Stevenson House made it possible to be with our daughter during the most crucial time of her life.

Wednesday 26 June, 2019

Our daughter, Poppy, was on her way to a hospital in London for a lifesaving operation. Just hours

before, we were having our first cuddle and introducing her to big sisters Skye and Daisy. But here we were, at a loss with our hearts shattering into pieces, feeling completely useless.

The doctors broke the news to me at Basildon Hospital that my daughter had two rare conditions, trachea-oesophageal fistula and oesophageal atresia (TOF/OA). TOF and OA tend to occur alongside each other. TOF is where part of the oesophagus is joined to the trachea and OA is where the short section at the top of the oesophagus has not formed properly so is not connected to the stomach. It became clear that something wasn't quite right when Poppy was struggling to feed. We never thought that, at just a day old, she'd need major surgery on her oesophagus as it was causing her problems with eating and breathing.

There wasn't enough time to think about the whys, what ifs and how it came to this. Our daughter was sick and the fear that she might not even survive the ambulance journey was all-consuming.

I encouraged Andrew, Poppy's dad, to go to London while I tried to be discharged, which was around 30 miles away. That night, he called me to say that they would be operating on our daughter the following morning. It would take six hours to repair her oesophagus. He assured me that he'd be there for Poppy as a nurse on the neonatal intensive care unit (NICU), where Poppy had been admitted to, introduced him to the House Manager from a place called Stevenson House. He was given a room just a few minutes away from Poppy's side. We later found out that Stevenson House is run by The Sick Children's Trust, a charity separate from the hospital, which gives parents a place to stay for free while their child is treated in hospital.

The day of Poppy's operation went very slow. I felt useless being so far away and it was heartbreaking being surrounded by new mums and their newborns.

Eight hours later, Poppy was out of theatre and I discharged myself from Basildon Hospital. When I arrived at the Royal London Children's Hospital, I pushed through the NICU door, scared as I walked into the unknown. I got to Poppy's incubator and was shocked. She was so swollen with wires covering her body and cannulas in both hands. I could hardly see her through it all.

Over the next two weeks, we desperately waited for the doctors to say Poppy was stable enough to be woken up. It felt like there were so many stumbling blocks and hurdles leading up to this, she'd had a blood transfusion and was also diagnosed with sepsis. Stevenson House was so important as it meant that during this crucial time in our daughter's life we were only ever a few minutes away. Finally, at 18 days old Poppy was brought out of her induced coma and I was able to hold her the next day. She opened her eyes and melted my heart.

Life had become very different to what it was. We decided to split ourselves between the children. While Andrew stayed at Stevenson House, I would often travel back home every night to ensure Skye and Daisy's lives were kept as normal as possible. Stevenson House could've supported us all as a family, as there was plenty of space in the bedrooms with pull out beds along with two single beds, a living room and even a playroom. But the children had school, so Sundays were a special day for us as they'd come and visit Poppy but we'd also get to spend time together as a family which in those weeks was rare.

It felt like Poppy was finally making progress and we could be there to see it for ourselves and help her because of Stevenson House. Although the surgery on Poppy's oesophagus was a success, we learnt TOF/OA is a lifelong condition and there was lots of stuff we needed to know to ensure we could care for her at home. Being supported by The Sick Children's Trust meant that we could be really involved in Poppy's care because we were only ever a few minutes away and could be on NICU whenever. It was useful, because the more we practised the more confidence we gained. We even did a resuscitation and choking course as part of it which was a real eye opener. NICU had become such a safe place for us and our daughter that it was daunting leaving there, but we felt we could do it. Without Stevenson House there, it would've been a lot harder to gain the skills to look after our daughter and spend as much time with her.

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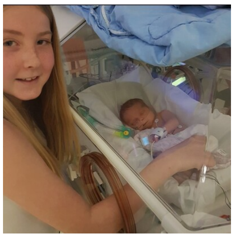

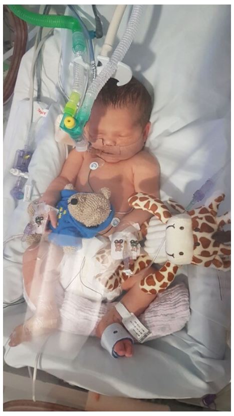

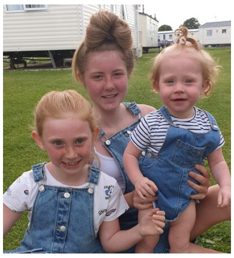

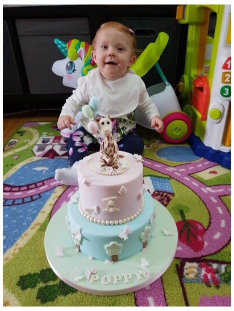

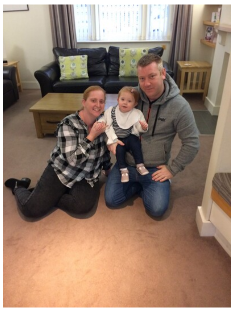

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Poppy is now 18 months old and she’s doing incredibly well and managing to eat which is amazing as we were told that she may never be able to. We were also warned that she might not meet her developmental milestones, whereas in fact she’s quite advanced.

Since leaving London, our journey hasn’t been easy. Poppy has been back in hospital on several occasions and we’re very conscious that a cough or cold could lead to A&E. But I always remind myself when we have scary moments and bad spells how lucky we are with Poppy, we know there are many other children who have had an awful time with TOF/OA and our daughter is thankfully doing very well.

Sam Bullock, Poppy’s mum

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