When Summer-Mae was strong enough we were invited to take her to a tea party at Treetop House and we caught up with the other families and staff.

Monday 22 January, 2018

My daughter Summer-Mae is nine years old. She is my sixth child and adored by her brothers and sisters. Summer-Mae is also severely disabled. She has cerebral palsy and is non-mobile, with a global developmental delay that puts her at just two years old. She also has severe epilepsy and hearing loss along with eyesight and speech problems.

However, until September last year, she had only experienced brief episodes of hospital treatment, mostly at Bassetlaw District General Hospital in Worksop, which is close to home. Everything changed for us over the summer when we were on holiday at the end of August in Filey, North Yorkshire. Summer-Mae became very unwell and we rushed her to Scarborough General Hospital where they immediately admitted her onto the intensive care unit. It was terrifying as I watched my little girl being placed into a medically induced coma and ventilated to help her breathe. How had our family holiday turned into such a nightmare?

For three days Summer-Mae remained in hospital, but then she took a turn for the worse and I begged the doctors and nurses to do something more to help my little girl. They contacted Sheffield Children’s Hospital, who sent a special transport team to Scarborough to collect Summer-Mae. I have seven children, aged from 17 down to just nine months. Gracie, my youngest, was only five months old at the time, but thankfully we were able to drop her off at her grandparents and could take the other children back home which is on the way to Sheffield. All the kids were very distressed by what was happening, but at that point I could only think about my daughter who would be all alone in hospital.

When she arrived at Sheffield Children’s Hospital Summer-Mae was taken straight to the paediatric intensive care unit (PICU) and the nurses on the unit tried to explain to us what they were going to do and how the doctor wanted to treat our daughter. I can’t explain to you what it was like that first night – not knowing what was wrong with my little girl. I honestly thought I was going to lose her. We sat all night in a tiny room off PICU, unable to sleep, but exhausted.

It took doctors four days to diagnose what was wrong with Summer-Mae. An early X-ray had shown she was suffering from pneumonia, but that wasn’t enough to explain the severity of her condition. Then they discovered she had a terrible viral infection. As the doctors began to administer antibiotics Summer-Mae remained ventilated – after a few days she was switched onto an oscillator, a higher form of ventilation because her lungs seemed very cloudy and congested, but they moved her back onto the original ventilator a couple of days after that, before finally waking her up after eight days of sedation.

We heard about The Sick Children’s Trust when we arrived at Sheffield Children’s Hospital as we were told that we couldn’t stay with Summer-Mae on the intensive care unit. The Sick Children’s Trust runs free ‘Home from Home’ accommodation at the hospital, and others around the country. My initial reaction was panic. I thought the accommodation would be a long way from my daughter and I wasn’t prepared to leave her alone. But the next morning a lady came across to talk to us and show us around. I couldn’t believe Magnolia House was literally down the corridor!

We stayed at Magnolia House for two and a half weeks. It was amazing. Exactly what it said on the tin – a ‘Home from Home’. We had a double bed to sleep in and even our own private bathroom. My partner Craig stayed with me when he could, but it was also important for him to be at home with our baby, Gracie, and the other children, who were very unsettled and worried about their sister.

When the doctors woke Summer-Mae up we had to take a step back – things did not look good and we thought she was going to be ventilated again. Instead she was given a mask, which covered her entire face. She didn’t need to be sedated though, which was a good sign, and she was transferred onto the high dependency unit (HDU). It wasn’t easy though – she was a totally different little girl and didn’t know who we were. She couldn’t speak and seemed to be paralysed. I was unsure as to whether to let her brothers and sisters visit her because I didn’t want them to be traumatised, but in the end we decided Summer-Mae needed her loved ones around her.

My children were shocked to see their sister, but it was definitely the right decision to let them visit. They played her favourite music, talked to her and held her hand. After saying goodbye to Summer-Mae we all went back to Magnolia House. It was warm and welcoming for them and we could all sit and watch TV.

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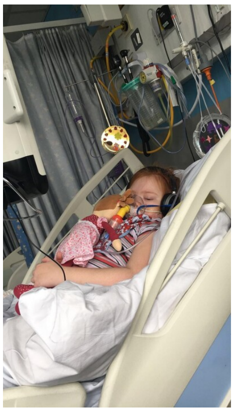

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There were other families around too who we ate meals with and became friends. When you are stuck on the ward all day you can feel so isolated and alone, but back in Magnolia House there are parents going through similar experiences to you. It helped us to stay positive for Summer-Mae and there were always the amazing staff close to hand ready to sit and listen. I can't really explain what a comfort it was and how it took away a little bit of the worry, especially those first few days when we didn't know if Summer-Mae would pull through.

As Summer-Mae grew stronger we moved over to Treetop House, which is another 'Home from Home' run by The Sick Children's Trust at Sheffield Children's Hospital. We met more families with children in the hospital and had more visitors from home. Treetop House was just as warm and welcoming.

Finally after six weeks in hospital Summer-Mae was discharged and we brought her home. However, after three days we were back in Sheffield again. Summer-Mae had more fluid on her lungs and yet another chest infection. She needed over a week on intravenous antibiotics and another two administered through a tube fitted directly into her stomach.

Once again The Sick Children's Trust supported us at Treetop House; apart from being in a different room, it felt as though we hadn't even left.

Another great thing about never being more than a few minutes from Summer-Mae was that we were really involved in her treatment. The doctors taught us how to change her nasogastric tube because Summer-Mae was no longer able to eat orally. And we were also shown how to administer the antibiotics and epilepsy medication. Without The Sick Children's Trust I could never have been so hands on with my daughter's recovery and, had it not been for the 'Homes from Home', I doubt we would have got her home so quickly.

A full two and a half months after her first admission, Summer-Mae was back where she belonged. Since then we have had a few more admissions, but fortunately they have been locally. We bought Summer-Mae an iPad for Christmas because when she was in Sheffield Children's Hospital a therapist came around with one and showed her movie clips and interactive painting games.

She is still being monitored closely and over the winter is on antibiotics as we don't want her to come down with any more infections. She is getting back to her normal self and has started to talk a little bit again. Hopefully, she will be going back to school next week and, funnily enough, we met another family in Magnolia House who have a little boy at the same school – we have become good friends with them and it is nice to keep in touch. I don't know what the future holds for Summer-Mae, but I do know she has a very large family right by her side and is surrounded by love!

Emma Openshaw, Summer-Mae's mum.

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