



Parley

Parents And Relatives
Listening and Empathising
with You

Beth's Story

It was 21 May 2003 and I was booked in for a Caesarean at the Royal Surrey Hospital, as I had had a previous section. All ante-natal scans had been fine and nothing abnormal detected. The delivery went well and we were taken back to the ward. A paediatrician came to check the baby over and said that he had a small anomaly at the base of his spine that she would like to get checked out. As far as I can remember, he had an area about the size of a 1p piece of see-through bluish skin at the base of his spine. He was taken away and brought back to me a couple of times in the first 2 hours. Then a doctor came to us and said that he was to be referred to a specialist at another hospital and that he would have to go now! They phoned around the specialist neurological hospitals and said that Kings Hospital in London would take him. I said that I wanted to go with him (as I had had a Caesarean I could hardly get up and drive myself there). They were quite annoyed that they had to transfer me too.

Ryan (my baby) was taken by ambulance up to Kings on his own and then the same ambulance came back for me (3 hrs later), because we were told that 2 patients are not allowed to travel in the same ambulance. Ryan went to the neurology ward and I went to maternity (about 1/2 mile apart). As I could not walk, I did not see Ryan again that day.

Late at night the consultant, Mr C, came to see me and said that Ryan had Spina Bifida Occulta and that he would need to operate within 24hrs of birth to prevent as much damage as possible. It was very scary because I was on my own in a hospital I did not know, being asked to sign a consent form for something I did not understand. I had to trust that they knew what they were doing and I signed the form. I assumed Ryan was being fed by a drip (I had wanted to breast feed).

In the morning I could stand it no longer being apart from him, so I stood up, had a shower and then walked the 1/2 mile (carrying my bag) to the neurology ward. There was no-one around to help me. When I found him, he was in special care being prepared for his operation. He went down soon after that. My husband arrived and we

waited for him to come back. The hospital was really grotty and when he came back he went into the children's section of the neurology department. I sat beside the cot - the other children, some quite old, were quite distressed and there were some really ill babies in there. He did quite well and after 24 hrs I was able to start the breast feeding. Mr C said that he had removed fatty tissue from around the spine, but that long term effects remained to be seen. He seemed completely normal to me. After 3 days, we came home!

After about a week, I was changing his nappy when I noticed that the wound had opened up. We took him to the local A and E and they wouldn't touch it - they said we had to go back to Kings. So we drove all the way up there and waited to see Mr C again. When he eventually came, he took one look at the wound and said that we would have to stay in that night. He said it looked like an infection. I didn't understand at that time why they couldn't just sew the wound up again. We were given a small room in the main neurology ward. They tested the wound to see what the infection was. The next day, the test results were not back so we couldn't leave. The nurses simply dressed the wound by packing cotton wool inside the wound! I wondered how it would ever heal. We stayed in this small room with no information until the third day when a nurse walked into the room with a notice saying 'barrier nursing', said 'it's MRSA' and shut the door on the way out. I didn't know what this meant and I just wanted to go home. My baby wasn't ill and the room was very small and stuffy. Everyday the nurses came to dress the wound and he started to be given the really strong antibiotic Vancomycin. This antibiotic has to be given three times a day intravenously. Because he was just a tiny baby, almost every other time they came to administer the drug, they would have to find a new vein. This would involve calling a more senior doctor who would sweat and pull him around terribly to find a new vein. In the end they had both arms and feet used up and they tried going in his neck. We were not getting hardly any sleep and I didn't know when or if we were going to get out. I tried to ask questions but they were very cagey. It turned out that the intra-venous antibiotics needed to be given for a week to kill the MRSA. The wound healing would only start once the MRSA had gone and would take several weeks after that. My husband and I put lots of pressure on Kings and Guildford Hospital to get us transferred back to our local hospital. I couldn't understand why the local hospital wouldn't administer the drug. They kept refusing to take us back there. Incidentally, we were allowed to wander around the neurology ward amongst other very ill patients and to go down to the cafe and outside the hospital. The doctors rarely washed their hands or wore gowns etc in our presence. I only since realise the

dangers of MRSA. Eventually, with the help of a very kind nurse at Kings, we were transferred to Guildford hospital.

We were in hospital (Kings and then Guildford) for a total of 10 days and then trying to get the wound healed for another 10 weeks! Guildford once again refused to help when the wound over-granulated and they sent us back up to Kings for a very simple procedure that could have been carried out by any nurse. Eventually the wound healed and we could move on. I was generally very frustrated by the lack of information and failure to take responsibility by the hospitals.

Regarding the Spina Bifida, Ryan had to go for tests to establish the extent of symptoms. He had an MRI scan and invasive bladder function tests. The experts were very negative and painted a very black picture of all the things which were likely to go wrong i.e. bladder/bowel. It was like they were talking about a different person as he seemed completely fine to me. Until we passed each milestone such as walking and potty training, I worried that he wouldn't manage it. The professionals were overly pessimistic and I wish I could have talked then to someone with a child such as mine. I don't feel we were given a very balanced view - maybe these experts see so many severe cases that they think that is the norm.

He is now 4 and I have almost forgotten that technically he has Spina Bifida. He has NO symptoms and although in theory he could develop some, frankly I doubt he will. I just wish the experts had not dwelt so much on the worst case scenario (and frightened us to death) and that the hospitals had been more open and helpful in the early stages. The experience has definitely opened my eyes and I would be very happy to talk and sympathise with anyone going through the hospital system. It can be very scary and you can feel very helpless and alone.

I found a local kinesiologist very helpful in the first year. She told me that he was fine and that the doctors were being over-pessimistic. She gave me confidence to believe that my gut feeling was in fact correct. She had a very calming effect on the situation.