AIMS For a better birth...

Generalised hypermobility: Emma's story

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By Emma Dickinson

I've got a condition referred to as generalised hypermobility. I'm actually under the hospital to find out if I have Ehlers-Danlos Syndrome,[1] which the GP thinks I have, but I haven't been officially diagnosed yet.

When I was pregnant with both my daughters, I experienced severe pelvic girdle pain, to the point that I couldn't even walk.

With my first pregnancy I was actually housebound from 26 weeks. I didn't come across an awful lot of help, even though there was nothing I could do. The midwives I saw were largely dismissive and said "it will just go when you're not pregnant".

I had to give up my job and I couldn't leave the house unless somebody could physically help me into a car and then help me where I was going. So I just didn't leave the house. I had no help, no guidance as to what else I could do.

This was in 2017. By the time I was pregnant with my second child in 2023, there was a charity called Pelvic Partnership. I searched them out to get as much information as I could because when I went to my midwife's appointment, they didn't have a clue. I had to help myself. I organised private physiotherapy, got some crutches and bought myself a mobility scooter so I could get around.

When I went into midwife appointments, they'd always ask, "why have you got that?"

I'd have to explain that I couldn't physically walk, but I never really got any help from anyone within the

maternity service, which I found quite hard to understand because this is something that a lot of women get.

Unfortunately I did have a severe case of it because of my hypermobility. The GP should really have picked up on that as a sign of Ehlers-Danlos Syndrome. In fact, this should probably have been diagnosed years ago.

With my first pregnancy, everything was quite good, but in a first pregnancy you don't really know much. Whenever we couldn't feel our baby move, the midwives were very good, telling me that it's okay, come on in, we'll get her checked out. I went a couple of times to get her checked because she just did not move very much and I was very small. When I was 38 weeks, they said that she wasn't growing anymore and because I had little movement, they recommended induction.

Well, I didn't really understand it, so I put my trust in them and just did what they said, which now I wish I never did. I wish I had left it.

I was induced with a pessary at 11pm. Within a couple of hours I was having all these period-like pains but the midwives said, "no, no, it takes 24 hours before you really feel anything", but it was definitely something. We started timing it and when they were coming every couple of minutes we let them know, but they refused to check me saying that they didn't do anything like that for 24 hours. This didn't make sense to us but then you put your trust in what they're saying because it's your first time.

When they were less than a minute apart and I was in a lot of pain I asked again and they very begrudgingly agreed to check me. I felt I was being a nuisance but they had to admit that I was in labour and I was transferred to the labour suite.

I got PTSD (post traumatic stress disorder) after this birth, so a lot of it kind of goes a bit blank.

What I remember is that when I got to the labour suite it all happened very quickly. I remember saying to them, this is really, really bad now. When they checked they were surprised that I was already seven centimetres. They popped the waters and within ten minutes, I could feel my body pushing. No matter how much I told them that I couldn't control this, they kept telling me to stop. They kept saying that I didn't need to push as I was only seven centimetres. I said again and again that I wasn't controlling this, but again and again they told me to stop. The pain caused by trying to force your body not to push was SO horrible. I thought I was going to die. Yet they just made me feel like I didn't have a clue what I was doing.

It was then recommended that I have an epidural. I said I didn't want one and the doctor left. No one offered any other help and because the pushing urges were coming so fast I changed my mind about the epidural. At this point they said that they would have to check me first. I asked why they couldn't have checked me when the uncontrollable pushing urges started, but they said, "we can't*keep* checking you", even though they had only done this twice before. Sure enough, when they did check they could see the baby's head.

They didn't listen to me. If they had, I would not have had to go through that horrible feeling of trying to

force my body not to do what it should be doing. They made me feel like a wimp, that I was not strong enough for it, that I couldn't cope with the pain. I found that very hard.

One of the things with the neglect was that I literally couldn't walk or move because of the pelvic girdle pain. Trying to give birth in a bed where you can't lean over or roll over without your hips popping out of place - I was in excruciating pain. Yet they kept telling me to move as if they didn't know. And I thought, I can't physically do it, I need help, but they didn't help. They completely neglected my condition.

As the baby was about to be born they cut me and afterwards they had to stitch me up. The midwife who was doing the repair was chatting to another midwife and neither were sure how to stitch me up. I wondered what was going on. I didn't like this at all. It was not very reassuring and it was very painful as well. They called for a senior midwife but she wasn't sure either. She explained that because I was very swollen they didn't want to stitch too tightly. She was telling me about it as though she was asking me to tell her what to do, and I hadn't got a clue. It made me feel like they didn't know what they were doing and there wasn't much reassurance at all throughout that whole time.

After they'd done that, I was then left alone in that room. I had the baby at quarter past four in the afternoon but I wasn't cleaned up. I kept asking if I could have a shower but I needed help because of my condition and they were too busy. I was in an awful lot of mess. It was all the way up my back; blood and everything and they just wouldn't let me go. I didn't have one until half nine at night. It was very embarrassing when my mum and dad came because I had to try and hide all the mess.

At some point later in the evening I was told that Evie, my daughter, had low blood-sugar. They said it was because I hadn't put a hat on her. I explained that it was really hot and that I knew you shouldn't overheat babies, and she said that every new baby needs a hat. I felt told off for causing my child to be ill.

The whole time we were in that room Evie seemed quite content. She just was laying there quite happily asleep. I was trying to breastfeed and kept saying, "is this working? I don't know", but she didn't really feed on me much at all. She just slept.

I didn't move to the ward until half nine in the morning. I was stuck in that labour ward by myself with the lights on and not having a clue what was going on. I remember having chest pain so they did one sort of check on me there, but that was it. In all that time I was only given one slice of toast. I had nothing else. When I moved to the ward in the morning, I asked if I could have breakfast but breakfast had been and gone.

I was finally on the ward and trying to breastfeed, but I hadn't slept for 48 hours. I was falling asleep with Evie kind of asleep as well thinking that she might be breastfeeding, but she wasn't. She just slept pretty much the whole time, and I just wanted to leave because I had lost all my dignity. So I left.

When I came home, I tried so hard to breastfeed. She really wanted the breast but she screamed and screamed all night. I had great support from the community midwife but nothing came out. My breasts never got big and we never got a single drop. Basically she was starving. That was really hard. Once we got on the bottle, we were good. From then on it was really kind of plain sailing. She's a great baby. She

slept well, she fed well, and then I had no issues because I was able to put everything behind me. I could bury it.

Even though I know I didn't have a traumatic birth like some women have, the neglect and how they made me feel was enough to put me off ever having children again.

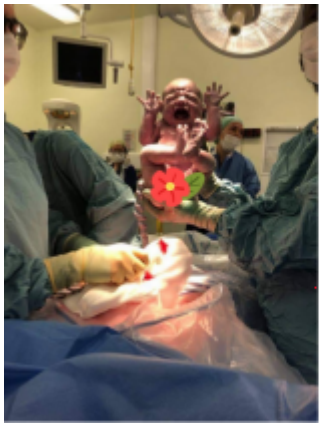


My plan for increasing our family was to adopt, but my husband really struggled with the idea of being able to love another child in the same way he loved Evie. He suggested that I try to get help from the doctor, and that's what I did.

I fell pregnant straight away. It was good, but also very scary because it brought everything back and I wasn't able to bury the PTSD. I had multiple panic attacks, all sorts of different things going on and I just really struggled. I was put straight forward to doing CBT (Cognitive behavioural therapy). I got that instantly. It was a bit of a shock because I told them on the Friday that I was pregnant and they moved it forward and I got my first appointment on the Monday. The CBT lady really helped me to understand that things could be different this time.

I received my care from a different hospital this time. I had extra midwife appointments with the mental health midwife. She was so good, she really, really helped me. She gave me extra sessions with the CBT, and she recommended hypnotherapy. I felt like I was awake the whole time, but it helped me to realise that I can also think of the first birth in a happy way and that helped me to cope with it a little bit better.

In the second pregnancy the pelvic girdle pain was worse than the first, and I didn't think I could do the second birth naturally. I hated the idea of laying on my back because that's how I gave birth last time and I knew that memory would give me panic attacks. Even with help I physically wouldn't be able to move into other positions, so we discussed the option of an elective c-section. This was scary but I thought, actually, I'm in control this way. The midwives were very supportive and helped me arrange this, but then it turns out Ivy was breech anyway, which kind of made me feel a bit better because it would probably have been a c-section anyway. It felt like the right decision. On the day it took a while to get to the theatre because I had to walk there on my crutches, but the staff were great. I got to see baby Ivy come out and the surgeon said it was a textbook c-section.




This time I felt cared for and listened to. I was sponge-bathed straight away, and when I was able to get out of bed on the second day they helped me to have a shower. I had the option of my own room in case I felt panicky, but I felt fine to go to the ward. When Ivy wouldn't settle, a student midwife even took her for me for a bit so I could get some sleep. It was really lovely to have that support.

I was keen to breastfeed so this time I went to some breastfeeding workshops before Ivy was born. The midwives tried to help me in different ways but it was still very hard and very painful. I really, really did try, and they tried as much as they could. Unfortunately, breastfeeding never did get off the ground but at least I know I had milk that time, which reassured me that the first time I really didn't have any.

I asked to stay an extra day, even though they could have discharged me, mainly because I still couldn't walk. I had the pelvic girdle pain plus the caesarean pain and I felt I couldn't go home until I could move.

There were two things that could have been better. I wish they had warned me about passing blood clots. I had a bit of a panic when I passed a clot the size of an orange. Ivy was meant to be a twin but one died early on. When I saw the clot I suddenly thought, oh no, it's the twin so obviously I freaked out and I got really upset. The midwife reassured me that this wasn't so. She explained that when a new mother is in bed for a while the blood pools inside and clots. Then when she gets up, the clot comes out. They should really tell people about this.

The other thing was that while pretty much everything at this different hospital was good, the surgeon made a comment which he really shouldn't have. On the ward round he said again that the c-section had gone really, really well, and then he said, "oh, are you going to have lots more?" I said, "no, no, I've had PTSD", and he replied, "oh no, you'll change your mind". He shouldn't have said that to a woman who's got PTSD and has just given birth. It was quite insulting in a way. Like a lot of people, he had no real empathy. I've never forgotten the pain. Never. But on the whole I couldn't fault that hospital.

Since then we made the decision and took steps to keep our family the size it is. I couldn't go through that pain again and now I don't have to worry. I can walk again but always have pain in my joints. I think that's all down to this potential Ehlers-Danlos Syndrome. If it is, there's nothing they can do. It's just pain management. I can still be a mum, I can still do everyday things, I just struggle with it at times.



Sometimes I reflect on the reasons why the midwives did not care for me well during my first birth. These are my thoughts:

- I understand how understaffed they are. I could see this was also the case in the second hospital.
- They could have had lots going on that day.
- Perhaps they couldn't help me to shower because there was another woman giving birth, another emergency.
- They probably do feel bad each time they make a mistake at work.
- It must be very distressing for midwives when they aren't able to care for people properly because there simply aren't enough of them.
- They are run ragged. It must be a very stressful job.

But these things weren't right:

- Midwives may be *guided* by textbooks but they should always listen to and observe the individual. They repeatedly didn't listen to me.
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The midwives didn't seem at all aware of my condition. They must have known how severe pelvic girdle pain can be.

- Replacing birth-stained bedding and washing the mother should surely be part of the immediate care the mother receives - part of the birth process.
- Any mother should expect to receive meals and other basic care, and to feel safe and comfortable. Physically unable to fend for myself, I was left for an evening and a night without this.

I did think at one point about becoming a maternity assistant and potentially going on to do midwifery. I'm a nanny myself, so I work with babies. When I looked into the whole stress of the job though, I didn't think I could do it. I would want to be there just to support the mothers and that seems hard to do in the midwife role. Maybe I could be a maternity assistant and just there to do the support bits. I've been at my best friend's birth. I was there to support her and I saw how badly she was treated at times.

And that's the problem, I've spoken to a lot of women and I'm not alone. You listen to other women and you realise that you're not the only one that's gone through this kind of behaviour. No, far from it, far from it. I have heard many stories of women who were started off on the induction process and then simply not believed, simply not believed that they're in labour.

I feel like maybe they induce more women than they probably should. A lot of people I know will get offered induction, and I'm sort of thinking, why? There will be just the smallest thing, and, "oh, well, we could induce you". I feel it's because they have beds available at that time that they think, if they induce this one now, she's not going to clog them up later on.

One person I know was offered induction with her second baby and she actually said no, because of what happened when her first birth was being induced. She said that she didn't need to be induced, that she would rather it happen naturally. They advised induction because they thought her baby was too small, but she said, "no, no, no, I want to birth naturally", and she did. She left it naturally and went to her due date and had the birth, had the baby, and the baby was a really great weight.

And then my sister-in-law, she got induced and had a load of problems. Everyone I know that gets induced tends to have problems. I feel like they're taking the whole, 'oh, let's just induce them' attitude too far. I think people say yes because they do not know any better. You put your trust in the midwives because they should know what they're doing. You think, oh, well, if she thinks I need to be induced, perhaps I should, but actually, a lot of the time you probably don't.

Author Bio: Emma Dickinson from Bury St Edmunds is a mum of two girls and an ad-hoc nanny for lots of families.

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1 Editor's note: Ehlers-Danlos syndrome is a group of inherited disorders that affect connective tissues — primarily skin, joints and blood vessel walls.