

Anita's Diary

Anita Kiernan has been a subscriber to STARS since 2007 and is one of our most proactive members. Regular readers of the STARS newsletter will have read her articles on getting married, holding on to a job, giving birth and now the ups and downs and joy of looking after Eva Joanna, born on 18 May 2009. Anita has POTS and vasovagal syncope.



For a few days during October 2008 I was in hospital. I was 9 weeks pregnant and experiencing severe pregnancy sickness (hyperemesis gravidarum), and feeling so faint I could barely lift my head off the pillow without nearly passing out ...naturally I was terrified! But as readers of the last newsletter will know, there was a happy outcome to this story: our lovely, healthy daughter Eva was born in May '09, weighing 9lb 6oz. Throughout my pregnancy I called her my Magic Baby for, despite the many medical ups and downs we had, my syncope problem became better than it had been in years as the pregnancy progressed!

As anyone who is pregnant (particularly for the first time) will know, every day is a rollercoaster of excitement and worry (The baby's moving! It's stopped moving! It's moving too much, I can't sleep!), and the concerns naturally multiply for any family with a syncope problem to manage, in amongst all this. Just as every individual's symptoms of syncope vary, people have very different experiences of pregnancy and birth, which makes it very hard for medical professionals to predict how the two conditions will manifest themselves when combined. Information available to the general public from books and the web often refers to the fact that fainting is common during early pregnancy as a consequence of normal physiological changes; but there is scant information on the effect of pregnancy on those who are *already* sufferers of syncope. There are many medical websites online of varying quality, often with message boards containing largely depressing or distressing personal anecdotes regarding syncope and pregnancy. I steered clear of these after the first, brief, frightening look! I needed to focus on myself and my baby and planning as best we could for the potential scenarios ahead without scaring myself and my husband too much in the process!

The First Trimester:

When I was 5 weeks pregnant, I had a very small bleed, which is very common, and after blood tests and another scan at 7 weeks, we saw a little blob on screen with a beating heart. Phew! It was still early days but the morning - sorry, all-day sickness - continued to let me know that I was definitely still pregnant. Perhaps foolishly, I hadn't fully considered the effect of pregnancy sickness on my syncope problem beforehand. My sister had carried twins with barely a single day of nausea, so I didn't think about it too much when planning a family...but for me there was no escaping it from day one! I can't stand up quickly without pre-syncope spells or collapses, so dashing to the Ladies at work sometimes proved difficult - I spent many days at my desk trying very hard not to vomit in my bin! Unfortunately by Week 9 I felt dreadful, like I had tonsillitis, with a horrific headache as well as the usual nausea and vomiting. My POTS symptoms were much worse and my heart rate was continually high for several days, even at rest. The Practice Nurse said I probably had a bug and sent me for an eye test due to the headaches. Needless to say, by the following afternoon I was so tachycardic and breathless that I could hardly walk, I was feeling so sick and faint, and was admitted to hospital with hyperemesis gravidarum (basically, pregnancy sickness that gets out of control so the person can't eat or drink enough for the body to cope). The resulting dehydration had sent my syncope condition out of control. Hyperemesis itself is not uncommon and it is usual for pregnant ladies to require fluids through a drip and medication to help when a severe case occurs.

However, the hospital staff had not come across POTS and we had a difficult few days in which I could barely lift my head up off the pillow without feeling like I was going to pass out (a bit difficult to avoid when you're retching!) and the nursing staff, though kind, had little understanding or appreciation of how to manage my condition - and not enough time to ask me and find out. Some couldn't understand that I couldn't walk to the bathroom myself (pregnancy is not an illness...) though they could soon see for themselves what happened when I tried to stand up. And as a former nurse myself, it wasn't pleasant for me to be on the receiving end of the bed-baths for a change!

My husband printed off information for the ward staff but it wasn't always handed over with each shift change, which was frustrating. But this experience in the first few weeks of pregnancy made us determined that we would attend any future antenatal care armed with syncope information, and keep multiple copies to give to each different health professional we came across. I would definitely recommend anyone else who is in this situation to do the same, and prepare it well in advance if you can - we were seen by medics earlier than normal due to the bleeding and the sickness, and weren't prepared - pregnancy is so unpredictable! We included generalised information about POTS, information about STARS with contact numbers, my consultant's details and latest letters, and a summary of bullet points about my personal symptoms: what is "usual" or "normal" for me, what my triggers are, and what I needed in the event of dizzy spells or collapses.

Naturally my husband and I had many questions about the potential impact of my POTS on the baby, and fears about how I would manage the birth and look after our baby safely once born. This worry intensified with the hyperemesis and deterioration of my medical condition. By the time of my 12 week scan, we were relieved to meet a great obstetric and midwifery team who contacted my consultant for advice, and monitored me more closely than usual, helping us to plan a safe birth. Taking or withdrawing from medication can be a huge worry when planning a family and must be carefully managed by medical professionals; fortunately, by the time I became pregnant, I had stopped mine already. But aside from medication, there were still many questions - will my baby be harmed by my fainting/pre-syncope spells? Can the baby inherit my disorder? When should I seek medical attention if I collapse? What if I bump my bump?! Fortunately the 12 week scan showed the baby was developing normally in spite of the sickness, dehydration, and week of semi-consciousness!! So whilst many questions were unanswered, the baby seemed ok so far.

2nd Trimester

By 16 weeks the sickness had mostly gone and I was starting to feel fantastic, loads of energy, and less pre-syncope spells than I'd had in years. The light-headed attacks were less severe, and the collapses reduced to wobbles. My other symptoms reduced, including the palpitations, the tremor in my hand, the problems going from cold to hot rooms, feeling faint when I coughed or sneezed; and my hands and feet were warm for the first time in years! My exercise tolerance increased so I could climb a flight of stairs again without feeling faint, and I felt confident enough to join the gentle aquanatal class at the swimming pool, led by a midwife and a physio, who were very supportive of my disability. In the meantime the obstetrician had arranged appointments with the anaesthetist to discuss pain control in labour so we could start planning early, and I saw the physio about back pain and ligament pain (I had also had a recent diagnosis of Joint Hypermobility, which might have been exacerbated during pregnancy as all the ligaments naturally become looser). Fortunately I didn't collapse much during this period; any wobbles remained upright or were caught by my husband or sofa!

The 20 week scan revealed an apparently healthy little girl and all was looking good, though I had a low-lying placenta so I wasn't allowed to lift anything. I had another small bleed at 24 weeks which caused a panic due to the low placenta...to cut a long story short the doctors were initially talking

about extremely premature delivery, but everything was fine and we can now look back and laugh at the thought of what we must have looked like - me, my husband, and my brother and sister-in-law dashing to the maternity ward straight from a Viking-themed fancy dress party! Despite these hiccups, my syncope was the best it had been for years.

3rd Trimester

As time went on and I got bigger and more cumbersome, my POTS deteriorated a little, but was still a marked improvement on pre-pregnancy. I just had to be even more careful to change position slowly, not stand for long, eat small amounts regularly and drink plenty. I struggled to put on my shoes, never mind my compression hosiery (that was a learning curve for my husband!), and joints and ligaments all over my body became very sore. I lost a lot of sleep as I could not get comfortable and turning over was excruciating around my pelvic ligaments in particular. I was very worried about the effect of sleep loss with having a baby, as my POTS is always so much worse when I'm tired, and the more tired I get, the more episodes I have, which make me even more tired - it becomes a cycle. But, amazingly, my body coped much better than usual with this sleep deprivation, which gave me some hope for after the baby was born!

I had a scan at 34 weeks to see if the placenta had moved, and it was then that they told me I was having a big baby. I was tested for gestational diabetes, which I didn't have, and booked in for another scan at 38 weeks to check the baby's size again. At 37 weeks I was so exhausted and in too much pain hobbling round the office, so I finished work a week earlier than planned (but very pleased I'd made it that far!). I saw the physio again who gave me crutches for the Symphysis Pubis Dysfunction (a problem with the pelvic ligaments) to take the weight off my pelvis. Another comical sight - a close family member described my shape (afterwards!) as the Mr Men character Mr Greedy on crutches! I also found myself in hospital for a day that week with a Urinary Tract Infection - another common complaint of pregnancy (in for a penny, in for a pound.). Finally the 38 week scan predicted that the baby would be around 11lb at birth in two weeks time, with an error margin of 1lb, so potentially a 12lb baby if I went overdue!!!

The Birth Plan

Throughout my pregnancy, once I had recovered from the sickness, we planned a natural birth, since I was much more well than usual. The anaesthetist recommended an early epidural to help me in case a long labour made me too tired and potentially too faint to cope. He also agreed to providing early IV fluids to prevent dehydration in case I found eating and drinking difficult in labour, and to help keep my blood pressure stable (some pain relief methods can cause the blood pressure to drop as a side effect). We wrote a birth plan which essentially said that I would follow medical advice throughout labour, but we wanted the team to be aware of the problems I faced and we didn't know how my syncope would be affected when in pain, or when trying to change position in labour (getting on and off beds and "birthing balls" might not be ideal and kneeling/squatting would be out of the question!). I often feel on the verge of passing out when I cough, sneeze or exert pressure on my lungs (such as blowing up a balloon) and we had no idea if bearing down to give birth would also trigger episodes. Therefore my birth plan was less about how I wanted to give birth, and more a list of bullet points to advise the midwifery team and any new staff on a shift change of my syncope triggers and needs. I had received such excellent antenatal care and attention that we were comfortable that this was going to work. The anaesthetist had also reassured me that by having the epidural I would be able to have a caesarian easily if it became apparent that my body wasn't coping with labour, minimising risk to me and the baby.

Although we had prepared this plan with the antenatal team, we didn't know until 36 weeks whether or not we would have to have a caesarian regardless, as anyone with a low-lying placenta

needs to deliver by c-section for safety reasons. The scan revealed that the placenta had moved so the plan for natural birth was back on again...and then the baby size became the issue! So we were then offered an elective caesarian again! This was the hardest decision we'd ever had to make. Most people expecting large babies are not offered a c-section, but there were concerns that it could prolong my labour and make it harder for me to cope, and result in an emergency caesarian which is not desirable for either the hospital or mum and baby. There was also a risk to the baby of getting stuck (shoulder dystocia) and we had a frightening conversation about the consequences of that for me and the baby. We were torn between wanting to manage to give birth "normally" but with unknown outcomes as regards my POTS and indeed the recovery period afterwards, and having a caesarian with at least 6 weeks recovery from major abdominal surgery (collapsing and falling post-natally would be very painful and would not be good for healing that wound!). There were many aspects to our constant discussions but in the end we felt it was safer for our baby to be delivered by caesarian, and at least the recovery period would be a "managed risk" - we would be able to prepare more for my needs after the caesarian birth than for the unknown outcome of a labour which might take a few hours or a few days (and could still end up with a caesarian!). The compromise we went for was for Eva to arrive naturally up until her due date, and if she didn't come by then, we would have the caesarian...Needless to say, she was obviously cosy in there!

The Birth

The day Eva arrived was the most special day of my life, along with my wedding day. We took in a CD we'd made of our favorite songs and I was crying before they'd even lifted her out, just listening to the song I walked down the aisle to! Just a few minutes later Eva was born, and was passed straight over for a cuddle on my chest, with my husband right there with us. Naturally there were a lot more tears, although Eva herself seemed very content! I did feel extremely faint not long after this, when a drug was put in my IV line. I don't know if it was related to this but it felt like it to me! My anaesthetist was amazing throughout, very reassuring, and I soon felt better.



Unfortunately, the obstetric team was unable to stop the bleeding after the birth (which can sometimes happen in either natural or caesarian delivery) and so I had to stay in theatre for another hour or two for a procedure, and needed a couple of blood transfusions afterwards. My poor husband was a bit concerned as he'd been waiting for ages with Eva in the recovery room, but he did enjoy his extra long first cuddle with his daughter!

And afterwards...

My post-natal care was excellent I was able to make a really good recovery from the c-section. I was only in hospital a day or two longer than normal, in spite of the bleeding complications. When I first got out of bed on day 3 I collapsed and caused a bit of a panic on the ward, but I gently kept mobilising with some help and was so proud of myself when I looked after Eva on my own that night in hospital. It was painful, exhausting and so scary, picking up my daughter from the cot and doing everything I could to avoid either feeling faint or hurting my abdominal wound, whilst learning how to breastfeed. I was so tired but utterly exhilarated by the morning when I realised I had managed the hardest night of my life. It was a positive start to life with my new baby.

Since having Eva my syncope has become a little worse again, though still nowhere near as bad as I was before I was pregnant. I thought for a while that there might be a hormonal component to things as my deterioration seemed to coincide with reducing and then stopping breastfeeding by 6

months. However, my doctors have told me it is more likely that my syncope improved due to the blood volume expansion after the first 16 weeks of pregnancy; and the gradual decline in symptoms correlated with my body and blood vessels returning back to their “normal” state post-natally. I am due to see my consultant in January 2010 to discuss a new medication and management plan, and I am pleased to report that at the time of writing my syncope problems are still proving to be a challenge but are not currently as bad as in 2007/8, my worst period. Furthermore, the problems I had during my pregnancy (the hyperemesis, the bleeding, UTI, low-placenta, SPD etc) were all normal and experienced by many pregnant women without syncope. I might have felt unfortunate to have suffered all these things – looking at the list, I didn’t exactly sail through pregnancy easily! – but I actually felt the best I had done in months, even years. So I was willing to trade having all these “normal” pregnancy related events, worrying though they were at the time, for a few months with virtually no fainting.

Reading the article written by Clare, in a previous STARS newsletter, had given my husband and I faith that it was possible to look after a baby safely with careful management and thoughtful choosing of baby equipment and arrangements at home. Several people on the STARS message board gave me support, encouragement and useful tips in those first weeks, for which I’m very grateful. People without syncope take it for granted that they can just get up to wind a baby, or stand for long periods rocking and soothing a child, or pick their baby up from playing on the floor, but none of those things are easy for me and have to be planned each and every time throughout the day; similarly my husband always baths Eva as I cannot kneel down and then safely get up at present. There are many little things that are hard to deal with physically and emotionally, when my syncope problems frustrate and upset me. But we are coping well as a family and I've been able to do so much more than I anticipated. I know that each person's experience of pregnancy and birth is highly individual, much like each person's experience of living with syncope. Combining the two means there are no hard and fast rules or answers. I know that some people will not be so lucky and may deteriorate during this time; others may even develop syncope or POTS following childbirth itself. But I also know that pregnancy plus syncope can still equal happy families!

