Scott House took away a lot of the anxiety my teenage daughter was feeling and enabled her to relax before her operation.

Monday 23 April, 2018

When she was just three weeks old Darcy collapsed in my arms and had to be resuscitated. It was terrifying, but thankfully we were already at Ulster Hospital when it happened. I had known there was something wrong with my baby – call it a mother's instinct – and, against the midwife's advice, I had taken her to my local A&E.

Our story would have been a very different had we not already been at the hospital when Darcy stopped breathing and that is a thought that has haunted me ever since.

Once Darcy was stable, we were immediately rushed to the Royal Belfast Hospital for Sick Children with a police escort. Darcy underwent all sorts of tests in order to try to determine why she had suddenly stopped breathing. It was incredibly scary to know there was something wrong with her and in that situation I think one's default position is to fear the worst. Darcy was diagnosed with cardiac dysrhythmia, which is an abnormal heartbeat. An ECG scan had revealed she had tachycardia, which meant her heart was beating life-threateningly fast.

From that point onwards Darcy, who is almost 14, has been under the care of a fantastic consultant paediatric cardiologist, Dr Brian Craig. With regular check-ups throughout her life and copious amounts of medication Darcy has been, for the most part, very well. As a child she had a few hospital admissions when things flared up, but on the whole the medication she took kept her condition under control and she lived a relatively normal life.

Over the past couple of years, however, the medication seemed to become less effective. Eventually she was on such a high dose that there wasn't much more Dr Craig could do. The cardiac dysrhythmia was really affecting her quality of life. She was exhausted and had little energy. We even had to cancel her 13th birthday party because she was so unwell and she would often be sent home from school because her heart would go into episodes of tachycardia. It was so upsetting to see my brave girl struggling to keep up with her peers and so, after much debate, the decision was made that Darcy would undergo a catheter ablation. This is a procedure where thin, flexible tubes, called catheters, are passed through the blood vessels to the heart. The catheters record the heart's electrical activity and pinpoint where the abnormal heartbeat is coming from. This area of the heart muscle is then destroyed using heat, which creates scar tissue and prevents the area conducting electricity thus eliminating the abnormal heartbeat. However, because the Royal Belfast could no longer carry out any heart surgeries, we would need to travel all the way to Newcastle upon Tyne in Northern England for the operation.

And so we found ourselves at Freeman Hospital on a Sunday morning, five days before Darcy's scheduled procedure. We had assumed we would be staying within the hospital, so it was a huge relief to find out about The Sick Children's Trust. When we were told about the charity and that we could stay in a 'Home from Home' called Scott House with a private bedroom, kitchen facilities and a direct phone line to the hospital, all totally free of charge, and just a few minutes' walk from where Darcy was to have the catheter ablation, I couldn't believe it.

Darcy had to come off all medication before the procedure because the surgeon needed her heart to misbehave in order to locate the heart tissue causing the dysrhythmia, which meant it was important we were close to the hospital in case something went wrong. However, she had been really anxious about being stuck on the ward with children much younger than her. So she was over the moon when the team at Scott House told us there was room for her to stay too!

Being in Scott House felt a lot more age appropriate and in the days leading up to her operation Darcy was able to relax there. She could FaceTime her friends, watch television and be a teenager. My husband, Gareth, brought her siblings over from Ireland, and, although they stayed in a hotel nearby, during the day we all hung out together in Scott House. I have a lasting memory of us all eating takeaway pizza in one of the two kitchens there, with my 18 month old baby, Sebastian, becoming wildly excited by the well-stocked playroom!

On the morning of Darcy's operation we woke up in Scott House and headed over to the hospital at 7am. It was a nerve-racking few hours whilst she underwent the catheter ablation, but within no time she was back on the ward and recovering well. By that evening we were back in Scott House. Darcy was groggy

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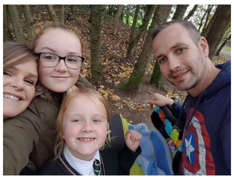

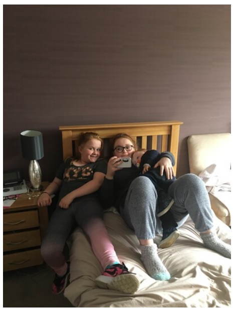

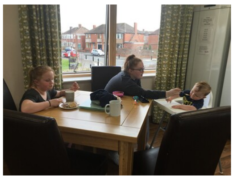

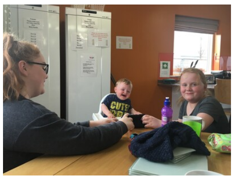

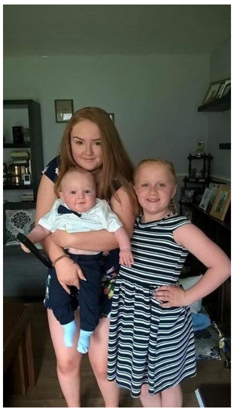

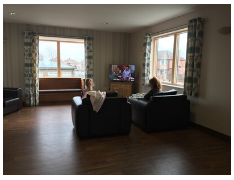

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from all the medication and didn't feel very well, but at least she was in a comfortable bed in a homely environment and by the next morning was back on FaceTime to all her friends in Ireland, who had been so worried about her the day before. She definitely made the most of the Scott House Wi-Fi!

The procedure has been life changing for Darcy. Her recovery was quicker than anybody could have hoped for and her quality of life has been transformed. My gorgeous girl has infinitely more energy and no longer has to take medication three times a day. This means simple things, like suddenly deciding to stay over at her friends' houses is possible, where as in the past her medication dictated her movements. Although she is still under the care of Dr Craig, the hope is that it won't be long before she is fully discharged!

We will never forget Scott House and the eight days we spent there. From the incredible facilities to the lovely staff, it was such a comfort to us when we found ourselves at a hospital miles from home. The Sick Children's Trust truly is an amazing charity that makes all the difference to families like ours.

Leanne Fulton, Darcy Hoffman's mum.

About The Sick Children's Trust

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.

We support 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.
www.sickchildrenstrust.org

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