

## May-October 2009 The First Six Months...

After the birth of my daughter Eva in May 2009, I was totally overwhelmed with love and excitement at finally holding my baby in my arms...and terrified about how I would safely hold her when we got home from hospital. I have POTS, and the thought of feeling faint or collapsing while cuddling Eva, or while near her, was so frightening. When planning a family, my husband and I had spent a long time discussing our coping strategies for every scenario we could think of in order to make things safe, and if we hadn't believed it was possible, we would not have had a baby. However, once she was actually here, the reality was very scary! But after the 3<sup>rd</sup> night in hospital – the first night of looking after her on my own without much assistance from the midwives - I realised that if I could manage this in hospital while recovering from a complicated caesarean, then one way or another I would be able to cope when I was in my own home with my husband, family and friends to help. Eva might just need to learn the meaning of the word “patience” a little quicker than most children (though that was obviously quite a big ask of a newborn baby!).



In spite of our worries, Eric and I were over the moon to become parents. I was feeling relatively good, symptom-wise, considering my body was recovering from surgery and also a post-partum haemorrhage. I was tired, anaemic, and my heart-rate struggled to settle down in the first day or two but the blood transfusions and large volume of IV fluids really helped. Despite fainting when I first got out of bed on Day 3 (not too surprising!), overall I was not doing too badly. I had far more pre-syncope problems when I was sick for the first twelve weeks of pregnancy! I had been very concerned that the tiredness from looking after a baby would make me very poorly, along with the physical stress on my body while it was healing itself. But I had slept so badly in pregnancy that I think Mother Nature had prepared me somewhat, and amazingly my body actually responded pretty well after the birth, all things considered. When I was a nurse I had not been able to work night shifts due to the effect on my POTS...yet now I was managing with baby-induced sleep disruption far better than anticipated.

During the second and third trimester of my pregnancy I had felt more well than I had in years. We wondered if the “magic” protective effect of the pregnancy would wear off with the birth, but my dizziness did not rapidly deteriorate as feared. We wondered if the hormones had something to do with my relatively good health during this time as I was breastfeeding, but my doctors have since advised that it takes a long time for the body to return back to normal post-pregnancy and the real deterioration of my symptoms from about 5 months onwards was probably more linked to that. But at this stage, week 1, we didn't care what the reason was; we were just really happy that I hadn't reverted to falling over every time I stood up! I still had dizzy spells and the unpredictable nature of POTS made it hard to avoid every potential trigger, but it was definitely better than I anticipated in those early days.

In those first few weeks I was also really scared of having a fall and damaging my healing caesarean wound. It felt a bit painful on the few pre-syncope wobbles I did have, since my abdominal muscles had been cut in half (or so it felt!), therefore trying to keep stable and safe during pre-syncope episodes was harder work than usual! But I was given plenty of analgesia on discharge from hospital, and made use of it, which allowed me to mobilise gently and participate in caring for Eva. I know pain itself can be a trigger for some people, and the side effects of stronger painkillers can cause problems for others (we can't win!); from my perspective I just had to plan ahead for every manoeuvre and accept any help offered while changing posture or position.

I'd spent much of the first week of Eric's paternity leave in hospital so the second week was amazing – learning to be parents together, and still miraculously free of severe symptoms. This was definitely helped by having a lovely husband that did everything around the house and so I didn't have to lift a finger other than to feed my baby. I think this really helped me to avoid getting overtired (being tired is usually a definite trigger for me), and we accepted any help coming from family members who made meals and so on. We'd also stocked up the freezer in advance with loads of homemade dinners so it took the pressure off us both. We went for a stroll on the second day I was home from hospital as I was desperate for fresh air, but I was much more exhausted than I'd anticipated – tired, palpitations and lightheaded after a few minutes slow walk to the local shop - it reminded us not to get complacent. It told me that I needed to listen to my body and even on "good" days I shouldn't push myself, but simply try to keep on an even keel. The outing did make us laugh though – we passed an older lady who came over to look in the pram, and asked immediately if it was our first trip out with the baby – she was a retired midwife and said she could spot a mile off that we were apparently "pushing the pram like new parents"! I'm not sure if that was more to do with Eric steering the pram with nervous pride or me hanging on to him thinking I might pass out!

Eric and I wanted to be open about my problems with the health professionals we came in to contact with, but deep down I had been slightly worried that they may be judgemental about our decision to have a baby with my fainting problems. But it wasn't a decision we'd taken lightly, and when we told the Health Visitor about POTS, she was just pleased we had thought things through in detail from a safety perspective, and she was in fact very supportive. We were completely upfront with her, as we had been with the midwives, and told her how well I was at the moment (comparatively) but that we weren't sure if this would change at any moment.

I'd struggled to go out alone or use public transport before my pregnancy; and I knew that doing many activities with a baby would be a challenge for my POTS since things like going to playgroups or baby massage groups involve kneeling or bending down (some of my worst triggers). The Health Visitor offered to look in to what local services were available to help us and one of the things she informed us about was a "buddy scheme" in our area to help new mums who had physical or social difficulties. This meant that a volunteer could come with me to help me get Eva safely on and off a bus to a play group if necessary, and be there to lift my baby up from the mat and into the pram, for example. It really lifted my spirits to know there may be some help if I needed it, which meant that I wouldn't become socially isolated.

About four weeks after Eva was born I joined a breastfeeding support group at the local SureStart Centre, and I think I cried every week for the first three weeks! I would be laughing with them one minute about how amazing it was to be a mum, and in tears minutes later, totally overwhelmed by how hard it was to adapt to breastfeeding

and the changing routines and lack of sleep...whilst planning ahead and risk-assessing every manoeuvre I made to ensure I could protect Eva. The Health Visitor and the Peer Support mum at the group made me feel normal because, a few tears aside, I was coping with all the usual mum and baby worries as well as dealing physically with the caesarean and then my POTS on top. The health visitor at the group helped me to start getting in the mindset of what I was achieving rather than what I wasn't! And there we were, a few weeks after the birth, out and about, me and my lovely healthy baby. I was very grateful.

I began to feel the effects of my POTS fairly soon though, especially when trying to wind Eva and soothe her. My exercise tolerance had improved a lot post-pregnancy, but my standing tolerance still wasn't great. I remember asking people on the STARS message board for advice and there were plenty of good ideas, such as buying a bassinet on wheels to move the baby safely between rooms, or using a Moses basket on a rocking stand to help soothe Eva if picking her up was too dangerous for long periods. Another idea was to use the pram or travelcot downstairs for naps to avoid climbing the stairs unnecessarily (another trigger for me), and to sit in a rocking chair instead of standing up to wind her. They were good tips and most of all it made me feel I wasn't on my own – others had been through it and managed!

Still, I won't pretend it was easy when I couldn't just rush to pick Eva up or stand jiggling and rocking her for ages like any "normal" mum would instinctively do. I had to keep reminding myself that I was fortunate to have a baby at all and that her safety was the main thing. Sometimes this meant having to just sit and watch Eric walk the floors soothing Eva on the difficult nights. It was agonising, wanting to hold her and take my turn to stand there rocking her, but knowing that it was not safe, as I was feeling too lightheaded to chance standing up with a baby in my arms. Eric is a fantastic parent and I know Eva was in more than capable hands; nevertheless I frequently had a mental battle with myself to do what was safest for Eva (sit and watch) rather than what came instinctively (to jump up and see to her myself). For all the times I tried to have a positive attitude, I don't mind admitting that tiredness, hormones and sheer frustration led to tears on several occasions too. I distinctly remember one time I sat sobbing in the chair in the nursery after I had fed Eva - I felt too faint to stand up to put her in the cot and Eric was downstairs making tea. I felt trapped in the chair and really frightened for a few minutes. I knew that I should just sit there until he came to see where I was, but the panic took over and I was just overwhelmed with that feeling of "why can't my body just work normally?"!

Naturally it was difficult in the daytime when Eric was at work. There were plenty of times when I couldn't pick Eva up quickly when she cried, as I often feel like I am going to pass out when I straighten up from leaning over. Everything had to be done extra slowly and as any one who has looked after a little one will know, babies don't like to wait, especially when hungry! It's all very well being rational and knowing that the baby won't starve if she has to wait another couple of minutes, but my hormonal, tired, and pre-syncope self struggled to listen to the sensible voice on many occasions! While there were practical solutions to many situations we found ourselves in, sometimes there was no answer to the emotional rollercoaster of motherhood with the added complication of syncope. Sometimes I just needed a good cry, and sometimes I needed Eric to tell remind me that I had to be strong for my baby – we knew it was going to be hard, and sometimes it was really hard, it was as simple as that.

For all the difficult moments there were some amazing memories too. For instance, my husband always bathed Eva (since standing up from a crouching or kneeling position causes some of my most severe spells) and one day Eric asked if I wanted

to get in with Eva. I had been quite well that day and naturally the bathwater was only cool. I had my grabrails and bathseat nearby, Eric would be getting the baby in and out, and it was a good day, symptom-wise. I risk-assessed it, and then in I got! Eric handed Eva to me and he washed her while I held her, crying my eyes out because I didn't think I'd ever get to bath my baby. I might not have the freedom to do it myself but just to participate in it at all felt like a special miracle when I'd mentally prepared myself for the possibility that I might never be able to bath my daughter. It's a task that a lot of people take for granted, but it meant the world to me!

Many women can't drive for a few weeks after a c-section but this didn't affect me as my licence had already been revoked due to having reflex syncope attacks when I cough or sneeze. I was able to get taxis a few weeks after the birth when I felt able to lift the baby in the car-seat, and so I joined an NCT coffee group for new mums, which gave me a sense of normality. I also found this way of meeting people much easier than community playgroups which I later tried, as I found I couldn't rely on there being chairs near the play areas and they were often very busy and hot. The worry of collapsing around all those other babies was also just a bit much. But I did find it easier to socialise in small groups at people's houses, where I could put Eva on a play mat with the others and I could sit near her and use the sofa to pick her up in stages like at home.

There were a few awkward moments though. I remember one time when Eva was a few months old and I was at the house of one of the ladies from the coffee group. She had advised me to use her son's nursery to change Eva's nappy, so up I went. Their baby was not sleeping in the nursery yet so there was no furniture in the room and just the change-mat on the floor. I should have trusted my instincts but I foolishly thought I might manage if we were quick...typically a full change of Eva's clothes was required, which meant I was kneeling down for ages and then had no furniture to help me slowly get up, before I could even think of lifting Eva up. I had a horrible moment of realisation at the situation I had got myself in, and had to crawl to the top of the stairs and call for help to get myself and baby up off the floor safely. It was totally humiliating. My new friends were lovely and very helpful, but I left feeling demoralised in my ability to care for Eva. But as other good friends pointed out, I was caring for her by asking for help when I needed it, rather than just carrying on trying to stand up, hoping it would be ok. I'd misjudged the situation upstairs, when I was normally so careful to avoid putting either of us at risk. But more importantly I hadn't ignored the warning, I asked for help, and we were both fine, even if my pride and confidence were a little dented. I had to remind myself constantly: so what, if I couldn't always just pick my baby up? As long as she was safe, that was what mattered. I was still managing to feed her myself, and comfort her and keep her washed and warm. None of those simple tasks were easy but we were managing them together. I guess the point of this story is that I did feel low in confidence sometimes, but I steeled myself to the difficult moments, learned from them, and kept on trying to make the most of this special time with my baby.

I was invited by the Health Visitor to a Baby Massage group, along with all new mums, and I did find this very difficult. I had been managing well enough to be able to walk to local groups without help, so I thought I would try this one too, and explain to the Nursery Nurse about my problems on the phone first. I hoped I could put the mat on the table and sit on a chair to do the baby massage but when I got there it was a packed, busy room with no facility for this. So when the introductions were taking place I told everyone briefly about my condition – I didn't want the other mums to think I was being rude if I didn't get up to chat at the end of the session, as I'd need to wait for them to get their babies out of the way first since standing up after the session would be quite challenging for me. The Nursery Nurse thanked me for my

honesty and agreed to pick Eva up for me while I got myself up slowly on to a chair first and drank plenty of water and circled my ankles and the usual things. So the first session went relatively well. On some occasions though, the Nursery Nurse seemed to forget that I had a chronic condition and needed this help every week, and she just left the room as soon as the session finished! Fortunately the other mums now had a little understanding of my needs and were happy to help me out.

It was a humbling experience but people were actually very kind – I was glad in the end that I hadn't tried to hide my problems, and I gratefully accepted the help of friends and thoughtful strangers. This meant Eva and I could still participate in "normal" life, like other mums and babies. Nevertheless, I did feel different a lot of the time, and sometimes resentful that I had this condition which affected every thing I did every single day – if I wasn't being symptomatic then I was constantly mentally planning what moves I was making and how to avoid or reduce the risk of my triggers as far as humanly possible.

As the first few months passed I was starting to struggle more. Even on the good days I had to plan and act as though it was a bad day – it would be one thing if I collapsed and injured myself, but quite another if I hurt myself with a baby in my care - what might happen to Eva downstairs if I collapsed at the top of the stairs? And although I usually had semi-conscious spells rather than full loss of consciousness, every few seconds that I couldn't speak or move were a few seconds that she could potentially roll towards a sharp corner, or fall over while trying to stand up. I tried not to go upstairs any more than necessary once I'd come down in the morning and I brought spare clothes down ready for Eva.

The Health Visitor was the one who said to me right at the beginning, just put the change-mat on dining table rather than kneel on the lounge floor – who cares what people think, you can wipe the table down when you need to use it. Changing Eva was always problematic though, because if a full change of clothes was required I couldn't stand up for long periods without feeling lightheaded, with a racing heart, hot sweats and the wobbles. So for dirty nappies I usually had to change her on the floor near the sofa, which was worse in terms of me getting up afterwards, but better than fainting from standing for too long and leaving Eva high up on a table. There were no hard and fast rules; I just had to risk-assess each situation, trust my instincts and listen to my body, day to day, hour by hour. I was lucky that I have a fantastic husband who was always steadfast in his help both in looking after Eva and in supporting me. He never once made me feel that I might not be able to look after Eva or that I might put her at risk, and his faith in me gave me confidence in myself and in all the things we were managing to do together.

All the advice people give about mums resting when baby rests is definitely the right advice, and especially to mums with syncope – you have to give your body a fighting chance, and not worry about the washing up! Despite a few hiccups, embarrassing moments and general frustrations, we made it through first few months. I did feel sad that I couldn't be like most new mums and just bundle the baby in to a car seat and go to whatever groups and classes or shops that I felt like. If I'm honest there were several times I felt frustrated by my condition and a bit trapped at times, as POTS had caused me to lose some of my independence and made me rely on other people a lot more than I'd like. But all these moments were soon outweighed by the joy of having a baby, watching her grow and develop, and knowing that she was safe and loved, which was more important than anything else.

My pre-syncope spells got noticeably stronger, lasted longer and occurred more frequently around the 4-5 month post-natal mark. It was not as bad as pre-pregnancy

but enough to make me extremely relieved when I got my appointment through for autonomic testing in London, when Eva had just turned six months old. I missed her like mad during my week-long stay, though Eric was staying with a friend in London and brought her in to see me each day. After a battery of tests, some repeated, some new, the POTS diagnosis was finally fully confirmed (after 15 years!) and I was to come back to London in the New Year, 2010, to commence a treatment plan. It had been a momentous six months and we could only look forward to what the next year would bring for our new family.