

Birth Stories – Pre-eclampsia and Premature babies

Pregnancy

I enjoyed a pretty straightforward pregnancy. I had a little scare at the beginning, but once that passed the pregnancy was going really well. The 'morning' sickness at the beginning was not too bad and I felt terrific in the second trimester. In fact, we were on a 'trip of a lifetime' before the baby arrived – this included loads of swimming in the ocean and hiking – bliss!

I had my 20-week scan whilst abroad. We were very impressed with the level of care we received and the scan of the baby was beautiful. We could clearly see the four chambers of the heart, the tiny hands and feet – it was all so exciting!! I appeared to be in perfect health and things were on track for a healthy delivery and baby.

Upon returning to the UK, we attended NCT antenatal classes. Due to the timing, we ended up taking the classes much earlier in the pregnancy; little did we know this would turn out to be very necessary! Although at the time, we still thought we would have a straightforward birth. I wanted a home birth and was looking into birthing pools. My husband on the other hand wanted me to go to the hospital – he didn't mind if it was water or land birth – he just didn't want it to happen at home!

Around 25 weeks gestation I started to experience swelling. My ankles were huge most of the time and some days my hands would be so big it was uncomfortable. In fact I ended up having to take off my wedding rings, as it was too painful. I also started to have 'off' days. I couldn't exactly pinpoint what was wrong I just didn't feel right. I felt like I needed to rest, but couldn't put my finger on what I felt or why. I kept thinking this must be part of pregnancy and perhaps its normal to have 'off' days. Every now and then I would see stars or streaking – again I would blink this away thinking I must have sat up too quickly.

I had been reading *What To Expect When Your Expecting*, which had some information about pre-eclampsia. This worried me, so during my next visit with the health visitor I explained how I felt. My blood pressure appeared to be fine and the protein in my urine was normal, so she said not to worry about it, but if I did see stars again it might be worth having my blood pressure checked. After this I thought I must be paranoid and should stop worry about things – my pregnancy really was going well and these things must happen as part of pregnancy!

I continued to have 'off' days and the swelling got worse. In fact not only were my hands and feet swollen my face was huge and the rest of my body started to catch up! My husband and I were planning on travelling to Cumbria to be Godparents. We thought we would take some extra time and spend a week walking and enjoying the lakes. This meant that I had to change my next antenatal check. I decided to move my appointment forward rather than back a week. I still felt a bit strange so to satisfy my own paranoia it would be best if I got checked out before I went on the trip.

Finding out about Pre-eclampsia

My husband went with me to the antenatal appointment. I was almost 30 weeks gestation. There was a student midwife there that day and she asked if it would be ok if she did the check. I explained how I was feeling and how swollen I was. She took my blood pressure whilst my regular midwife checked my urine sample. My blood pressure was very high and my protein level was a 3 (it should be 0; 3 is considered high). The midwife quickly asked my husband if he had noticed my swelling. He said yes, I was much bigger than normal. At this point I started to cry. I had read about pre-eclampsia and I had all the signs – my perfect pregnancy was disappearing. Not to mention I was startling the student midwife – I don't think she had seen anyone break down like that before! My midwife advised us that we would have to go straight to Addenbrookes. I could go home and collect a few things (they may keep me over night), but I needed to get there as soon as possible. They quickly checked the baby's heartbeat and sent us on our way.

When we arrived at Addenbrookes, they were waiting for us. We were taken in straight away and put on a monitor to check the heartbeat and movements of the baby. They continued to monitor my blood pressure and rechecked my urine. The tests made them suspect pre-eclampsia and I was promptly admitted to Lady Mary Antenatal Ward. Not only was I upset about potentially being unwell – I felt like my chances of having a home delivery were promptly going out the window. This was even more upsetting as we had toured the hospital the night before and I was determined to have a home delivery rather than be in the sterile, clinical hospital setting – what I had decided to be my worst nightmare.

Staying in Hospital

The ward was filled with other pregnant women experiencing some sort of complication. I found this really sad – I thought pregnancy was supposed to be natural! I was put on a bay with 5 other women and asked to collect my urine for 24 hours, as this would give a better protein reading. Great, not only was it going to be difficult to sleep with 5 other people around, my blood pressure checked every 4 hours, I would also get to carry around a jug collecting my urine. This was definitely the last thing I thought would be part of my pregnancy!

The staff were fantastic, they kept smiling even as many of us on the ward were unhappy about the situation we found ourselves in. When I met the doctors they said they would need to monitor my protein and blood pressure and **if** I were to make it to 34 weeks I would be doing good. I only heard 34 weeks and decided that was a good time to give birth – 6 weeks early is perfectly acceptable right? They also gave me a steroid shot to help develop the baby's lungs, which I found quite distressing that they were preparing for a potential earlier delivery.

As the days past, it was determined that they may have to deliver at any moment and I would need to visit the Neonatal Intensive Care Unit (NICU) to understand what to expect when I delivered a premature baby. I kept putting off visiting the unit. However, the doctors were not going to let me get away with stalling – I was to visit immediately. This was particularly scary to me – the last time they did a full ultrasound of my baby; they noticed that she was particularly small, did not have a lot of amniotic fluid and I was beginning to starve her. All of which can be typical with pre-eclampsia.

I found the neonatal visit incredibly depressing. This was not supposed to be how my pregnancy would turn out! I always thought I would have a healthy, plump baby to bring home from hospital and what I saw in the neonatal unit was far

from that. Babies were held in cumbersome incubators and connected to loads of machines. Some babies had monitors all over their tiny bodies and parents had to 'look in' on their babies and were not able to hold them any time they wanted. The experience was overwhelming and not at all what I expected for my pregnancy or baby.

That night as part of the regular monitoring of the baby the midwives could not get a sufficient reading of my baby's movement. We even had my husband come in to talk to the baby to try and get some movement – we did get a small amount, but not much. The doctors said it was enough for the gestation and therefore they would leave me for now. My blood pressure was still high, but not too dangerously high. My protein levels remained high. All of this meant I would stay in hospital and could not even leave to go home for a few hours. The doctors wanted to start making a plan for delivering my baby. They did not feel I would make it to 34 weeks and thought if I were lucky I would make it to 32 weeks. I wanted to at least try for 32 weeks. All this was under the premise that at any time I could become very ill and they would need to deliver by emergency caesarean. At this point I decided to stop feeling sorry for myself and recognise that I was getting fantastic medical care and that everyone was considering and doing what was best for the baby and myself. By changing my attitude the rest of my checks were much more promising.

Whilst the positive thinking was helping, my blood pressure started to steadily rise and my blood tests revealed that my body was not coping. The Doppler scans of the baby were also starting to decline. Therefore, I would need to have a caesarean delivery and a date would need to be agreed. Whilst I found all of this incredibly scary I felt the medical team were excellent about including me in all of the decisions and allowing me to say how I felt. At one point I was sure that I didn't need to deliver so early and really started questioning why we would need to move forward. My doctor was excellent about explaining what was happening to my baby and me and why this was in the best interest of us both. At this point I was so worried about the baby and the complications that come with a premature baby that I didn't really care about myself. Whilst my husband was the exact opposite, he was only worried about me and if I would be ok and would worry about the baby later.

It was comforting having so many other pregnant women around. We each had our own complications and fears about delivery. Those of us that knew we were going to have a caesarean were able to talk about our fears and drive the midwives crazy by asking loads of questions. It was also helpful to ask those that had already delivered how they were feeling and what it was like to have a caesarean. When it came to my delivery date, I almost didn't care about the delivery – I was nervous, but I had moved on, I was now more worried about my baby. It seems funny how I was so concerned about the birth itself and now I was more than happy to have a clinical delivery – almost forgetting how important a home birth was to me.

Delivery – Meeting my Baby

The delivery itself was fine. I was numb from the waist down and was awake during the delivery. My husband was by my side throughout the delivery and was able to cut the cord. I was ill several times, but that was because my blood pressure shot up (the pre-eclampsia showed its true danger after delivery). I lost a lot of blood – 3 pints worth as it turned out my placenta did not want to separate from the womb, so it took them longer to 'put me back together again.'

All of it was worth it, when I briefly saw my baby girl before they whisked her off to the neonatal unit. She was much bigger than I thought she would be and she appeared healthy. After surgery, I was taken to a clinical recovery room where I was closely monitored. Due to the pre-eclampsia, my blood pressure was dangerously high and I couldn't have the standard pain relief. They were able to give me another form of pain relief, but I was pretty out of sorts. My husband was able to visit our baby and brought me back a picture, promising that I could visit her the next day.

Having a baby in the Neonatal Intensive Care Unit (NICU)

I finally did get to see my precious baby girl. I was still pretty out of it the first time I saw her, I was taken in a wheel chair to her cot and couldn't really understand what the doctor was telling me. All I cared about was that she made it through delivery and was lying in front of me. She was connected to loads of monitors and needed help breathing, but the doctor was so positive and made it sound like everything was going to be OK. I couldn't stay long because I was so unwell, but at least I was able to see my little baby.

After a few days, I was able to get up and about on my own. I was still a patient at the hospital which meant I was close to my baby at all times and therefore I could stay with her as often as possible. At times I still found the unit to be overwhelming. There are complex machines keeping your baby alive and you quickly have to become accustomed to monitors going off and learning what the machines do and the medical terminology behind what is keeping your baby alive. The environment is completely sterile, very ill babies surround you and the opportunity to cuddle your baby the way you were expecting during pregnancy is not an option – in fact I didn't get to hold my baby until she was nearly a week old.

There were some very low points while she was in hospital. It is difficult when you know the medical team are performing a painful 'procedure' and find out they worked on her for over an hour and were not able to complete the procedure and will have to try again the next day. A very difficult time for us was when we were on our way to visit her one day and were stopped to be told that perhaps we should wait a couple of hours because she suddenly had more difficulty breathing and would need to be ventilated. Most of all it was difficult not being able to bond with her the way you imagine you would be able to. I could hold her little hand, but I couldn't pick her up or put her to my breast and cuddle her to let her know that she would be OK. Instead I had to leave her alone in her cot. Apparently premature babies don't like to be touched much and actually become more distressed the more you handle them.

My husband and I kept a positive outlook. It never crossed my mind that she might not survive. Whenever you spoke to the doctors or nurses they would always be truthful about what was happening with your baby, but seemed so positive that you just had to think everything was going to work out fine.

Through all this, I believe having a positive outlook is what kept us going. We would focus on how well she was doing and I would do all I could to help her. She was being fed intravenously, although after a few days they wanted to start feeding her my breast milk via a tube. I knew I wanted to breastfeed so I was determined to pump and make sure she got her mommy's milk. I started to hand express and the nurses would feed tiny amounts to her every hour.

Our little girl was born 8 weeks early weighing 3.9lbs and promptly dropped to 3lbs where she remained for nearly a month. Having a tiny baby became the

norm. I thought the average birth weight was huge and couldn't imagine having such a big baby! I was so proud of every little development she would make.

After a few weeks in Addenbrookes NICU, we were transferred to Hinchingsbrooke hospital. There was a bed shortage and Addenbrookes needed the 'healthier' babies to be transferred to make room for those that were more critical. Although a transfer was distressing to us, we also remained positive that this meant she was improving enough to be moved and we certainly wanted to ensure other babies had the best possible care they needed. Our transfer was smooth and moving to Hinchingsbrooke meant less intensive medical care and more 'hands on' parenting. We were able to hold our little girl more and for the first time I started to breast-feed. She took to the breast far better than anyone imagined she would and I was relieved to know that I could feed my baby. I really pushed to get her home as early as possible, particularly as I could not drive after the caesarean and did not live close to the hospital. After a further 2 weeks we were able to bring our baby home.

Bringing our baby home

We brought our little girl home while she was still under her birth weight and tube feeding. She could breast feed, but the majority of her milk was fed via a tube. The day we brought her home was scary – but I know that is the case for every new parent! We were just so happy to finally be home again as a family. I spent nearly a month in hospital and my daughter did the same so our homecoming was overdue!

I was nervous at first. My family live abroad so I knew I didn't have any support 'around the corner' to help, plus my husband was in a new job and didn't have much leave, particularly as he had spent so much time with us while we were in the hospital. We managed to get through the first few scary weeks and were grateful for the support provided by the neonatal team at Addenbrookes and our health visitor. They were all so helpful and made sure we had what we needed at home. They lent me a breast pump so that I could continue to feed via the tube and were very good about answering our questions.

We didn't find out the sex of our baby until she was born and decided on her name whilst she was in the neonatal intensive care unit. We named our precious baby Annie Jane – after my and my husband's grandmothers whom we felt were strong women. We needed her to be strong to pull through her tough beginning and she has done a remarkable job!

If you were to look at Annie today, you would say that she is small for her age, but you might not guess she was premature. The first 6 months were tough, she had bad colic and reflux, but she has come through all that. She is a fighter and we are enjoying her more and more everyday. Looking back at pictures and our experience, we are lucky to have our baby. If it weren't for such excellent medical intervention we both might not have made it.

My pregnancy and birth didn't end up the way I had planned; having a premature baby helped me to truly understand what a miracle birth is and how lucky we are to have these wonderful bundles of joy. This was a scary experience and not something I would want others to endure, but if things don't turn out the way we expect/want them to it can still be a happy ending. I can certainly say we are very grateful for what we have and cherish each day.

Cheryl France, proud mother to Annie Jane France

Pre-eclampsia Your Questions Answered:

What is pre-eclampsia?

Pre-eclampsia is high blood pressure (greater than 140/90mmHg) developing during pregnancy in woman whose blood pressure was previously normal. It is often accompanied by excessive fluid retention and less often by the presence of protein in the urine. (Oxford Medical Dictionary)

What are the symptoms?

Symptoms include: swelling, sudden weight gain, high blood pressure, presence of protein in the urine, headaches and changes in vision; although some women that have rapid onset of the disease report few symptoms.

Does my midwife/doctor routinely check for pre-eclampsia?

Yes, during antenatal visits, women routinely have their blood pressure and urine checked.

What percentage of pregnant women has pre-eclampsia?

Pre-eclampsia affects 10% of the pregnancies. It usually occurs at the end of pregnancy although the earlier it starts the more the severe it is likely to be.

What is the treatment?

The only 'cure' for pre-eclampsia is delivery of the baby and placenta. Treatment during pregnancy may include monitoring and taking high blood pressure medication. If there is concern that the baby may need to be prematurely delivered, steroids may be given to the mother to help baby's lungs develop quickly.

Where can I find out more information?

If you are at all concerned, talk to your health care professional. If you want to find out more information, the web is always a good start. The following web pages provide useful information:

<http://www.apec.org.uk>

<http://www.preeclampsia.org/>