You just don’t imagine how quickly life can change. We had just returned in high spirits from a family holiday and only a few days later Faith was in theatre having a brain tumour removed.

Tuesday 16 January, 2018

On Friday 1 September 2017, I took my then five year old granddaughter Faith for an eye test and the optician spotted something there that didn’t look right. He didn’t know what it was, but thought it might explain why Faith had been feeling a little tired and referred us to Cumberland Infirmary in Carlisle for an MRI scan.

From that moment on things changed very quickly as the specialist broke the news that Faith could have a brain tumour and needed an emergency transfer to Newcastle upon Tyne. My sister, Paula, was with me at the time and the two of us went in the ambulance with Faith as she was ‘rushed to Newcastle’s Royal Victoria Infirmary (RVI) where we were met by neurosurgeons and the oncology team. I think it was more traumatic for me at that point because Faith didn’t really understand what was going on what with being so young, but in my mind I was already considering the worst possible outcomes as I contacted my partner, Faith’s grandfather Richard, and filled him in about what was going on and told him to hurry to RVI.

Once the tests had been carried out our worst fears were confirmed. Our granddaughter had a cancerous brain tumour and needed lifesaving treatment. We were placed on ward 1B at RVI, which is the neuroscience unit, and the next three days were the longest of our lives. Doctors spoke to us about Faith’s post-operation treatment plan, radiotherapy and chemotherapy, and I, in turn, tried to explain to a confused Faith what was going on. Fortunately, I was able to stay with Faith on the ward those three days because she was disorientated and homesick.

We knew about Crawford House and The Sick Children’s Trust as my brother had used the service about 20 years ago when his baby boy was seriously ill, but it was such a relief when, on the day of Faith’s major surgery, a nurse on the ward told us the charity had a room available. I only stayed there for three nights whilst Faith was in the paediatric intensive care unit (PICU), but Richard was there for over two months. We can’t explain in words what it meant to our family to have a safe space, which was on the hospital site, but away from all the medical equipment and hospital environment.

Living so far away from RVI in the North Western corner of the Lake District meant it was hard for family and friends to visit us regularly, but having Crawford House meant that when they did, there was somewhere we could chat, drink tea and comfort each other together. Also, as I was staying on ward 1B with Faith and later on the oncology ward, knowing that Richard was at Crawford House gave me such a sense of security. I knew that if anything went wrong, he was right there, only a couple of minutes from us.

Faith’s older sister, Kacey, who is only 12, stayed at Crawford House at the weekends with my 16 year old son, Jay. Gail, the House Manager, was able to offer us a second room when they stopped over, and that was so important because Kacey was really struggling to come to terms with the fact that her sister was in hospital and Faith’s rehabilitation after surgery was an uphill battle.

After the surgery to remove the brain tumour, Faith was diagnosed with posterior fossa syndrome (PFS). PFS involves a variety of signs and symptoms including mutism or speech disturbances, an inability to swallow, move, or even see clearly and at the same time the sufferer can experience extreme emotional volatility. We had been told it could happen following the operation, but we hadn’t had the emotional capacity at the time to acknowledge what the doctors were saying. There was a 30% chance Faith would suffer from PFS, but when she began to show symptoms in the days following the operation, we were shocked. The doctors explained it to us a essentially a form of locked-in syndrome, so that Faith was aware of us and what was going on, she knew we were right there, but although she was trying to stimulate a response, she was unable to move or communicate verbally with us. It was devastating to witness, but I can’t imagine how much worse it was for Faith.

Faith was aware we were right there wither her, but was unable to communicate with us for six weeks after her operation. Physio, rehabilitation and speech therapy began, but still our little girl couldn’t formulate a response. Doctors told us that everything was still there, the information still existed in her brain, but that Faith wasn’t able to reach it. Although, this explained PFS to us, it didn’t make the reality

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any easier. Faith was very distressed and we could see how disorientated and confused she was. Slowly though, as the weeks passed, Faith began to regain her motor ability.

Having Crawford House there was key to this as we were eventually able to take her off the oncology ward for short periods of time and we would spend our time in Crawford House. Different family members would make the two hour drive to visit us and tentatively reintroduce themselves to Faith over tea in the kitchen or while watching television in the sitting room.

A few weeks after the operation Faith had been moved up to the oncology ward for the beginning of radiotherapy and chemotherapy treatment – she underwent six weeks of radiotherapy and luckily it went well and finished in time for Christmas on 8 December. There were a few worrying days when she got an infection in her Hickman line (the plastic tube inserted into a vein in her chest which was being used to administer drugs following surgery), but thankfully she was ok.

It was such a relief when the radiotherapy treatment ended and Faith could finally come home to her family. She is still learning to walk and talk again and is very unsteady on her feet, but she is our beautiful Faith and knows who we are. Chemotherapy rehabilitation is about to begin and will mean making the journey to RVI once a month for four months. Hopefully Crawford House will be there for us again, because Faith will need three days of intensive chemotherapy, followed by one day off and then a fifth day of stem cell treatment.

Faith turned six at the end of November and although she was still in hospital, we celebrated in Crawford House. The staff are amazing there and always asked us if we needed anything. They came around the ward each week and were so kind to Faith, especially in those tentative few weeks following the surgery to remove the brain tumour. After we took Faith home we received a Christmas card from The Sick Children’s Trust in the post, which was a lovely gesture and although we made sure it was very gentle, we did manage to enjoy a lovely family Christmas, and appreciate what we all have.

Julie Baker, Faith’s Grandmother.

Company Contact: