Family of baby born unable to swallow support charities

Thursday 21 December, 2017

Freddie Capes was diagnosed with trachea-oesophageal fistula and oesophageal atresia after a sonographer at a special scan advised mum to arrange an appointment at her local hospital. After birth, Freddie was transferred to Sheffield Children's Hospital and underwent the first corrective operation at just 24 hours old. The Sick Children's Trust supported his family at Magnolia House, whilst Freddie received treatment. Fortunately, Freddie has made a remarkable recovery and his family are excitedly preparing to celebrate his first Christmas. As a thank you to the charity, Freddie and his family have joined in The Sick Children's Trust's first ever Christmas appeal! Mum, Gemma Capes, tells their story:

"It was the sonographer at a 4D scan who advised me to arrange an appointment at my local hospital. I had booked the extra scan as a treat to myself for my 32nd birthday. All the check-ups and prenatal scans had been absolutely fine up until this point so at 30 weeks I decided all I wanted for my birthday was to see my son.

I went straight to the Diana, Princess of Wales Hospital in North Lincolnshire, near our home, for more scans to find out if there was a problem. When the scan picked up that there was too much fluid around Freddie I panicked. They transferred me to Sheffield Children's Hospital for further investigation and diagnosed my unborn baby boy with tracheo-oesophageal fistula (TOF) - where the upper part of his food pipe ended in a pouch - and oesophageal atresia (OA), which meant the lower part of his food pipe was connected to his wind pipe. In the weeks leading up to his birth we knew it was likely he would need emergency surgery shortly after he was born. I didn't even know if I was going to be able to hold him before he got whisked away.

Freddie arrived naturally on 25 July 2017 at the Jessop Wing in Sheffield's Royal Hallamshire Hospital. The doctor put him on my chest for a few minutes and I was able to gently kiss him before he was taken to the special care baby unit (SCBU). At just eight hours old Freddie was urgently transferred to the Sheffield Children's Hospital, but I had to stay at Jessops. That was awful. Knowing your baby is in a different ward to you is bad enough, but he was in a different hospital. It was so hard, but at least I knew my partner Wayne was with him and he was receiving the best possible medical care.

We had learnt about The Sick Children's Trust before Freddie arrived when I was researching TOF and OA and joined a Facebook support group. When reading some of the posts I read about a family who had stayed at Magnolia House, a 'Home from Home', where they had been given a room and could walk to their baby's hospital bedside in only a few minutes. It seemed amazing that this charity offered totally free accommodation for parents like Wayne and myself, who needed somewhere to stay whilst our son was seriously ill.

Freddie was born unable to swallow and so he had his first operation at less than 24 hours old. The doctors performed surgery to reattach his oesophagus and separate it from his trachea. We hadn't known before he was born, but the surgeon also saw he needed to have part of his duodenum reattached to his stomach also. By the time he was in theatre I was there with Wayne at Sheffield Children's Hospital and we had been given a room at Magnolia House. We stayed there for two whole months, whilst Freddie recovered from the operation and doctors continued to treat his condition.

Magnolia House was amazing and, I have no idea what we would have ever done without it. We live in Grimsby, which is over a three hour round trip. It doesn't bear thinking about. Having a bit of normality each day in a homely environment and receiving support from the house staff and other families staying there was a lifesaver. Whilst our family and friends could offer words of comfort, they didn't really understand what we were going through, but the mothers and fathers staying at Magnolia House did. I still keep in touch with a few parents, some of whom have been staying with The Sick Children's Trust for months and months. We would drink tea together in the kitchen and talk about our days and the progress our babies and children were making.

When Freddie was in hospital I didn't really want to leave his side, and with a direct phone line from the nurses' station on his ward to our bedroom, I felt like I never really did. A few weeks into our stay though I needed to go to Meadowhall Shopping Centre to buy some clothes and other necessities, and Rachel, the Assistant House Manager, gave me her travel card so I didn't even have to buy a tram ticket. Their kindness and support towards me and my partner was endless. I could never thank them enough.

I am happy to say that Freddie recovered from the operation quite quickly and we were able to take him

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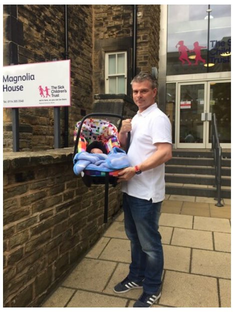
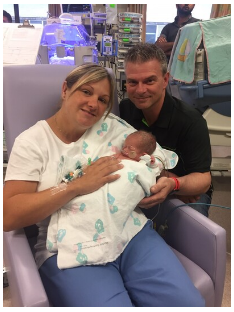
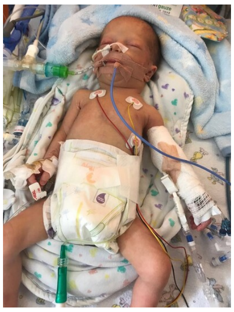
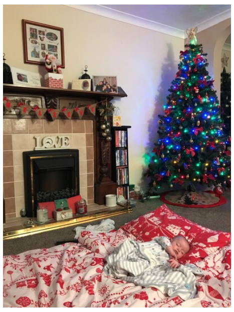
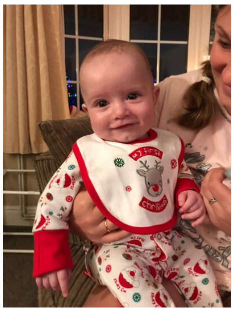










home on 20 September, just short of two months after he was born. Taking Freddie home for the first time felt like a huge milestone – we were so excited. Now that we have been home a few weeks I think the trauma of the rollercoaster we went through at the beginning of Freddie's life has started to sink in. At the time everything is a total blur and you can't think straight – you just walk like clockwork from your bedroom at Magnolia House to the ward and back again twice a day, but we nearly lost our baby boy and I will never forget the love and support we were shown by The Sick Children's Trust when we thought he might not make it.

It is almost Christmas and we are so excited to be celebrating Freddie's first after a milestone year. We are planning on spending it with family with Freddie's nana cooking Christmas dinner. Freddie might even get some food on Christmas Day as we have started weaning! Looking back it doesn't feel like we went through what we did, as now we see a happy bouncing baby boy, who can't stop staring at the baubles on the Christmas tree and whom everyone comments on how healthy and smiley he is!"

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.

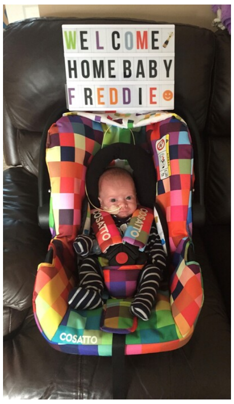
Jane Featherstone, CEO at The Sick Children's Trust says: "No child should wake up on Christmas morning without their family around them. But this Christmas, many families with a critically ill child in a specialist hospital will face a long journey to be at their child's side.

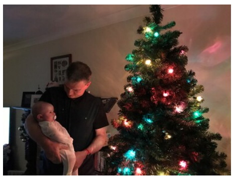
"A donation of £30 will give a family a place to stay in one of our 'Homes from Home', just moments from their sick child. It costs The Sick Children's Trust £13,140 to run our ten 'Homes from Home' across the country over the Christmas period, keeping families together at one of the most important times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

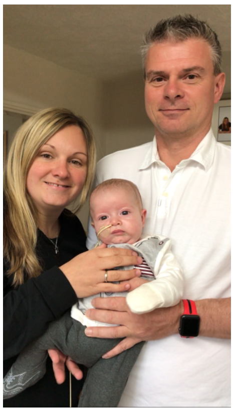
To keep a family together this Christmas, please visit: https://www.justgiving.com/campaigns/charity/sickchildrenstrust/alliwantforxmas.

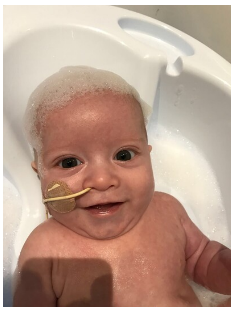
To watch the Christmas appeal film, visit: https://youtu.be/qpgKkZuPWmc.

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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