



Parley

Parents And Relatives
Listening and Empathising
with You

Abigail's Story

Abigail was born with Spina Bifida which we now know to be Spina Bifida Meningocele (highly visible by a fluid sack, hair patch and dimple on her lower back).

I had to have a caesarean section at 37 weeks due to pre-clampsia of which a paediatrician was present to check over the baby. She went into the recovery room and told my mother that Abigail was perfect. After being moved into the recovery room after a long period of stitching (having lost a lot of blood), the Midwife upon weighing Abigail stated in shock in front of me that Abigail had Spina Bifida.

She then left immediately, with my partner to see a paediatrician and I was left alone in recovery totally distraught and concerned about what may happen to my baby girl and that she had a severe disability. We were told that Abigail would be seen by a paediatrician and would be tested upon to see what extent the severity of the Spina Bifida was.

No one came for 2 days to check her head for hydrocephalus, her bowels, her bladder/kidneys or her movements straight away. We could have irreversibly damaged her organs if something had happened without her being checked. We were also left without any support, information, or counselling for Spina Bifida and didn't know where to start looking. I kept asking Midwives questions about it and no one could help or advise. I felt extremely isolated and nothing for comfort.

Consequently, this resulted in me not bonding with my baby, and struggling to deal with Post natal depression which led to me disregarding my daughter for 2 weeks and a major guilt complex as I thought I had caused this imperfection. As we had no one to talk to or support, I was not aware that I was not to blame and Spina Bifida happens within the first 14-28 days of conception.

We have been for ultrasounds and an MRI scans and even though the

radiographer was fantastic and offered superb support as well as Abigail's paediatrician, we were still not given any information on support or counselling to explain why this has happened. Having spoken to my GP about my Post natal depression he contacted the hospital for genetic counselling and a chat as to why this may have occurred and I received a letter full of leaflets about Spina Bifida Hydrocephalus (which is the severe form of Spina Bifida) which put me into a deeper depression.

My mother then contacted the Spina Bifida association (ASBAH) who have come out to meet and talk to me. If it wasn't for her contacting them I would not have thought to have searched for this charity. No one offered this information to us, we were left to go at it alone and not in the right frame of mind to surf the net and search for organisations.

I was deeply concerned and affected by the support and treatment of my local hospital and the lack of information and intelligence of the staff in regards to Spina Bifida and the way that it was handled from birth until now. I was later informed that there are no procedures in place for when babies are born with any disabilities or impairments of any severity.

I wrote a letter of complaint to the hospital board and I am now pleased to say that they have appointed a member of staff to offer information and support to new parents and relatives in this situation.

Abigail is now waiting an operation when she is 1 year old to undergo having her spinal cord and nerves de-tethered and re - aligned to enable her to go on to have a physically normal life.

I am the founder of Parley for reasons that I feel other Parents and Relatives deserve the support and information simply and easily and to access other stories to feel comfort and support.

I am lucky because Abigail has not yet been affected by her condition however as a parent I struggle to come to terms with the fact that she has to undergo major surgery at a very young age.

Thankfully Abigail will not ever recollect the operation and will have no lasting memories.

2 years on...

Abigail underwent major spinal surgery in March 2008 to correct the nerves and spinal cord which were tethered to the outside of her back covered by a protective fluid lump.

It was terrifying, this Spina Bifida is rare and we could not find another case like it or speak to anyone who had been through it.

On arriving at St Georges onto the neuro ward, I was ready to turn and run the other way. We were told that they had found a double tumour on Abigails MRI scan and this too had to be removed.

The cannular and the blood tests were hard enough to go through, the thought of the operation was a nightmare.

They went through the MRI in great detail layer by layer and explained they had to remove a complex double tumour as well as sorting the cords and nerves. I was petrified but didn't cry. They said it was nothing to be concerned about but that it would just make it a bit more complicated and was benign thank god.

The next day and 5 ½ hours later standing in recovery, the surgeon lifting Abigails blanket, tickled her feet and she wiggled her toes. It was the most amazing feeling in the world. She was not paralysed and the operation was a success. Now we had to recover.

It was not easy, she leaked spinal fluid and blood from her back, she had to lay on her front, we couldn't pick her up, I couldn't cuddle her.

It was heartbreaking, but she kept on smiling and kept all the other parents and patients going with her cute and chubby ways

We also had some problems as our surgeon went away and left another neuro surgeon to watch over Abigails recovery. He messed up with a minor situation with her sutures which resulted in Abigail having to return to theatre to be reopened and restitched.

She was so brave and just took it all in her stride.

I can't go into detail about her operation as it is still very raw so this is lightly touching on it. But now 2 years on at 2 years and 4 months old, Abigail walks and talks like you would not believe it. If it was not for the large scar on her back you would not know that she had a problem at all.

She jumps and runs and dances and climbs like any other 2 year old.

It feels like a blur and I still get very sad and upset thinking about what she went through, but she is now amazing and fully recovered and is the cutest, bravest and most independent little monkey who we love with all our hearts.

Don't lose hope if you are going through the same. We never expected Abigail to recover so well without and problems at all. Of course we

still have milestones to reach and potty training still seems miles away as her bowels are not hugely great, but this could be toddling problems rather than her Spina Bifida.
Only time will tell x

