When Alfie was born he was so tiny he weighed little more than half a bag of sugar.

Monday 19 March, 2018

At 23 weeks pregnant things started to get a little bit worrying because my baby didn't seem to be getting any bigger, but it wasn't until I was 28 weeks that I was told my placenta was failing and that Alfie was very small and would need to be delivered within a month. This was on Monday 21 August. It was a shock. But if Alfie could stay in for another four weeks it would give him a chance to grow some more and gain extra strength. However, the next day the consultant told me that actually Alfie would need to be delivered within a fortnight and asked me to come back to the hospital the following day.

Anxiously I went home to rest, but later that night I began bleeding. It was absolutely terrifying. I thought I was going to lose my baby. As my husband, Lewis, rushed me to Leeds General Infirmary (LGI) we had no idea what was happening with Alfie and when we arrived the doctor almost immediately performed an emergency caesarean. The reality hit, I really might lose Alfie.

At just 28 weeks and four days gestation, Alfie weighed 545g – little more than half a bag of sugar. He was so severely growth-restricted that he measured more like a 24 week old baby. We were told that babies weighing less than 500g could not survive. And looking at my son, who was absolutely tiny, I continued to fear the worst.

Shortly after Alfie was born the nurses on the neonatal intensive care unit (NICU) mentioned Eckersley House and The Sick Children's Trust. They told us the charity provided free 'Home from Home' accommodation on the hospital site for parents and families like us, with a seriously ill child in LGI. Truth be told, I was initially a bit sceptical about sleeping in a shared house and didn't think it was for me. Home was only around 40 minutes away and I had gone from fearing the worst for Alfie to going into denial about just how poorly he was. I even told a nurse on NICU that home was not that far away and I thought I would sleep better in my own bed. Refusing to acknowledge the seriousness of Alfie's prematurity, I told the nurse it would be better to offer a room at Eckersley House to a family whose child was seriously ill.

Alfie was just two days old and I was still recovering from the caesarean in hospital, when Lewis and I got a call from the ward telling us that Alfie was deteriorating. I was no longer in denial. I knew my baby was a seriously ill child and so we asked to be put on the waiting list for a room at Eckersley House. We were extremely lucky that one had just become available so Lewis moved in immediately, with me joining him once I had been discharged.

If it was not for Eckersley House I am really not sure how I would have coped for those ten and a half weeks. It became a real lifeline to me and my husband. It enabled us to be close to Alfie, but also provided us with some sort of normality in a situation which was far from normal or how I had expected my time to be after having my first child. Jane, the House Manager at Eckersley, was amazing and nothing was ever too much trouble. She and the other staff were so supportive, without being overbearing, knowing when I was feeling low and needed reassurance or a hug after a bad day on the ward.

The rooms were great too, and I need not have worried about not being able to sleep away from my own bed. Although permanently concerned about Alfie, I knew that there was a direct line from our room to the ward and if anything changed we would be first to know, and would be with him in minutes. Given the circumstances I actually slept OK, because spending all day every day in hospital becomes exhausting very quickly. We also got to meet other parents in Eckersley House in a similar situation, which made having Alfie in hospital less of a lonely time, as they could relate to what Lewis and I were going through.

On 6 November, Alfie was transferred to St. James's University Hospital, which is also in Leeds, and we had to say our goodbyes to Eckersley House. It was a mixed experience for me because I was pleased Alfie was getting stronger and was well enough to be transferred, whilst at the same time I was sad we were headed to another ward in another hospital and not home. And that this time there would be no Eckersley House to support us.

Fortunately, we had Alfie home in time for Christmas. He was discharged on 7 December and to have him at home is amazing. I think that now we are out of hospital it has really hit us just how much our baby has gone through and how much he has had to fight so far in his little life. We feel so lucky to have him home, which is a feeling most parents take for granted. Christmas Day was an amazing time for us this

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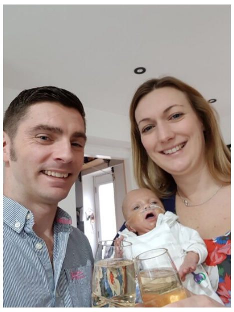

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year and we spent it with all my family – Alfie was the centre of attention alongside my Grandad, Alfie's Great Grandad who is 98, almost a century older than him!

Alfie’s main problems revolve around his size and prematurity. He came home requiring oxygen, but has since come off this. He is being reviewed by the liver team at LGI because his liver is not working as effectively as it should. Doctors are confident that this is due to his small size and should improve with time as Alfie gets older. His thyroid is also underactive and so he remains on medication for that.

Alfie is going from strength to strength and I cannot be prouder of how much fight and determination this little boy has. We have several hospital appointments for follow ups, but hopefully at this stage, Alfie will not need regular treatment.

Holly Knight, Alfie’s mum.

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. For more information visit: www.sickchildrenstrust.org

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