

Beginnings

The words "he's a good colour" broke through the silence as the nightmare of my first pregnancy reached its peak and was finally over at 30 weeks. The Neonatal Team paused briefly by my side so that we could see our little boy who stared at us quizzically with one eye open before being whisked away to the Neonatal Intensive Care Unit (NICU). The surgical team seemed to relax and conversation started to flow, there had been none until this point. Our first child, a boy named Aidan, entered the world weighing 948g, 2 lbs 1 oz by an emergency section.

I was delighted when I discovered I was finally pregnant, after 18 months of trying to conceive it felt as if we had finally got there. We had recently returned to Cambridge and we eagerly started planning for this welcome new addition to our family. My husband was frantically preparing for his final actuarial exams and I was busy teaching music.

I do remember thinking at the 20 week scan that it was a bit odd that I still didn't fit into maternity clothes but the scan appeared to be fine so I pushed that thought to the back of my mind. I never did fit into maternity clothes as around 26 weeks we discovered there was a serious problem with the baby's growth which was slowing down considerably and falling off the percentile chart; the placenta was peeling away and an early delivery would be imperative.

Around 23 weeks I began bleeding, was admitted to the hospital and after a few days discharged being told women do bleed as long as I wasn't going into labour there was no real concern. This pattern continued, I got to know the drill well; phoning the Delivery Unit, popping up to the hospital, internal examination, Anti-D if necessary, and, as long as the bleeding wasn't bad, then home again to rest. I was eventually booked a scan to check the baby's growth, there then followed an immediate referral, to the Fetal Medicine Consultant at the hospital, and admission, until delivery.

I spent 4 weeks hopping between the ward and the Delivery Unit. My poorly formed jelly-like placenta was restricting the blood flow to the baby, fluid levels were abnormal and the baby's growth had more or less stopped. The baby was seriously compromised, in order to preserve the brain the body had stopped growing, the blood flow to the brain was restricted but not so much as the body. It was a question of timing to get the baby out at a point before brain damage occurred, that is providing the baby didn't die in-utero. Through this there were

periods where I was bleeding badly, I remember a room full of consultants where I was struggling to keep up – losing lots of blood quickly leaves you feeling weak and dizzy – and understanding that delivery might happen and the outcome at 26 weeks was grim.

Clearly this was a desperate period, we clung onto what little hope we had and somehow waited. We visited the Neo-Natal Unit, met the staff and began preparing ourselves for the long rocky road of uncertainty which lay ahead. The care we received from everyone at the hospital was outstanding. My consultant has to be one of the most compassionate and skilled doctors I have ever met and our child is a testimony to his expertise. Late one Sunday night the heartbeat dipped on a trace and kept dipping; the baby was getting tired. The consultant on call wanted to respond and, after faxing the trace, he gave the go-ahead to deliver. The realisation that this was it, finally there was an end, was an exciting state to be in and no sooner than I had signed the consent forms was I walking into the Operating Theatre shaking.

The Journey

The next five days were spent recovering from surgery and shuffling to and from NICU to see our beautiful, but significantly growth restricted, baby clutching small amounts of expressed milk. We left the hospital still clutching the breast pump as expressed breast milk was the best thing I could do for my little boy. I dutifully expressed milk every three hours, setting alarms for waking during the night. It was a strange, hot and brightly lit world of Intensive Care Medicine we had entered and it felt as if we had suddenly embarked upon a crash course of paediatric medicine; there was a new language we needed to digest, understand and speak.

Leaving the hospital without my baby is one of the most emotional journeys I have undertaken. I felt as if part of me had been severed and removed. The house was cool and empty, a welcome contrast from the hospital but not right, something always seemed missing whenever we returned home. My husband returned to work and I caught the bus to shuttle between homes; The hospital was starting to feel like a home and suddenly we had a routine – days sitting quietly by an incubator, inwardly glowing with pride but equally fearful. I treasured the moments when we could hold our baby, sing him a song, change a

nappy and do something normal that enhanced my status as a new mum and gave me a sense of ownership of my baby and an element of control.

Behind this was the reality that some premature babies do die and anxiety levels were at an all time high. Like most parents of premature babies we experienced highs and lows and we had our share of set backs – surgery, brain scans showing light patches (could be an indicator of brain damage), and significant de-saturations (not enough oxygen reaching the brain).

We were fortunate in that our baby didn't need ventilating at delivery, after an initial wobble he was well enough to hold, and gradually he was able to tolerate tiny amounts of milk, 0.5 mls given through a tube from his nose to tummy. Slowly we got there – there were times when the pressure seemed too much to bear, times when I wanted to scream, cry or just grab my baby and leave. As I reflect upon these tense and difficult days I remain indebted to the tireless staff of nurses and doctors who worked in NICU day and night and wonder at the amazing jobs they do.

We did eventually leave the hospital after 6 weeks in NICU followed by 6 weeks in the paediatric ward. Our child did survive every hurdle including a respiratory arrest where resuscitation was needed. Growth remained a concern; Aidan remained on the bottom percentile but was starting to show every sign of developing into a healthy child. We were given Open Access to the paediatric ward (immediate hospital access if we were in any way concerned), we had many outpatient appointments to follow up Aidan's development and slowly these early days faded and we found ourselves getting on with every day life.

I still cringe when I remember some of the comments we endured when venturing out – why is he so small? how old?, do you want to hold a proper baby and see how they really feel?, at least you didn't have to go through the last months of pregnancy!!

Of course I realise how different events could have been. Aidan is currently finishing his first year at school and, like any 5 year old, loves school, his teacher, riding his scooter and climbing anything. His growth has remained a problem, being short in height and low in weight for his age, so last year we embarked on a course of Growth Hormone Treatment which involves daily injections of growth hormone. This is working and is he catching up in height and weight. I'm still

unsure as to how exactly we survived this peri-natal period and where these experiences leave me as a parent – humbled, relieved, shaken, determined, softened - and yet we have gone on to have two other children aged 3 years and four months without the placental problems encountered in the first pregnancy.

Aidan was recently asked to take a photo of himself into school; do I send a photo of him at about 5 months old still looking small and convincing as baby or a photo of him as he really was filled with tubes and in an incubator? Aidan readily accepts his shaky start to life, loves looking at baby photos, and confidently proclaims that “he was born early and small and red and that lots of doctors and nurses had to look after him until he was well enough to go home.”

And perhaps that is the best part of it all, that Aidan has no memory of this and is a happy carefree child, blissfully unaware of the turmoil we, as parents, lived with. I can't imagine life without him.