so much uncertainty surrounding the family.

Harry and I are big rugby league supporters and one weekend when Henry was in hospital, Hull FC were playing Leeds Rhinos away and I managed to get tickets to the game. Even though Hull ended up losing, it gave me a chance to bond with my oldest son and have a nice day out, knowing I was never far from Henry and could come back home to Eckersley House afterwards and make Harry tea in the kitchen. The staff were so good with Harry, they were so kind to him and took an interest in how he was getting on at school and what he'd been doing with his friends. When I finally left to go home in November, I made a donation of £50 to The Sick Children's Trust. I would have liked to donate a lot more but we gave what we could and the staff were so grateful – they don't expect anything.

When we took Henry for his chemotherapy appointment at LGI recently, we dropped in and left a Christmas card. I caught up with a few of the families that I had become friendly with while staying there. That had been something so reassuring about Eckersley House – in the beginning, amidst all the uncertainty – it was a comfort to meet parents in a similar situation, who were a few weeks further into their chemotherapy treatment. They shared their stories with Alex and me, which helped to know what to potentially expect throughout Henry's treatment.

It has been hard for Henry. He was only meant to be at LGI for four weeks, but because of a few problems along the way our stay ended up being longer. However, his treatment is going well and he is now an outpatient at LGI, which means we are all home for Christmas. That's incredibly special as we didn't know if we would all make it home again at all.

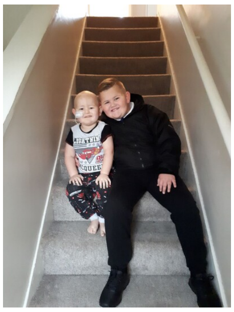
Because of what has happened, Alex and I have agreed we will all spend Christmas Eve and Christmas Day as a family, just the four of us. The boys are already getting excited! Henry is obsessed with the Paw Patrol toys and Harry is with gaming… they both have long lists, and we'll just have to wait and see what Father Christmas brings them. Alex and I owe Dr. Mary Barraclough everything. Without her, Henry would not be here today."

The Sick Children's Trust is a national charity which supports around 4,000 families every year. The charity relies entirely on voluntary donations to keep its ten 'Homes from Home' running, providing vital support to families with children undergoing lifesaving treatment in hospital. This Christmas it expects that every room in every house will be full with families, caring for some of the UK's sickest children.

Jane Featherstone, CEO at The Sick Children's Trust says: "No child should wake up on Christmas morning without their family around them. But this Christmas, many families with a critically ill child in a specialist hospital will face a long journey to be at their child's side.

"A donation of £30 will give a family a place to stay in one of our 'Homes from Home', just moments from their sick child. It costs The Sick Children's Trust £13,140 to run our ten 'Homes from Home' across the country over the Christmas period, keeping families together at one of the most important times of the year. Your donation can make this possible."

To keep a family together this Christmas, please visit:
https://www.justgiving.com/campaigns/charity/sickchildrenstrust/alliwantforxmas.



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To watch the Christmas appeal film, visit: https://youtu.be/qpgKkZuPWmc.

For more information on The Sick Children’s Trust and for other ways to donate, please visit http://www.sickchildrenstrust.org/Donate/.

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