



Parley

Parents And Relatives
Listening and Empathising
with You

Victoria's Story

On Wednesday 26th March Abigail was admitted to St Georges for spinal surgery on a paediatric neurosurgical ward.

During our time there, we experienced some of the best and worst moments of our lives and met some extremely inspirational parents, children and nurses who I am going to introduce to you to give you hope, strength and a feeling of survival.

"Unity", "Support", "Family", "Godsend", are all words that the parents of all the children used to describe how they felt about the support we gave each other during our stay.

I will tell you our story from my point of view of each person, how they made me feel and how without them I would not be who I am going to strive to be today.

Natalie and Isabelle

Natalie is a wonderful mother to baby Isabelle of 4 months. Unaware of her strength, Natalie has been through an extremely tough time for the past 4 months having only had Issy at home for 6 weeks of her life. Issy suffers from Hydrocephalus due to a cyst in her head and unfortunately went into respiratory and cardiac arrest in front of her parents and was rushed into theatre to have her shunt replaced on the same day as Abigail's operation. Natalie was the first mummy to smile at me through her worry and anxiety and made me feel very relaxed. Due to an embarrassing bout of hiccups whilst waiting in the intensive care waiting room whilst our little girls were being operated, we clicked and became on speaking terms. Once Issy had returned from Paediatric intensive care to Ocean Ward we began talking a lot more and I asked how Issy was and Natalie opened up to me. I could see a truly amazing woman and Natalie was telling me that she felt guilty that she didn't see that Issy was so poorly and that she blames herself for her illness. I comforted her and explained how I felt about Abigail and how I also blamed myself, and told her that we have been

sent these babies as we are special people who can cope and this is happening to us to make changes for other people and for a reason to change the world. She later told me that this really helped and that she had shut herself off from other people as no one understood what it was like to have a baby born with an illness and that talking to me gave her hope and comforted her as I understood to some degree. We then became friends and Natalie and her husband played with Abigail and spent time with us and they are filled with hope that Issy will survive and live a happy and prosperous life. We will continue to be friends for a long time. Issy is now home and doing very well.

Kelly and Josh

Kelly is a mother of 2, 4 year old Josh and 11 year old Conner. Kelly came onto the Ward as my next door neighbour half way through my stay with Josh who was diagnosed with a brain tumour the day before. Josh was set for surgery to have the tumour removed and unfortunately had a seizure the day he arrived. A crash team was called and they managed to stabilise Josh and rushed him into theatre to drain the build up of fluid on his brain. I have to say this was one of the hardest times of my life and kept thinking that this could have been my child and couldn't even begin to imagine what it was like for Kelly and her partner. After the operation I spoke to Kelly and asked her how she was feeling. She opened up to me and felt that it wasn't really happening and was very numb. I tried to make her feel as strong as possible and spent a lot of time laughing and talking about our lives away from the problems of our children and we started to become very close. During Josh's tumour operation, Kelly and her partner felt comfortable to return to the ward with me and my partner and spent time with us to fill the time which was a honour and a privilege. Kelly still remained strong and I will always remember thinking of how I envy her and that I would not have coped so well in her situation. ON the day we were discharged from the hospital it all hit home with Kelly and I didn't want to leave her but knew all would be ok. Her partner later told me that she was also upset that we were leaving which was overwhelming as I felt I had really made a difference. The support network that I had offered Kelly she described as being fantastic, great, agodsend and many other lovely words. Josh is getting better now and is fighting a long battle but with his mummy's strength will return to normality in no time.

Wendy and Paige

Wendy is a mother of 4 including 3 year old Paige who amongst many illnesses suffers from Hydrocephalus, brain damage, and has to be fed through a tube into her tummy to name but a few problems. Paige is a twin and due to unfortunate circumstances is now in Hospital for the foreseeable future. She is a huge inspiration to other children and has fought her whole life giving us hope and strength to hold onto. Being told Paige is brain damaged and non responsive, Wendy has done her utmost to give Paige the best life she possibly can through reading, singing, playing, listening to music, massage, and mostly love. Wendy will never give up hope that Paige will return home with her, and with this inner strength, Paige is holding on determined to survive. She responds to bright lights and whilst singing to her let me know that "sing a song of Sixpence" was her favourite song, she loved the story of "Snow White and the Seven dwarfs" especially Sleepy. Paige unfortunately during our stay became very poorly and had to be rushed to theatre with fears that she may not return, but she did and not even going to intensive care thanks to her mummy's support and determination. She came back on to the Ward and looked wonderful. Abigail spent a lot of time with Paige and brought her a giraffe (like the Parley logo) to keep with her at all times to know Abigail is always with her for support. I befriended Wendy and became very close like sisters and helped her through a very bad week by offering unlimited hugs and a shoulder to cry on. Wendy became the sister I never had and I will always be there for her. We laughed, we cried, we shouted but amongst all we were there for each other at every level. You don't need to be qualified to be a friend to those in need. I now have a photo of Paige and will keep it with Abigail forever as she represents strength, hope and survival.

Emma and Lisa

Emma and Lisa made our stay in the hospital bearable and enjoyable in a strange way. Emma was the acting ward sister and Lisa was the play specialist and between them, they have been the best support any parent could have asked for. Emma didn't only have excellent nursing skills, but above all she genuinely cared and wanted to help. On numerous occasions Emma would play with Abigail and take her off with her around the ward to play and sit on her lap to give us a break and obviously to have a cuddle. All the parents respected Emma and trusted her to the nth degree and when Emma felt that our children were ok, we truly believed that they were and when there was a

reason to panic, Emma would be the one to let us know without hiding anything, and to be there to help and support.

Lisa was amazing, she oozes passion and has an obvious love for her job and made such a huge difference on the ward. Her ability to calm the children down during procedures and her daily visits just to say hi made the world of difference and was a god send. During Josh's seizure Lisa became everyone's strength and appreciated and recognised that due to all living in close proximity in the ward, that we were all affected and talked to us and made sure we were all ok even though it wasn't our child who had experienced it. This proved and showed the level of support that we had on offer.

And finally Abigail

Abigail is the bravest, happiest and most beautiful baby. She hardly cried during any of her stay in hospital even after contracting an urinary tract infection and her wound becoming infected. Her smile and giggles and ability to make the ward shine through her personality was inspirational and all the parents and nurses fell in love with her. She gave the parents hope and the children fun to play with. I am so proud that she is my daughter and I don't think Abigail will ever be forgotten.