



# Parley

Parents And Relatives  
Listening and Empathising  
with You

## Julie's Story

I'm Julie, I am 33 years old. I am 5' 1/2" tall and weigh about 6 stone 11 fully dressed! This is my story.....

It begins 2 day before Christmas on Thursday 23rd December 1993. I was pregnant with my 1st child and due on 18th January 1994, just short of 2 weeks before my 18th birthday. I went for my usual checkup at the doctors, and due anemia that showed up on my last lot of blood tests the week before was given Iron tablets to take once a day (bear with me it makes sense soon).

I was living in a 4 bed roomed house with my mum, my dad, my 15 year old brother and 3 sisters, aged 12, 9 and 6. The house had one storage heater in the living room, and a coal fire.

Christmas was as excitable as you would expect with such a large family, and sleep was not readily available. Needless to say I was a little tired. I only had the smallest of bumps, and could easily cover it with a big jumper, so no-one could tell, if they did not know, that I was pregnant.

On Monday 27th December at 2am I woke up with what I assumed was the iron tablet side effects (that include in the list diarrhea and constipation). So I plodded to the loo and back to bed. At 4am and 5am I did the same thing, now I was shattered and freezing cold! At 5.30 I woke up my mum to tell her I thought the iron tablets were playing my up. She said I should go down stairs as at least I'd warm up, and followed me down. After calling the hospital, and being told to take my time my mum woke up my older brother (on leave from the army) who was sleeping with his girlfriend in the dining room to ask for a lift. I couldn't sit down so I arrived at the hospital on all fours in the back of a Corsa, after being bounced off the roof a few times by the speed bumps (not that my brother was panicking MUCH!!)

At 6.45 I was taken into the labour ward and told off for not being at the hospital sooner as I was 9 1/2 cm dilated, and the baby was on its way. The midwife then gave me the gas and air and said that was my choice of painkillers! and at 7am I gave birth to a perfect little baby girl, with beautiful big blue eyes and little round belly weighing 5lb 11oz. I was taken to the ward at about 7.30. At 12 lunch time the pediatrician came to do his rounds and checked on her. I did not think anything of it when he said he thought she looked a little blue when she was feeding and had to go to Special care baby unit (SCBU) as they could monitor it, as she was early. I found out later that the doctor knew more than he was prepared to tell me.....

I joined Alice in SCBU shortly after, and was given my own room close to her. The staff were over the moon, they had had no babies for a month or so, and fell in love with Alice. They were all aware of the "problem" that Alice had but noone was allowed to tell me because of the doctor, he had told them not to say a word he would do it himself.

The following day at lunchtime, the doctor (who was about 7 foot tall and 7 foot wide) called me and Alice's father into the room that Alice was in and told us to sit down at the opposite end to her incubator. He then stood over the incubator and said..... "I have a few things to tell you about Alice..." I took in a breath "First of all she has Downs Syndrome, second of all there is something wrong with her heart, but I don't know what it is. We will take her to Newcastle for a heart scan when you get discharged in 5 days, if she lasts that long." He boomed. And as if that was not enough "Thirdly, because you are such a young mum I do NOT want you to feed her, change her nappy or even cuddle her. You should walk away, because she will never walk and never talk, and will probably be a cabbage for the rest of her life, and it's YOUR fault" none of what he said sunk in. My whole world collapsed around me. But I was numb. I couldn't say a word.... "well, any questions?" I could only think of one.... "can I call my mum?" he just tutted.

The Sister ran into the room and took me into the office. She handed me the phone and ran back to where the doctor was still stood. I heard a lot of shouting including her saying "What the hell do you think you are playing at?"

I heard the phone pick up and my dad answered "Is mum there?" "No she's at work". My mum was working at a special needs unit not far from the hospital doing her nurses degree. "It's Alice, she...." that's when some of what he said hit me and I could not say another word. Sister had appeared behind me at some point and took the phone, I don't have a clue what she said, and I don't know what kind of time scale it was but I remember that my mum was with me, and I was crying.....

A few things I think I should mention before I go on. During the 24 hours when Alice was in SCBU, and I was unaware that she had "a few problems" I had bonded with her. She measured 48 cm long She was a very alert little girl, with huge perfect blue eyes, 10 little fingers, 10 little toes, 2 arms, 2 legs, 1 little round belly with a button, 1 nose, 1 mouth with lips and 2 ears. She had been laid on oneside when I was carrying her and it was a little more sticky out than the other but she was perfect to me and everyone who met her! she made everyone smile and the nurses giggle with her antics. Sister Stockall in particular.

Prem babies have a habit of being sick after food, so they lie the babies on their side, and put a rolled up towel in to stop them rolling off the "tray" in the incubator. Alice did not like the towel in her space and somehow managed to throw it off 3 times.

On the other hand she was not a good eater. Her lips would turn blue when she was feeding, and one feed would run into the next. She was already showing signs of stubbornness and intelligence.

Back to where I was.... Crying.

I was numb and going through all of the questions you would expect at that point, although I did not speak for about 24 hours my mind was screaming "why me?", "what did I do wrong?", "how did I make this happen?", "WHEN is she going to die?", "why can't I just die?" .....

Because I was on such a state it was as if I had cotton wool in my ears, I could just about make out some things that were going on around me, but not much. But I do remember my mum and Sister talking about me crying saying that I should sleep, and that doctor needing shooting! I was given sleeping tablets but they didn't help. I fell asleep at some time during the night, but I have no idea what time it was.

I broke my silence to say "take her", the nurses couldn't work out what I meant so I had to elaborate "take her and find out what is wrong with her heart, I don't want to wait to find out if she is going to die" I blubbed.

They arranged the ambulance and took her the same day. I was told she would only be 2 hours..... When after 5 hours she still wasn't back I was panicking more. I was told to try and not worry she was fine, was stealing the hearts of everyone in Newcastle, but there was an ambulance shortage to bring her back. I was pacing still crying, and my milk had arrived (any mother understands)

When she arrived back after what seemed like forever (about an hour later), Sister called me into Alices room and gave me the good news..... "That doctor got it wrong" she said "There is nothing wrong with Alice's heart." "So why does she go blue then?" I asked puzzled.

"Its because when a baby is born there is a little valve between the heart and the lungs that closes, so when they breath the blood goes to the lungs to get oxygen" Alices hasn't quite closed properly, its quite common in early babies" "so what exactly does that mean then?" I asked wondering how long the operation would take.... "well if we give Alice extra oxygen, it will heal itself" I was so relieved and hugged her. "the thing is she will have to have a box over her head too feed the oxygen into, and you may have to feed her in the incubator to keep it constant" But I didn't care the relief that my little girl was not going to die was so immense she could have told me she would have had to be fed by tube.

The next few days Alice showed more of her stubbornness, the box was placed over her head, and the oxygen feed plugged into the side of it. Alice liked her space and the towel was easily removed, so the box was just another thing to get rid of. At least 3 times we found she had lifted it and moved it, and every time she would get it just above her eye brows, leaving a red line. She made us all laugh. "Certainly Not thick this one" was one of the comments from one of the nurses.....

Within 2 weeks, Alice had stopped turning blue. She was still a tediously slow feeder, and I still didn't really understand a thing about Downs syndrome. I had a visit from the doctor, and all he could say was "I'm sorry I didn't tell you earlier, but I had a migraine." He was then dismissed by the hospital and moved to a country "where he did not have to pay taxes". I had been visited by a social worker for the disabled children's team. At first I wished she would sod off because I thought she was there to take Alice away. But she turned out to be an absolute God send. She told me that what the doctor said was wrong. Alice would probably go to a mainstream school, and would not be a cabbage, although she may need a little more help to reach her milestones. The team of physiotherapists, speech therapists etc would help her and me get there.

Alice was discharged, and I took her home to my mums house and finally relaxed a little.