AIMS For a better birth...

Type 1 diabetes and maternity care: Jane's story

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By Jane Furness

My daughter is two and a half years old now, but I still have daily flashbacks of our pregnancy and birth together. My husband and I had 'planned' to have two children but after my first experience of the maternity system as a 'high risk' mummy, I swore ''never again''. It took until after the first birthday to even consider another, and here we are in the third trimester expecting our second child!

I've just 'celebrated' my 20th anniversary as a person living with type 1 diabetes; I'm pretty expert and confident in my personal condition. I knew how serious pregnancy would be for someone like me so I quit my teaching career to focus on it full time (including two-hourly checks throughout the night – good practice for having a newborn!). In the end, I had the best control of my whole 17 years in the lead up to and during pregnancy and birth. Even the diabetes consultant said she had never seen anything like it. This made me feel so positive and proud of all the sacrifices I had made to keep myself in the best condition for Baby.

Within three months, I was pregnant. I live in Northern Ireland where there are only a few hospitals who 'deal with' pregnant people with diabetes so I formed a list of questions and asked them directly for answers so I could make an informed choice about where to receive my care. My first appointment and scan was at seven weeks, and I knew my care would be obstetrician-led. One of the first things the endocrinologist said to me was ''We won't let you get past 38 weeks''. The language and tone was shocking. And even at this very early stage where I knew much less, I had a sense that this wasn't right. So I did an immense amount of obsessive digging and reading to find some better outcomes than induction before 39 weeks because I truly believed that Baby would come when she was ready if I stayed healthy,

and I was fully aware of the risks of induction, which I wanted to avoid.

Choosing to stay out of work gave me plenty of time to research and become informed in EVERYTHING to do with a positive birth experience that suited me. It was amazing how much I learned that I wasn't being told at my antenatal clinic. I was learning more on Instagram than I was from any doctor. This is where I started to have doubts about what was to come. I read lots of birth stories, researched statistics and pregnancy/birth outcomes with diabetes and, in the end, I knew that a home birth was so right for me, my husband and Baby. COVID-19 restrictions had a huge part to play too as this was all throughout 2021 and there were still strict rules in hospitals.

I wanted some connection with midwives as I wasn't seeing any at all so I booked to see my local community midwives around 20 weeks. I mentioned about wanting a home birth and was flippantly told, ''Oh no you won't be allowed that''. I knew my rights and decided not to give up on what I felt was the best decision; the decision that would keep me calmer, keep my diabetes in better condition, allow for the best support during labour and birth, and statistically result in better outcomes. But I'm not stupid and of course I knew the risks too, especially living 50 minutes from the hospital that would 'deal with me'. But which option is risk-free?

At the beginning of the third trimester, I wrote to the Head of Midwifery at the hospital about my home birth request. This started a huge chain of interventions before Baby was even born – multiple 'meetings' (interrogations more like) with Heads of Community Midwifery, Obstetrics, Paediatrics and the maternity service, most of which involved a panel of them sitting in front of me with scary stories about stillbirth, shoulder dystocia and newborn hypoglycaemia, both in person and on Zoom. Nobody was backing down and nobody wanted to support me, but I wasn't backing down either. They were very shocked to hear how well informed I was and what statistics I knew!

Everything changed when I got in touch with two local doulas and it felt amazing to even just speak to people who trusted me to manage my condition and birth my baby the way I felt was right. Even better, the health Trust was feeling more pressure from more women to have home births so they created a brand new 'Birth at Home' team, led by an amazing midwife who was happy to support me. I will never forget meeting her for the first time and sharing our belief and trust in physiological, spontaneous birth. It changed the whole pregnancy in that moment. From then on, the determination to have a home birth was REAL. I fought and fought, and eventually had an agreement and a personalised risk assessment done at home. I started having midwife-led appointments at home, deliveries of equipment, and Baby was on the way!

I should say, my pregnancy was entirely uncomplicated except one or two elevated blood pressure readings but they didn't last and they were linked to the 'white coat syndrome' I had been developing. My blood sugar levels stayed under amazing control. Without the big 'diabetic' sticker on the front of my notes, nobody would have even thought to use the label 'high risk'. Baby and I were 100% healthy and normal. (Funny though… the growth scans started to become abnormal after my request for homebirth and this was used against me but I knew all about the reliability of growth scans and my gut feeling did

not match the numbers on screen).

Our birth story

The first contractions woke me up at 3am on Saturday 6th November. I was 40 weeks and 2 days by this point. Before bed that night I had a clary sage foot bath, did some meditation, listened to a hypnobirthing track, and joked on WhatsApp with the doulas about the solar flares that were happening! Who knows what worked, if anything, but I was having about two contractions an hour and felt completely normal between them. I knew they were contractions because they felt different to Braxton Hicks which I had experienced a week or two before. This kept going evenly for about 8 hours and harvesting colostrum spurred them on. I could feel my pelvis stretching, some lower back sensations and bowel pressure.

My husband and I carried on doing odd jobs throughout the morning then had a relaxing afternoon in front of the TV watching Gregory's Girl (a classic!) but the contractions disappeared. They came back with a vengeance that evening though, and quickly ramped up to one every 10 minutes by 8:30pm when we called for our doula support. In the next half an hour, it was 2-3 every 10 minutes so we called the midwife. I thought it was all happening so quickly but it stayed like this all night. Time stood still but it was also a blur. I had no concept of what was happening around me but I knew I had all the support I needed.

At 1am I reluctantly agreed to a VE and was 3cm dilated, 90% effaced, S-1. I was so disappointed. I was so sure I should have been further on. But I also remembered that it could accelerate at any time. I was in and out of the pool we had set up in the living room, and tried to get some sleep in bed but ended up sitting backwards on the toilet for a while. My husband was testing my blood sugar levels every 20-30 minutes and giving me insulin whenever I needed it. I never went 'out of range'. I got back into the pool at 4am and discovered side lying which was amazing. Our doula was always on hand with massage and counter pressure during contractions (also amazing) and maintained our quiet, peaceful and calm home birth atmosphere.

The whole night was spent like this with very little change or progression. By 7am (now 7th November) I had dilated 2 more centimetres, completely effaced but membranes still intact and not bulging. I hadn't even lost my mucus plug. With this in mind, plus some minor ketones detected in urine and blood, the midwife asked us to consider a transfer to hospital, which we unenthusiastically agreed to. I was exhausted and feeling hopeless. I asked if I could go straight for a C-section out of desperation! Before stepping into the ambulance around 9am, my waters started to trickle.

As luck would have it, the ketones disappeared by the time I reached hospital and had a snack; and yet the cascade of interventions started with cardiotocography (CTG),[1] fetal scalp monitoring, pushing on my back and eventually forceps, episiotomy and an epidural in theatre. Not what I planned, not what I wanted.

I felt I wasn't listened to. I was heartbroken with *how we were treated*, NOT

because we didn't get to birth at home.

Because of the strain on the hospital maternity system and because of the lack of trust in physiological birth, the care I received in hospital, as I had expected, was the polar opposite of the home birth experience of care I had been enjoying.

Surprise baby girl arrived at 7:45pm on 7 th November, 7lb 4oz, 50cm, black and blue from forceps.

I understand the reasons for transfer to hospital but I also knew what would happen when I got there. I had read the stories and knew the 'vibes' at my hospital through the antenatal care. We felt ignored, gas-lighted, coerced and neglected during our short stay before I self-discharged. It's also worth noting that I did not ONCE get to speak to a diabetes specialist!

When I think about my daughter's birth, I have to consciously choose to think about the peaceful, warm and comforting part at home and when I do, I am so grateful I had fought for it. The threats of stillbirth after 39 weeks, the threats of 'big baby', shoulder dystocia and neonatal hypoglycaemia were all empty as Baby was perfect. She just needed 'help' getting out as her hand was by her face and I was beyond exhausted. My biggest achievement was fighting off the pressure for induction and awaiting spontaneous labour. This contributed towards me still having the vaginal birth I wanted. I still had optimal cord clamping, I still got to take the placenta home, I still had a perfect start to breastfeeding (which is still going!), and I still retained control over my own diabetes.

On the postnatal ward, the fear continued. Despite a great start to breastfeeding, the midwife wanted me to feed Baby the syringes of harvested colostrum to avoid neonatal hypoglycaemia*even though her blood sugars tested normal!* This was an insane amount of milk and Baby was not coping with this level of forced feeding. I was also heavily encouraged to keep her in the little cot as they didn't approve of me holding her all the time (*rolls eyes*). The last straw was when 8am struck like lightning with the blast of main lights and crash of curtains opening; no consent requested.

From that moment, my little newborn was so unsettled to the point of not feeding, and I totally understood why. We needed to get home. "But we usually keep diabetics a bit longer" was the excuse despite not one question about my blood sugar levels, insulin needs, food requirements or speaking to a specialist. I pushed for discharge ASAP. I laughed my way out as I carried my new bundle in a woven wrap but had to be escorted in case we didn't have a safe car seat for her in the car.

My post-natal care was the stereotypical story most women are experiencing nowadays; not a single diabetes follow-up, no 6-week GP check-up but a fantastic team of midwives and a super special health visitor who was our guardian angel for the 1 st year as part of the wonderful Star Babies programme.[2] The irony is; the diabetes 'care' team wanted all the control in pregnancy but abandoned us at birth in hospital, and had nothing to say postpartum.

My current pregnancy is quite different as my name is well known in the antenatal 'care' team and not one person has questioned my decision to plan a birth at home again. I had a big decision to make in

where to receive care this time as I was adamant I would never return to the same hospital, but I decided to have the support of the Birth at Home team (the only one in our country) and the fantastic new Consultant Midwife, both who fully support my choices.

I've gone even further in this pregnancy to decline unnecessary appointments (I'm expected to visit the clinic every two weeks for 2+ hours, and with my toddler in tow), and unwanted monitoring, and I request to see specific members of the team. It's definitely met with confused and surprised looks as it's clear the healthcare professionals aren't used to women saying 'no'. Compared to my first birthing experience where I felt I was confidently going into battle and with full confidence in my female body to birth my baby, I am drowning in nerves, anxiety and lack of confidence. Not a single other person believed I could birth my own baby without intervention or poor outcomes last time, and these experiences have significantly affected my own confidence this time, as well as escalated my fear in how I might be treated. I honestly just want to have a free birth. Part of me knows that isn't the most sensible option for my situation, but it's a thought of desperation.

I should also mention a small but significant event last year in my second pregnancy which ended in an early miscarriage, where my endocrinologist (NOT infant feeding expert) told me it was 'horrendous' that I was still breastfeeding my toddler and actively encouraged me to stop as it probably caused the miscarriage. I followed this up with a formal complaint but despite my husband being there for the conversation in question, she denied it all. I suggested she use some CPD[3] time to develop her knowledge to be up-to-date with the evidence around breastfeeding through pregnancy, as well as work on her bedside manners.

I cannot wait to be finished with the maternity system as a type 1 diabetic; it has not been a good experience in the combined antenatal endocrine 'care' system at my local hospital, and I am not afraid to advise people to search for better elsewhere. I have become an active member of the Maternity Voices Partnership to contribute to much needed positive changes in the maternity care system for everyone. The dream is for more personalised care and advice, as well as a working environment for healthcare professionals that they would be proud of for the right reasons.

Author Bio: Jane, Penny and Andy live in County Tyrone, and look forward to welcoming another family member in Summer 2024. Penny is excited to be a big sister and show Baby everything!

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1 Editor's note: CTG is a continuous recording of the fetal heart rate obtained via an ultrasound transducer placed on the mother's abdomen.

2 Editor's note: *Star Babies* is an enhancement of the universal *Child* Health Promotion *Programme* in *Northern Ireland*, where first-time parents are offered additional regular health visiting support from the antenatal period until the baby is 12 months of age.
https://pure.ulster.ac.uk/ws/files/92297088/91619546_AAM_Star_Babies_Evaluation.pdf

3 Editor's note: CPD is continuing, or continuous, professional development