Family of baby who holds her breath up to 15 times a day thank The Sick Children's Trust

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Sophia Giblin, Mum to Alayna, tells her family's story since the birth of her daughter:

Since Alayna was born The Sick Children’s Trust has been a lifeline for my family through some of the darkest days of our lives. The charity has given us somewhere to stay and eased our struggle, enabling us to be there by our daughter’s side whilst the doctors at Leeds Children’s Hospital have rallied together to determine the best way forward for our baby girl.

It all began two weeks after Alayna was born when I noticed she had changed colour – she had gone from a seemingly healthy newborn to blueish grey and was struggling to breathe. It appeared to me that she kept holding her breath. Scared, I took her straight to our local GP, who advised me to take her into hospital as a precaution. For the four weeks that followed the doctors at Hull Royal Infirmary tried to determine what was wrong with her. She didn’t have an infection. Neither a CT, MRI nor an ultrasound showed any signs of abnormalities. The doctors were as perplexed as my partner Jezz and I were. One thing was certain though, without breathing assistance Alayna’s life was in serious dangerous. The doctors in Hull told us the next step was to transfer our baby to Leeds where she would undergo further specialist testing and so, anxious and distressed, that’s where we headed.

Shortly after arriving in Leeds we received the devastating news that the MRI scan did in fact reveal a serious problem in Alayna’s brain. Too much white matter was detected, which meant the tissues in the largest and deepest part of our baby’s brain were wearing away. It was such a shock to Jezz and I as we watched our daughter being whisked away for another scan. Our broken hearts shattered further when the specialist explained that Alayna had an undiagnosed life limiting brain condition and we wouldn’t be going home anytime soon.

For the next month we dealt with not knowing what was really wrong with our baby as best we could. Jezz and I played tag team as one of us made the twice daily three hour commute to be with Alayna in Leeds, whilst the other stayed at home and took care of our sons, Harry, five, and George, two, in Withernsea. It was gruelling and not just financially, but emotionally exhausting. Neither Jezz nor I can drive so we had to take a bus and a train just to be with our baby. Jezz had to quit his job because during the week he had been working as a plumber in London and so we were also running out of money. Then one of the nurses told us about Eckersley House, and that it was a ‘Home from Home’ run by The Sick Children’s Trust and a place to help families like ours. We were put on the waiting list and crossed our fingers that a room would become available. Two weeks later, and with Alayna in gastrostomy surgery so she could be fed directly into her intestine, Jezz was given the keys to the house. Without hesitation I packed our bags and, with the boys in tow, jumped on the train to Leeds.

We had heard that Eckersley House was a lovely place run by fantastic people, but when we arrived we realised it was so much more. Everyone was friendly and welcoming – even the other families staying there, who were in just as much pain as we were, smiled and listened to our story. There were other young children staying there who the boys could play with. They all loved the playroom and house staff! For the duration of our two month stay Harry and George thought we were on holiday! Whilst the same was not true for Jezz and I as we felt like we were going through hell, we appreciated everything the house held, not least the fact we could see the window of the room in which Alayna was being treated from our bedroom. Having a room in Eckersley House meant we always felt connected to our baby. There was even a phone in our room direct to her ward so if anything changed in the night we would be there in minutes. The fact that we were able to stay there totally free of charge was nothing short of a miracle given our situation.

The sad day finally came when we had to say goodbye to our Eckersley family. Alayna was transferred back to Hull Royal Infirmary, and the rest of us went back home. It was strange to leave the comfort of our ‘Home from Home’ in Leeds, with Jane, her amazing team, and other families in a similar situation to us, and go back to our comparatively quiet and lonely house in Withernsea The long and tenuous daily 90 minute commutes to see Alayna in hospital in Hull began again. Leaving Leeds was hardest for the boys though because when we were in Eckersley House we were always together as a family. I know this is why they have coped so well.

Whilst there is no certainty about what is to come, Alayna has been diagnosed with muscle hypertonia and dystonia, which means spasms cause her to involuntarily hold her breath and this can be brought on

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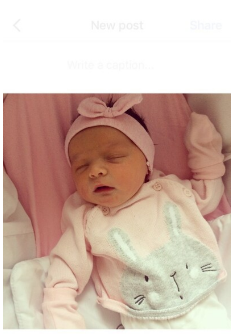

by anything. However, Alayna was finally discharged from Hull aged six months and we brought her back to our new home – a home that has been specially adapted to accommodate her. Alayna is on oxygen during the day, but at night needs a nasal ventilator and this breathes for her. We are still waiting on tests and for answers that may never come, but for now we are staying positive.

Our amazing friends and family have so far raised over £6,000 so we can build Alayna the most incredible sensory room in our new home. We are so grateful to them and to The Sick Children's Trust and everyone who has been part of our journey. One day at a time.

The Sick Children's Trust provides free 'Home from Home' accommodation supporting families with seriously ill children in hospital.

For further information about The Sick Children's Trust, please visit http://www.sickchildrenstrust.org/

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