

CHARLOTTE'S STORY.

It was our engagement party February 06. This was the first time that I realised my daughter Charlotte Rose was not her self.

At the beginning of the evening Charlotte was so excited. She was dancing with her cousin Jade and singing on the karaoke "Hey baby" at the top of their voices. Charlotte was also running round after her elder brother Joseph. They were best friends , even though there was a 5 year gap between them they spent a lot of time together. As the evening progressed Charlotte began to get very tired and ended up on the chair fast asleep. Normally She would be the last person on the dance floor at any party.

There had been a very bad virus going round the school and Charlotte had been sent home complaining of tummy ache and sickness. Although her brother Joseph hadn't had any sign of it. Usually Charlotte loved school and being with her friends but it had been very hard to persuade her to go to school all of a sudden.

I decided to take her to the GP's as I knew there was something wrong with her she wasn't herself. I explained how Charlotte had been complaining of stomach ache and feeling sick and that she had lost weight since xmas 05. At first I thought she was just growing up as she had

always been quite a chunky little girl and had always had a good appetite. But she had gone off her food and that wasn't Charlotte at all. The GP's conclusion was that she had the virus that was going round school and with that she had constipation. So I was given laxatives to help her. A week later there was no change, in fact she was worse. Charlotte was waking in the night screaming in pain and complaining of pain in her left leg. I took her straight back to the GP's and saw a different doctor. Again I was sent away with the same conclusion that she had a bad virus and that it would pass in the next week or so. In the end I took Charlotte to the GP's four times before they looked into her symptom's more. I knew that it wasn't just a virus. The fourth doctor took one look at Charlotte and sent her for an ultra sound scan at Hinckley Hospital. After the scan was done I was told by the consultant that she had enlarged lymph nodes in her abdomen and that she wanted to refer her to the Leicester Royal Infirmary for more tests. Instantly I knew that there was something seriously wrong with my little girl. I took Charlotte home and we tried to make the most of the weekend as it was mothers day on the Sunday, we decided to go to the safari park. Usually Charlotte would have been bouncing around in excitement to see all the animals. That day she spent a lot of it sleeping in the back of the car. Although she did manage to get her big brother to go on the haunted house ride after seeing the animals which amused her quite a lot. On Tuesday 28th March I received a phone call and a letter to say that the doctors would like Charlotte to go in that afternoon to the Leicester Royal Infirmary for more tests. I phoned her dad Chris as we were divorced to tell him the news. He came with us to the hospital. We were called into a

room by the consultant. We were told that Charlotte had developed a childhood cancer and that she would be admitted to Ward 27 the children's oncology unit. To be told that your child had Cancer is the most devastating thing in the world. Everything was going through my mind, but I knew that I had to be strong for Charlottes sake as she had a got a massive battle a head of her. I had to stay strong for her brother Joseph who was 10 years old. They were so close , they did everything together. They weren't just brother and sister but best friends. What was I going to tell him ?

We were shown to the oncology ward which was to be our second home for the foreseeable future. What we walked into and what we saw nobody could imagine. There were children from toddler age to teenagers attached to chemotherapy treatment and blood transfusions. Some were being sick and crying in pain and most shocking was that they had no hair. I then had to explain to my little girl why she was there. She asked me if she was going to be like the poorly children. I explained that she had got a big lump in her tummy that was making her feel poorly and that the medicine that the other children were having was to make their poorly lumps get better. Charlotte was a very clever little girl and nothing ever really got passed her, and so I tried to be as honest as I possibly could with her. The following few days were tests and scans. It was horrific, all Charlotte wanted was me and so every thing she went through I was by her side feeling so helpless and wishing that it was me going through it instead of her. As a mum you want to do everything in your power to help and protect your child but that had been taken

away from me in everyway possible, I just felt so helpless. Charlotte was taken to theatre for a biopsy she fell asleep in my arms as the anaesthetic took over. I lay her on the bed and walked out off the room, sobbing my heart out, everything was out of my control I felt so useless.

A few days later Charlotte was diagnosed with a very rare cancer called Neuroblastoma stage 4. A tumour had been found on Charlotte's left kidney and the cancer had also spread to her left knee and thigh bone.

It was explained to us that this type of cancer was very difficult to treat and beat. We were absolutely devastated but we needed to be strong and positive for Charlotte. We were told that she was to start chemotherapy straight away and that we would be spending a lot of time in hospital. Her treatment was going to last at least a year of which included chemotherapy, surgery, stem cell treatment and high dose chemotherapy, radiotherapy and then tablets . It felt like we were in a dream, how was I going to explain to my little girl what the doctors were going to do to her and that she was going to be made better by going through this treatment?

As this was not the truth nobody new if she was going to get better after all that treatment. We had no choice, if we didn't give her that chance she would die.

Charlotte began her chemo just before Easter 06. Its effects came quite quickly and she was very tired and sick. She was dealing with everything so bravely even trying to give me a smile through her pain to make me feel better. That was my Charlotte though always thinking about others even though she was going through so much. After all she was still only 5 years old.

Gradually as the first few weeks past Charlotte seemed to perk up a bit and managed to get up and play in the play room and even did some school work. Her cheekiness came back as she got to know everyone on the ward. She even started to tell the doctors and nurses how to do their jobs!

After a few weeks of chemo, platelet and blood transfusions, Charlotte was not only battling the cancer but every infection. Her immune system was nonexistent due to the chemotherapy she had gone through. She was in and out of hospital every time she had a temperature, as this was a sign of infection and could be potentially fatal to someone who hadn't got an immune system.

In May 06 Simon (my husband now) suggested that we brought our wedding forward originally planned for 2007. After everything we had been through the future wasn't certain anymore. So the decision was made to book the local registry office for the 10th June 06 which was 3 weeks away! We hoped and prayed that Charlotte would be well enough to be our bridesmaid. It gave her something to look forward to, she was so excited. How we arranged everything I just don't know. A week before the wedding Charlotte was admitted to hospital again with an infection.

Literally the evening before the wedding she was discharged. That evening we stayed at a hotel for the night with my sister in law and my niece for a girly night. Charlotte and her cousin Jade sat on the bed eating a McDonalds and singing Grease songs they were so excited to be bridesmaids.

Our wedding day was the most perfect day! It was the

hottest day of the of the year. Joseph my son gave me away and my little girl looked like a princess. Charlotte was smiling all day, you wouldn't have thought that she was in hospital the day before. She ate two meals that day, it was as if she got better just for our special day. Charlotte was dancing, singing and bouncing around like a normal 5 year old girl should. I was so proud of her she looked beautiful and I'm so glad we had her there to share our special day.

A week later we were back at the hospital for her next lot of chemo. Charlotte was due to go to Birmingham children's hospital to get her stem cells harvested. Due to the chemo treatment she had we were then told that her treatment would be delayed as the chemo had effected the amount of stem cells in her system, she literally had none left. So we went home and had some normal time together as a family which was really good as I was in hospital a lot with Charlotte and Simon was taking care of Joseph and still having to work as well. Charlotte really missed Joseph so to see them together again was brilliant.

Charlotte was admitted to hospital again just before her 6th birthday in July with another infection. I was determined to get her out of there for her birthday. She was allowed home for the day. We had her Dad Chris and his family and our family too for her party at home. She had lots of presents and although she didn't have much energy she made the most of the time she had out of hospital.

Charlotte's Surgery was booked for 26th July 06 but had to be cancelled too due to her platelet levels being too low. That weekend I found out that I was pregnant. Charlotte

had always wanted to be a big sister.

We told her straight away as we wanted her to know before she had her surgery. She was so excited, She was playing in the a garden with her pram and baby dolls and I new she was so looking forward to having a baby brother or sister.

On 9th August 06 Charlotte was taken for surgery on her left kidney. The consultant Dr Visser had warned us of the possibility that they would have to remove the kidney completely. It was the longest day of my life! Charlotte was in surgery for 8hrs. Charlotte came out of surgery and was taken to the children's intensive care unit to be monitored. The doctors had removed her left kidney and after all that they were still unable to remove all of the tumour as it had wrapped itself round a major artery. They also had to remove part of her bowel.

To our amazement Charlotte was sitting up after 2 days, squirting the nurses with a syringe and singing Grease songs with her headphones on. Within a week she was in the play room on ward 27. There wasn't even a moan from her she just got on with everything again, she was unbelievable.

A few weeks later we got to spend time at home again. We even managed to move house!

At the beginning of September we had to go to Birmingham to try for stem cell harvest but there was still not enough for them to be of any use to Charlotte. Charlotte had a bit of time to return to school for half days. She was so excited to see all of her friends and just be normal. Her first day back just happened to be photo day. So she had her photo taken with Joseph. She was back to being my beautiful independent bouncy little girl. Her hair had started to grow back and she was back to

bossing her big brother and us around. Nothing ever phased her. Even with having a Hickman line in her chest she still would hang upside down from the ropes by her legs at school. She scared me more than herself. I guess she just wanted to make the most of things as she had missed out on such a lot in the passed 6 months.

When Charlotte was first diagnosed I had booked tickets for us to go to the Disney on ice show as this time it was the princess Disney on ice. Charlotte was mad on Cinderella and Snow White. I kept it to myself though as I didn't know if we would be able to go because of her treatment. As it turned out because her treatment had been delayed we got there. Charlotte dressed up in her Snow White dress and was sat on the edge of her seat for the whole evening, bouncing up and down with excitement, smiling and laughing all the time. Me on the other hand, well I was crying my eyes out.

The week after Charlotte went back to Birmingham and finally got her stem cells harvested. Charlotte was doing really well she had put a lot of weight back on and seemed to have so much more energy. She even took part in her school play. As I watched my beautiful little girl, at the back of my mind I knew that in the next few weeks I would have to take her back to hospital to put her through even worse than she had already been through. Why? I kept thinking to myself. I had got my Charlotte back in the past few weeks, why have I got to put her through anymore pain? I knew that I had no choice. If I didn't give her that chance she wouldn't survive. The bigger question in my mind was would she be strong enough to get through the high

dose chemotherapy? Then I thought back to how she bounced back after 8hrs of surgery and having her left kidney removed. Charlotte was a fighter, she wasn't giving up. Her spirit was keeping me going as well. She dealt with everything so bravely.

Charlotte managed to attend her Dad's wedding reception and was dressed as their bridesmaid . She had a wonderful time and came back to me so excited that she had been their bridesmaid too.

It was a week before Halloween and Charlotte was due to go into hospital to start her treatment. I decided before she did that I would put a big Halloween Party on at home. So I decorated the whole house and invited all her cousins round. They all dressed up and the adults did too. We played games and tricks. It was lovely to see them so happy together. At the end of the night Simon set some fireworks off in the back garden as Charlotte would be in hospital for bonfire night as well. I knew this would be the last thing we would do as a family together for a long time.

The chemo started but this time instead of making her tired it made her hypo. She wouldn't stand still but at the same time it was making her aggressive and disoriented. A week later we were taken back to Birmingham to get Charlotte's stem cells put back in. This time we were taken by ambulance as her immune system was none existent and she would have to go straight back into isolation when she arrived back to ward 27 at Leicester. She sat on the bed chatting away to the nurses making them laugh as always, whilst connected to what looked

like a dialysis machine that was giving her the stem cells back which would help her immune system fight back after having the last chemo. I knew from what the doctors had told me that she would start to feel very ill quite quickly.

We returned to the hospital and were taken to the isolation room straight away. This was going to be our room for the next six weeks at least.

As the first few days went on Charlotte gradually got worse and was sick and had diarrhoea as her immune system went down even more. She was constantly being given blood transfusions and platelets. Charlotte's mouth and throat was so sore from the effects of chemo that she could hardly swallow. Everything was being pumped into her to keep her stable. Then her liver started to swell which was a reaction that we were warned about before she received the high dose chemo.

Bonfire night came and she managed to get to the window for 5 minutes but she was in too much pain and so I carried her back to bed. Her pain got worse and the doctors decided to give her morphine. The effects of the morphine were not nice either it made her itch and her skin was sore and bleeding.

A few days later Charlotte's immune system was a little better and so they moved her to a side room on the ward out of isolation. Although, Charlotte's pain was getting worse as nothing the doctors were giving her was controlling her liver swelling even more. It began to swell that much that it was squashing her other organs. In the end it was affecting her breathing and Charlotte was transferred to intensive care. We were told to wait outside as they wanted to tube Charlotte to help her breath. At one point we nearly lost her as she had began

to bleed internally but the doctors managed to stabilise her. For the next week we sat by her bedside willing her to get better.

Finally Charlotte was transferred back to ward 27 but she was hallucinating because of all the drugs she had while in intensive care. Then one evening she started to show signs of infection again. Charlotte lay in her bed after all her visitors had gone and asked “Mummy am I going to die?”

I didn't know what to say to her. She had been through so much, in the end I just couldn't bring myself to say anything else but “of course you're not sweetheart”.

After that she fell asleep. I knew then that she had finally had enough pain and being poked and prodded. I knew deep down that she had had enough and her tiny body couldn't take much more.

Charlotte had never mentioned death until that point ever! We always said to her that she was going to get better and tried to keep her fighting. So at that point it was as if she knew it was going to happen.

A couple of days later Charlotte had developed an infection in her Hickman line and had to be taken to surgery to have it removed. She was then taken back to intensive care again.

It was coming up to Christmas and I was again sitting at my daughters bedside willing her to get better, feeling so useless not being able to do anything to help her.

Because Charlotte's liver had been so badly affected by the chemo all the medication that the doctors were putting into her wasn't working. She was deteriorating fast. After a while the consultants called a meeting with me, Simon and Charlotte's dad and step mum Alison.

They explained that there wasn't a lot more they could do for Charlotte and suggested that we seriously thought about taking her off life support. We knew she had enough weeks ago but there were so many what if's, and the thought of losing our little girl and never seeing her again was the most devastating thing in the world.

It was the hardest decision that we ever had to make in our lives. As a parent you would never dream that your child would go before you, let alone have to make that decision for her.

On Monday 18th December 2006 we had to make that decision.

Charlotte Rose our beautiful little girl was taken off life support and she passed away in our arms. At last she was at peace and I knew that was what she wanted.

Charlotte fought and fought to stay by our sides but in the end this awful disease took over her tiny body. We couldn't let her suffer anymore even though selfishly we would have kept her with us.

Christmas was a complete blur. We knew even though we were grieving, that our son Joseph had his 11th birthday on Christmas eve. So we had a birthday party for him and his friends at the laser quest. At the same time we had to plan our little girls funeral, of which we couldn't have till after new year.

It was the 5th January 07 we had asked everyone to wear pink as this was Charlotte's favourite colour. Her favourite Disney songs were playing as we entered the church. The church was absolutely packed. After the

service Charlotte was carried out to Dancing Queen, which said it all really that is how everyone will remember her.

She loved to dance and sing even when she was ill she still got up and danced around the ward singing her favourite Grease songs.

We all miss her so much especially her brother Joseph, they were best friends!

Life will never be the same without her beautiful smile and character but I know she will always be with us in our hearts and minds.

Charlotte now has a baby brother called Alfie who is a lot like Charlotte in many ways. She would have loved him. She also has a little sister from her Dad and step mum called Annabelle.

Charlotte Rose was a real inspiration to all of us and all that new her. She fought everything that was thrown at her, she expressed her opinion about things, she definitely said what she thought and was the most beautiful, courageous, brave and determined little girl I have ever known!

REST IN PEACE MY LITTLE ANGEL ROSIE POSIE !