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When the Mother is Unwell

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When the Mother is unwell

When the mother is unwell

by Alex Smith

Christian Krohg (1852–1925)

Welcome to the June 2024 issue of the AIMS journal. The theme for this issue focuses on the experience of maternity care for those who embark on pregnancy already unwell or who become unwell at some point before or after their baby is born.

Pregnancy is often portrayed as a time of wellness and indeed, pregnancy and childbirth is, according to the World Health Organisation:
a physiological process that can be accomplished without complications for the majority of women and babies.[1]

Yet, according to a Danish study published in 2016[2], the overall prevalence of maternal chronic disease increased from 3.71% in 1989 to 15.76% in 2013, and a more recent study proposal[3] puts the figure for those in the UK having multiple pre-existing long-term conditions (two or more) at 20%. While the researchers acknowledge that the average age and weight of mothers has also increased during this time, and that this is associated with increasing incidences of chronic disease, age and size in themselves have not been counted as morbidities. The researchers also acknowledge that increasing awareness and recording of chronic disease, especially mental health conditions, may have some part to play in what amounts to a fivefold increase in the number of people who come to pregnancy already 'unwell'.

Another way of looking at those figures though is that four in five people (80%) embark on pregnancy free from any pre-existing illness, and should perhaps expect a far smoother experience of birth than the majority do.

Chronic health conditions are those that have lasted at least one year and require on-going medical care. They include asthma, heart disease, blood clotting disorders, thyroid conditions, autoimmune diseases such as various types of arthritis and inflammatory bowel disease, diabetes, high blood pressure, HIV, epilepsy and mental health conditions - all associated with a higher incidence of adverse pregnancy outcomes. In times gone by, a person with one or other of these conditions may have been advised not to marry or to have children, but that is not so often the case today and many can and do have healthy pregnancies and healthy babies.

In addition to those who enter pregnancy already being treated for a chronic condition, the normal physiological changes of pregnancy can unmask conditions for the first time.[4] For example, in pregnancy the blood clots more easily to reduce the risk of heavy bleeding during and after the birth, and this tendency can reveal conditions like hereditary thrombophilia[5] or antiphospholipid syndrome.[6] Another example would be related to the fifty percent increase in plasma volume during pregnancy. This increase is required in order to support the pregnancy and meet the needs of the growing baby, but it can unmask cardiovascular conditions in the mother, including arteriovenous malformations.[7] Symptoms of such a condition can be confused with those of pregnancy and consequently, a proper diagnosis seriously delayed.[8] A third example is related to the physiological increase in insulin resistance during pregnancy.[9] This clever adaptive mechanism ensures an adequate supply of glucose to the rapidly growing baby, but in people who are already insulin resistant (and many people are without knowing) this can manifest in pregnancy as gestational diabetes, with an increased chance of developing type 2 diabetes in the future.

Unwellness can also be experienced after the birth, either as an acute situation such as a blood clot or infection, or as the emergence of chronic conditions such as pain, incontinence or mental health conditions. It is hard to find research showing the extent of postnatal maternal morbidity (unwellness), but a study from 1995 found it to be “extensive and under-recognised”[10] and a 2023 report looking at the issue for women globally describes it as, “prevalent, enduring, and neglected”.[11] An NCT study found that many mothers felt, “left to their own devices”.[12] The focus of maternity care seems to be on ensuring a live mother and baby; postnatal morbidity, and especially iatrogenic morbidity (unwellness arising from medical treatment or mistreatment) is under-recognised and under-prioritised both by the cash-strapped NHS and by a society that no longer affords the mother a proper period of recovery.

The problem is exacerbated by the reduction in home visits from a midwife after the birth, and by the sense of being ‘signed off’ at the six-week check-up with the doctor. More historically, any collective knowledge and skills regarding postnatal recovery and the management of the long-term consequences of childbirth, ‘devices’ women may have shared and valued, were eroded by the advent of the professional midwife, and later by the NHS, when the message that 'the doctor knows best' could be taken to heart by rich and poor alike. In some other countries the grandmothers and aunties still offer care based on rest, nutrition, herbs, massage and belly binding.[13,14] We had similar practices in the UK, which have largely been forgotten, but not quite. Perhaps drawn by an ancient calling, and definitely through actual need, the grandmothers and aunties are re-grouping in the form of the postnatal doula and her like. If only their services could be free at the point of contact. A recent study from Ireland[15] found that new mothers would value extended professional support, but especially if this was personalised, skilled and respectful of the mother as the decision-maker. For many new mothers, a skilled postnatal doula would fit the bill exactly.

The combination of pregnancy and illness is an unusual one for the AIMS journal. While it is easy to understand why some people believe that all pregnancies and births should be medically managed - *just in case* - this actually turns out to be counter-productive. Disturbing the normal physiological process always comes at a price. When medical procedures and technologies are used routinely or without need, they do more harm than good - even for people with a pre-existing chronic condition. The two extremes of maternal health care, *too little too late* and *too much too soon,* have been discussed in the Lancet series of that name.[16] In summary it recommends that for *all* women:
The right amount of care needs to be offered at the right time, and delivered in a manner that respects, protects, and promotes human rights.

Perhaps with this balance in mind, Dutch doctors Paul Reuwer, Arie Franx and Hein Bruinse, have proposed a resurrection of O'Driscoll's 'active management of labour' in their book entitled, 'Proactive Support of Labor: The Challenge of Normal Childbirth'.[17] While ringing old alarm bells,[18] they have a lot to say about the harm caused by the overuse of some birth practices and from misplaced faith in birth technology, going as far to stress that:

For women with a complicated pregnancy (the minority) there is no better place to give birth than a hospital. For healthy women with a normal pregnancy (the majority) hospitals can be very dangerous. (Page 27)

They propose an approach to care that respects the physiological process of labour and, refreshingly, one that enhances women's satisfaction with childbirth. However, when a labour is regarded as being too slow, they very naturally apply their medical minds to the situation resorting to the oxytocin drip without consideration of non-medical techniques first. That said, for those who want or need to give birth in the hospital setting, their thinking is in line with the AIMS campaign for a 'physiology-informed' approach to care that benefits birth however and wherever it takes place.[19,20]

This brings us back to the care of women who are approaching or recovering from the birth of their baby while managing a medical condition of one kind or another. They too benefit from just the right amount of care, and care that respects, protects, and promotes their human rights.

A heavy handed, insensitive or unresponsive approach to care risks adding trauma to complexity.

A care plan for more complex situations must involve communication *between* the specialists involved as well as between each specialist and the mother. Without good interprofessional collaboration, misguided assumptions on the part of one practitioner or the other can result in advice that leads to poorer outcomes. When the medical condition is under good control, an attentive, responsive but low-key and gentle approach to care may be as safe or safer as routine intervention, when this is what the mother prefers.

What is certain is that in both complex and straightforward pregnancies, the mother has ‘inside information’. Just as with any other aspect of our physiological functioning, we sense when something is awry and when medical intervention feels welcome and appropriate. Bizarrely, given how frequently medical intervention is offered in the normal course of events, when women actually ask for an investigation or treatment, or when they tell a practitioner what they think may be wrong, they are often met with casual reassurance, resistance or delay. This can also lead to poorer outcomes. This lovely video reminds doctors to listen to women in these circumstances.[21] If *all* mothers (before, during and after their babies are born) were listened to and responded to with genuine warmth and respect, and if their care decisions were supported, outcomes would improve in every way and litigation cases would plummet.

* * *

The journal this quarter opens with Jane Furness’s wonderful account of self-efficacy in ensuring the best possible birth experience for her and her baby. Jane has type 1 diabetes but knows that, unless things change, a low-key home birth is the way to go.

Jane is followed by Rebecca Jarman who explains about peripartum cardiomyopathy (PPCM), a rare form of heart failure in women that only occurs just before or after childbirth. Rebecca’s mission is to raise awareness of the symptoms so that treatment can be started as early as possible. If more midwives and doctors were alert to the symptoms of PPCM, Claire Sheppard may have had a different story to tell. When Claire became ill after the birth of her baby, nobody really listened until it was nearly too late - even when she said that it might be PPCM.

Phoebe Howe also felt a surprising lack of support from her maternity care, both before and after the birth. When she found herself unexpectedly pregnant, support and treatment for her serious mental health condition just stopped. Emma Dickinson felt similarly disrespected. When she told the midwives that she couldn't walk or move easily, no one listened. When she told them she was in labour, she wasn't believed. Their stories illustrate the importance of listening, and of responsive, kind and compassionate care.

Insensitive care, fear mongering and mixed messages can be traumatising and cause lasting harm. Victoria Rixon, a midwife herself at the time, shares her diabetes and pregnancy story. Both she and Jane experienced a profound loss of confidence because of fear-driven care. One has to wonder whether confidence is intentionally undermined in order to gain the person's compliance.

Victoria is followed by Catharine Hart who shares her experience of pre-eclampsia and the subsequent care of a premature baby. She looks forward to a time when mothers and babies remain together throughout any hospital stay. Victoria Hilton from the Marfan Trust explains about Marfan Syndrome and about the very specialised care that people with this condition require throughout pregnancy and birth, and Kim Morley, a specialist nurse, explains the complex care required to ensure the safest possible pregnancy outcomes for people with epilepsy. Rounding up our section of themed articles, Lara Wilson, a specialist physiotherapist, explains about the impact of pregnancy and birth on the pelvic floor and all of the things that can be done to put that right.

Moving on to the AIMS Campaigns Team section, Anne Glover reports on an interesting and packed three days at the Doula UK online Conference 2024: Inspire & Connect. Members of the Team bring us up to date with two campaigns that are close to AIMS heart in their new Continuity of Carer Corner and in a report on their work related to the AIMS campaign for physiology-informed maternity services, and last but never least, we share what the AIMS Campaigns Team has been up to this quarter.

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6 Tommy's - Antiphospholipid syndrome. https://www.tommys.org/pregnancy-information/pregnancy-complications/antiphospholipid-syndrome-aps

7 Editor's note: An arteriovenous malformation (AVM) is a specific term used to describe a tangle of blood vessels with abnormal connections between arteries and veins. These are usually present at birth though may not be obvious.

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9 Editor's note: Insulin is the hormone that enables glucose in the blood to enter cells where it is needed. Insulin resistance is when this process has become less efficient and the body needs to make higher levels of insulin to do the same job. If the point is reached when not enough insulin can be made, blood glucose levels rise.

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20 AIMS (2021) Position Paper: Physiology-Informed Maternity Services https://www.aims.org.uk/assets/media/730/aims-position-paper-physiology-informed-maternity-care.pdf

21 Preventing maternal mortality: It's ok to ask - Royal College of Physicians and Surgeons of Glasgow and the Royal College of Obstetricians and Gynaecologists. https://youtu.be/qb7lntscULc?si=t4hRLnFQNcp2eZfV

Type 1 diabetes and maternity care: Jane’s story

by Jane Furness

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!

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 7th 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.

[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

Peripartum cardiomyopathy

by Rebecca Jarman RM

Author Bio: Rebecca is a midwife with over 30 years of clinical experience. She is currently working as a research midwife and is research champion for reproductive health and childbirth with the NIHR South London Clinical Research Network. She also serves as midwife representative to the UK Maternal Cardiology Society. With a special interest in peripartum cardiomyopathy Rebecca founded and runs a support group for Cardiomyopathy UK, supporting women affected by the condition across the UK and internationally.

Peripartum Cardiomyopathy (PPCM) is a rare but potentially life-threatening disease of the heart muscle presenting uniquely during the last few weeks of pregnancy or the months following birth. It causes the heart to weaken so that it does not pump normally, causing an otherwise healthy young woman to experience symptoms of heart failure for the first time.[1 (p.827)] It is associated with significant trauma, both physical and psychological, at a key life moment when becoming a parent. However, the good news is that with the right care and treatment, around 70% of women make a full recovery.[2(p.1401)]

A vital part of that recovery starts with early recognition and referral for diagnosis so that treatment can begin at an early stage of the disease and halt the progression of deteriorating heart function.[3(p.809)] The problem is that in many cases early symptoms of PPCM are not recognized as signs of heart failure as they overlap with common normal symptoms of pregnancy and are dismissed without prompting necessary cardiac investigations.[4(p.469)] Women often report instinctively feeling that their symptoms are not normal but rely on reassurances from healthcare professionals (HCP's), particularly if this is their first pregnancy and they have no previous experience to compare.[4(p.469)]

When women are not listened to or heard by HCP's they turn to other sources of information including social media platforms such as Facebook to seek support from others suffering similar symptoms where they may hear for the first time about Peripartum Cardiomyopathy. They then, like Claire, having identified the cause of their symptoms, have to self-advocate for appropriate care, often involving multiple visits to the GP. [4](p. 469)

Although, a relatively rare condition, affecting approximately 1 in 2000 births globally,[5] (p.154) PPCM is overwhelmingly the most common cause of pregnancy associated heart failure.[6](p.113)It may not be the first condition that those providing care to pregnant and postpartum women consider when making a diagnosis, however it is vital that they listen carefully to women's concerns, investigate for all possible causes of symptoms, and are aware and alert to the fact that heart failure can occur for the first time in pregnancy in an otherwise healthy young woman. Only 10% of the women who die from cardiac disease in childbirth have a known heart condition prior to their event.[7](p.47)Therefore, the overwhelming majority of women who die from cardiac disease in pregnancy do not have a pre-existing diagnosis, which would lead to greater surveillance in pregnancy. Indeed, they may well be on a low-risk pathway where their care is delivered solely by midwives. Cardiomyopathies account for a quarter of all cardiac maternal mortality figures and PPCM accounts for 20% of those.[7](p.50) It is therefore vital to raise awareness of PPCM in general and amongst midwives in particular so that lives can be saved.

What are the Symptoms of PPCM?

Physical Symptoms of PPCM include: • feeling breathless • having a fast heart rate and/or palpitations • a persistent cough, mainly at night, which feels like 'gasping for air' • being unable to lie flat in bed (needing to be propped up with pillows or to sit up) • noticing sudden and severe swelling of feet, ankles and hands (due to fluid retention) • sudden and significant weight gain (due to fluid retention) • excess fatigue • feeling or looking 'not quite right'.[8]

Emotional symptoms of PPCM include thoughts of impending death, fear, anxiety and feelings of panic.[9](p.16)

What is the cause and who is most at risk of developing PPCM?

It is not currently known what causes PPCM. There have been a number of speculative attempts to explain the cause for example, certain viruses and epigenetic factors. However, these factors remain speculative.[10] Currently, the only known factors associated with PPCM include age >30 years, African ancestry, pre-eclampsia and gestational hypertension, malnutrition, multiple pregnancy, multi-parity, diabetes and family history.[11](p.43)

How is PPCM diagnosed?

PPCM is a diagnosis of exclusion, there is no specific test to confirm it. It can only be diagnosed after all other potential causes of symptoms have been considered, investigated and excluded. [1](p.828) It is common for women to experience symptom dismissal or misdiagnosis initially with reports of 1 in 4 women being diagnosed with another condition before receiving their PPCM diagnosis. Misdiagnosis contributes to delays in correct diagnosis and treatment of PPCM. [4](p.471)

Investigations to confirm PPCM include clinical examination, electrocardiogram (ECG), blood test to measure brain natriuretic peptides (BNP) and potentially rule out heart failure, echocardiography to assess pumping function of the left ventricle and chest X-Ray.[1](pp.829-823)

Although not thought to be a familial disease, PPCM has been found to have a genetic component in 20% cases and genetic testing is now available to those with a diagnosis.[2](p.1405)

How is PPCM Treated?

Initial treatment will depend on the degree of heart failure at diagnosis and will be agreed upon by a multi-disciplinary team of clinicians including cardiologists, obstetricians, anaesthetists, intensivists and neonatologists where appropriate. Once stable, guideline directed therapies for heart failure will be used, with adjustments to medications depending on whether the woman is pregnant or breastfeeding. As pregnancy causes significant stresses on the heart, delivery of the fetus may be indicated to help improve heart function. Delivery also provides the MDT (Multidisciplinary Team) with a greater range of options for medical therapies to treat PPCM. The MDT will therefore carefully monitor the woman's condition and plan delivery accordingly. Mode of delivery is generally not determined by the PPCM itself but by the usual obstetric indications. Vaginal birth has advantages of lower blood loss which helps maintain haemodynamic stability and reduces risks of complications associated with surgical delivery.[10](p.126)

PPCM also increases the risks of thromboembolism and so anticoagulants such as heparin may be prescribed. In more severe cases cardiac devices may also be used and the woman may be recommended for heart transplant. [1](p.833-838)

What are the implications of receiving a diagnosis of PPCM?

Receiving a diagnosis is often a relief at the end of a long road of seeking help but having concerns dismissed repeatedly by healthcare professionals. Having a name for the worrying and worsening symptoms helps, however the rocky road to diagnosis and treatment often leaves its' mark with ongoing mental health impact.[12](p.8) In qualitative studies of women's experiences of PPCM themes of 'not being cared about', 'not being cared for', and 'not feeling secure' are described under the heading of 'exacerbated suffering'.[13]13(p.3) Women experience ongoing trauma, not only due to the physical symptoms and suffering which they may fully recover from, but trauma from not being heard and not being believed or supported by the healthcare professionals who are there to care for them.[12] (p.11)

Subsequent pregnancy following PPCM

Although most women will make a full recovery from PPCM and may even be able to stop medications, they have a high chance of relapsing in a subsequent pregnancy.[2](p.140)For this reason, it is important that they receive expert assessment of their heart function and take advice before entering into another pregnancy. Pre-conception counselling may be provided by an obstetrician, obstetric physician or a cardiologist with a special interest in maternal cardiology. Referrals can be arranged through the Maternal Medicine Networks or GP.

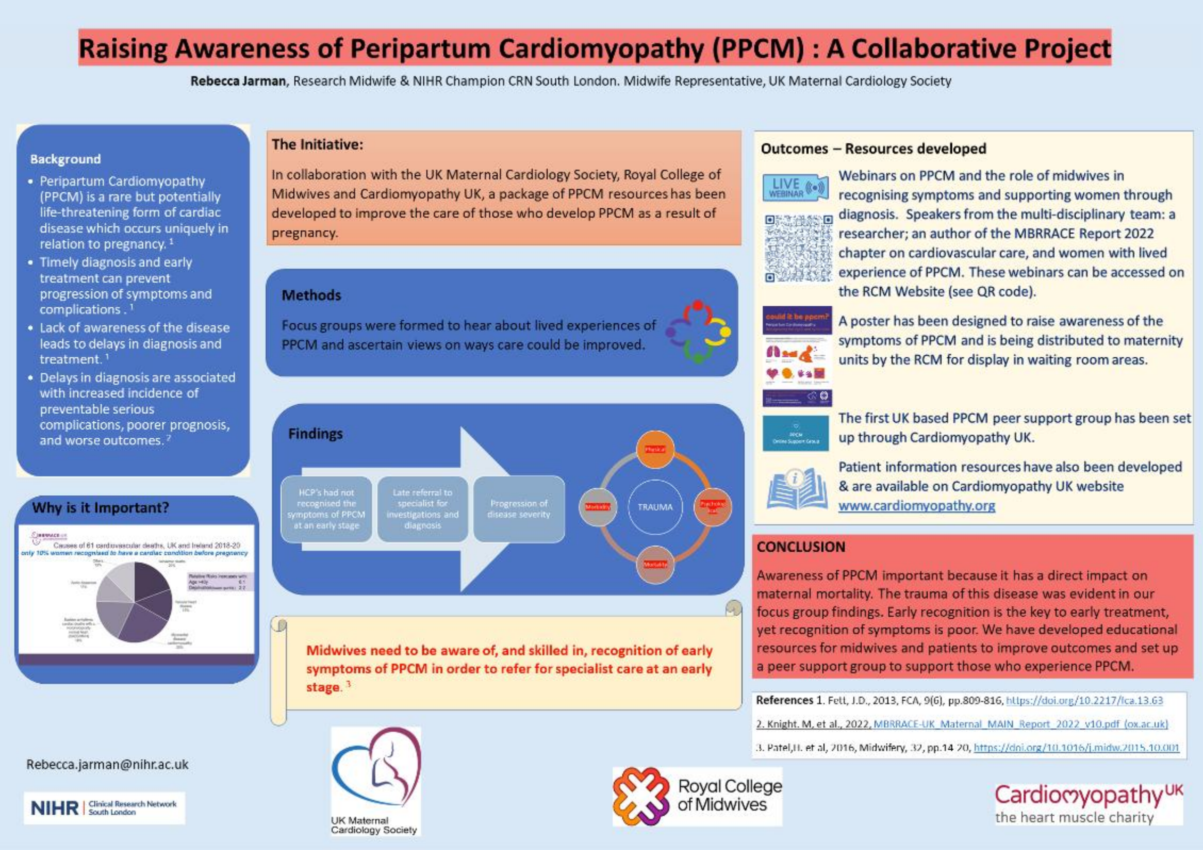
Raising Awareness of PPCM

PPCM is a serious, life-threatening condition which is poorly understood and recognized. Although rare, the incidence is significant and is rising.[2](p1397-98) It is vital to raise awareness so that symptoms are recognized, and investigations instigated in a timely manner. This will promote early diagnosis and treatment and provide the best chance of full recovery.

Patel et al, 2016, conclude from a Swedish study of symptoms in women with peripartum cardiomyopathy:
"Healthcare professionals, especially midwives who are mostly the primary care givers, need to develop competence and clinical skills to be able to detect PPCM symptoms earlier and differentiate them from normal physiological changes in pregnancy, and midwives need to understand the value of early referral for suffering women to a doctor. This is a challenge for all midwives"'[9](p.19)

Over the past couple of years, I have acted as Midwife Representative with the UK Maternal Cardiology Society (UKMCS) and led projects to raise awareness of PPCM in collaboration with the Royal College of Midwives (RCM). See Fig.1 (PPCM awareness poster). This began by forming focus groups of individuals who had received a diagnosis of PPCM (reached through the charity Cardiomyopathy UK) to hear directly about the effects of this disease. Participants were invited to share their symptoms and experiences of PPCM in online meetings. Their stories shocked me as I heard about the difficulties they experienced in getting a correct diagnosis and their feelings of fear, anxiety, isolation and guilt which were frequently ongoing and had huge impacts on their experiences of motherhood.

To date we have worked on a number of projects to increase awareness amongst clinicians. These include webinars, hosted by the RCM, with contributions from experts and women with lived experience of PPCM; and a co-created poster highlighting symptoms of PPCM which will be distributed by the RCM to maternity units across the UK for display in maternity waiting areas. I have presented on the topic at conferences, including the British Cardiovascular Society annual conference, and study days for maternal medicine midwives.



Raising Awareness of Peripartum Cardiomyopathy (PPCM) : A Collaborative Project

Rebecca Jarman, Research Midwife & NIHR Champion CRN South London. Midwife Representative, UK Maternal Cardiology Society

Background

- Peripartum Cardiomyopathy (PPCM) is a rare but potentially life-threatening form of cardiac disease which occurs uniquely in relation to pregnancy.[1]
- Timely diagnosis and early treatment can prevent progression of symptoms and complications .[1]
- Lack of awareness of the disease leads to delays in diagnosis and treatment.[1]
- Delays in diagnosis are associated with increased incidence of preventable serious complications, poorer prognosis, and worse outcomes.[2]

Why is it Important?

The Initiative:

In collaboration with the UK Maternal Cardiology Society, Royal College of Midwives and Cardiomyopathy UK, a package of PPCM resources has been developed to improve the care of those who develop PPCM as a result of pregnancy.

Methods

Focus groups were formed to hear about lived experiences of PPCM and ascertain views on ways care could be improved.

Findings

HCP's had not recognised the symptoms of PPCM at an early stage

Late referral to specialist for investigations and diagnosis

Progression of disease severity

Midwives need to be aware of, and skilled in, recognition of early symptoms of PPCM in order to refer for specialist care at an early stage.[3]

Outcomes – Resources developed

Webinars on PPCM and the role of midwives in recognising symptoms and supporting women through diagnosis. Speakers from the multi-disciplinary team: a researcher; an author of the MBRRACE Report 2022 chapter on cardiovascular care, and women with lived experience of PPCM. These webinars can be accessed on the RCM Website (see QR code).

A poster has been designed to raise awareness of the symptoms of PPCM and is being distributed to maternity units by the RCM for display in waiting room areas.

The first UK based PPCM peer support group has been set up through Cardiomyopathy UK.

Patient information resources have also been developed & are available on Cardiomyopathy UK website www.cardiomyopathy.org

CONCLUSION

Awareness of PPCM important because it has a direct impact on maternal mortality. The trauma of this disease was evident in our focus group findings. Early recognition is the key to early treatment, yet recognition of symptoms is poor. We have developed educational resources for midwives and patients to improve outcomes and set up a peer support group to support those who experience PPCM.

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NIHR | Clinical Research Network South London

UK Maternal Cardiology Society

Royal College of Midwives

Cardiomyopathy UK the heart muscle charity

Fig. 1

Additionally, I have worked with Cardiomyopathy UK to develop patient information resources and set up the first ever PPCM peer support group to address the reports of isolation by enabling women to meet others with PPCM in a forum where they can share stories, concerns and ask questions.

Awareness of PPCM amongst the general population is also important to aid early diagnosis. In view of this we have created a ‘PPCM Pledge’ (Fig.2), which was launched at the Cardiomyopathy UK National patient conference 2023, The Pledge asks people to commit to raising awareness by spreading the word and telling those they come into contact with about PPCM. Please join this mission by taking the PPCM Pledge!

Fig.2

CONCLUSION

Awareness of PPCM is vital because it has a direct impact on maternal mortality and morbidity. The trauma of this disease is compounded by a lack of awareness amongst those providing care. Early recognition is the key to early treatment and recovery, yet recognition of symptoms is poor. Further work is needed to raise awareness of PPCM to improve early diagnosis and treatment to prevent women suffering unnecessary trauma, long term disease and in some cases death.

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Peripartum Cardiomyopathy: Claire's story

by Claire Sheppard

Author Bio: Claire Sheppard born in Hong Kong but now living in South Wales, with her husband Stephen, 9 year old son Flynn and their two cats. Since being diagnosed with PPCM in 2014, she shared her experiences of living with Pregnancy induced Cardiomyopathy to help others understand their diagnosis better.

There are significant dates in everyone's life that suddenly change their path forever. For me, the day my dreams came true and I had my son, Flynn, was one of them. My pregnancy was everything I had dreamt it to be, until the very last month. At the height of summer, with my bump twice the size it should have been, I started having symptoms of, what I would later learn, was Peripartum Cardiomyopathy.

My waters broke naturally, three days before Flynn's due date. When I hadn't dilated past 2cm naturally, I was put on a hormone drip. After over 48 hours in labour, as our heart rates were both dropping, I was whisked into theatre for an emergency C section. Nine minutes later, my Flynn was born, loudly announcing his arrival to everyone as he was pulled from my tummy.

As is common for new mothers, I felt emotionally and physically drained after the birth. However, a week later, I noticed a crackling on my chest as I lay in bed at night, followed by an almost desperate need to sit upright and cough as I felt like someone was sitting on my chest and I was drowning. This continued every evening, and the only way I could sleep was by sitting upright after an hour or more of severe coughing.

Knowing something was terribly wrong, and with Flynn tucked up in his pram, I waited to be seen at my local surgery. Eight emergency appointments later, after seeing five different doctors, being given an incorrect diagnoses of a blood clot on my lung and gastric asthma, I was told I was just a hormonal, overanxious new mother. This was despite me mentioning that I thought that my symptoms sounded heart-related and could be Peripartum Cardiomyopathy.

My symptoms persisted, worsening until one evening my husband was so concerned he rushed me into A&E. I was gasping for air and felt extremely dizzy. Finally I was taken seriously and a blood test and echocardiogram were carried out. Within minutes, the Echocardiographer turned to me and told me I had Peripartum Cardiomyopathy. My Left Ventricular Ejection Fraction, a measure of heart function, was less than 18%. An angiogram was carried out which confirmed for sure his diagnosis was correct.

I was put in my own private room and started on a high dose of diuretics to help reduce the amount of fluid around my lungs which had been causing my breathing problems. I was also treated with a beta blocker and ace inhibitor to help my heart muscle. Flynn was not allowed to stay with me as I was too ill to look after him. Being away from him almost broke me, although fortunately my husband brought him to visit me every day. Then, on top of all this, I was told I would not be able to have any more children as future pregnancies could kill me.

Over the years my heart function has improved to 48-50%, and despite being medication-dependent, I can live an almost normal life. The health care I have had where I live in Wales has been neglectful. My cardiologist, after 6 years of treating me, decided there was nothing more he could do and signed me back to the care of my GP. I felt so lost and alone, scared for what the future would hold as I got older living with Cardiomyopathy.

Thankfully with the help of Cardiomyopathy UK, I am now under a new consultant at Bristol Heart Institute. I am being very well looked after, recently undergoing genetic testing that showed I have a faulty gene, which, along with my stressful labour, caused my condition. I am seen regularly and am having testing which should have been carried out when I was first diagnosed. Flynn is now nine years old and, despite being healthy, is awaiting tests on his heart, which I now know should have been instigated much earlier. Our journeys through life may not be what we plan. I am just so grateful to be here to watch my son grow.

Mental health and pregnancy - Phoebe's story

By Phoebe Howe

Author Bio: Mum of one living in Berkshire. Phoebe works as an early years music teacher, doula, and breastfeeding counsellor.

In early 2016, I was diagnosed with Emotionally Unstable Personality Disorder (EUPD, formally known as Borderline Personality Disorder) by a Psychiatrist after a tumultuous childhood and numerous symptoms impacting my daily life. That day, I was prescribed both an antipsychotic and strong sedative to manage these symptoms, and the next year or so was a whirlwind of side effects and emotional ups and downs.

Fast forward to August 2017, a breakdown in my long-term relationship led to me attempting to take my own life with the aforementioned prescriptions. After a stay in hospital, I left with – what felt like – my life in pieces and no support.

By the end of the month, I was still mentally fragile, nauseous, and dizzy. I turned to Google, concerned I was experiencing longer term effects of the overdose, but was instead prompted to take a pregnancy test. Not thinking much of it, my breath caught when the two lines were revealed. With the relationship breakdown still unbearably fresh, there was no way I could be pregnant. My next thought – how far along am I? Have I harmed my baby?

I called the doctors, in tears, to ask for advice, and was given an appointment that afternoon. Feeling scared and small, I cried as the Doctor coolly asked me to calm down. I was, on reflection, desperate for someone to tell me it would all be okay. Instead, with the pregnancy confirmed, when I asked if my baby was going to be okay after the overdose, I was told, with a shrug, that if the baby wasn't viable, it would pass. The Doctor proceeded to take me off my current antidepressants and told me to take folic acid, before reminding me to call to book in for a scan if I had not miscarried within the next couple of weeks.

The wait felt torturous and I was terrified, hurt and angry. I felt heavily judged by the Doctor and as if I had no right to want the baby that may be growing inside me. Now off my medication and in emotional limbo, the day of the scan couldn’t come soon enough. Shaking, the wait for my name to be called was almost unbearable. I practically leapt from my seat, holding back tears as the sonographer led me and my partner into a side room.

Heart racing, I felt completely unprepared for whichever news I was about to receive.

“And there’s your baby”.

The sonographer directed my gaze to the small ultrasound screen. There she was. It was at that moment that I knew I wasn’t living for myself anymore. I was living for that tiny little baby on the screen.

From then on, I was on cloud nine, with the majority of my pregnancy uneventful. I wasn’t offered any mental health support following my hospital stay and the news of my pregnancy, and I didn’t ask for any. I felt great, mentally. It felt like I had been given a reason to exist and, other than some physical discomfort, everything was smooth sailing. On reflection, I believe that the lack of any kind of ‘check-ins’ from any kind of services, alongside the general stability in mood, lulled me into what I can only now describe as a false sense of security. I felt fine, and was genuinely starting to believe that maybe pregnancy hormones had ‘cured’ me and my emotional dysregulation. What I didn’t realise, or expect, was for this to all come crashing down.

At 37 weeks, I visited the hospital due to reduced movements. After a scan, I was told I had ‘low waters’ and ‘needed to be induced’ the following day. Up until this point, I had a very clear vision of my labour – in a birth pool in the midwife led unit (MLU) – which included as little intervention as possible. However, my focus was my baby, and I adapted to the change of plan well. My induction process was a painful, draining experience that ultimately resulted in an emergency caesarean under general anaesthetic. Once I came to and finally got to hold my baby, I was in a haze of hormones, anaesthesia, and nothing felt real.

The following days in hospital were unpleasant. I couldn't pick up my baby due to the caesarean, and response to the call bell was slow. I had declined a blood transfusion and felt like I was being treated like a 'difficult patient'. I had no feeding support, and had a negative experience with a midwife feeding my baby formula milk, leading my mental health to decline – I felt like I had 'failed' my birth and was now failing at feeding my baby. Once discharged, I sought support for breastfeeding and began to, what felt like, regain some control.

However, what I now know as birth trauma was tormenting me daily, and I fell into a dark depression. I struggled to bond with my baby and process the birth, so I reached out to my midwife, who booked me into a 'birth afterthoughts' session.

This was a meeting with a midwife to go through my notes from labour and discuss the birth, and I wanted to use the opportunity to express how I wish things had gone differently, and suggest ways that my experience could have been improved. The meeting was ultimately a beneficial experience. I was able to ask questions and fill in some of the blanks resulting from the anaesthesia. However, when I expressed concerns over some of my care, I felt gaslit. My decisions were thrown back at me in defence of some of those made by my consultants and obstetricians. I left feeling small and sad.

The coming months were hard. I was struggling with depression and prescribed a low dose of breastfeeding-friendly medication, though I didn't get to see my regular doctor. Ultimately, I struggled this way until my daughter turned around one and a half, at which point I had been enrolled into a specific EUPD intensive therapy programme. I was put back on regular medication when she was two, once we had finished breastfeeding. Today, she is a week shy of six, and I am in a great, stable place mentally, although I do still carry my birth trauma and find my experience hard to talk about. Alongside my day job, I work as a doula, empowering and advocating for clients to voice their preferences, wishes, and concerns. I believe this role has wholly transpired from my own experiences with labour, birth, and the postpartum period. I am passionate about the rights of birthing people and the support new parents receive.

My recommendations based on my experience would be that:

- All pregnant individuals with pre-existing moderate to severe mental health concerns should be assigned a designated midwife, with extensive relevant training. This continuity of care should continue to 8 weeks postpartum, whereby handover to relevant local services would commence if deemed necessary. Recently, the Royal Berkshire Hospital has introduced a 'neurodiversity passport',[1] and a similar provision to this could be a beneficial addition to maternity care.

- Emotive language in healthcare settings needs to be addressed. I experienced this multiple times during the end of pregnancy, labour and immediately after birth. I felt pressured to make decisions based on language that felt coercive, that if I didn't make a certain decision, I was taking responsibility for any subsequent outcomes. Informed consent is imperative and I believe the use of emotive/coercive language is not conducive to this.[2]

- If a new parent is unable to pick up, hold, or feed their baby following birth, a dedicated healthcare assistant (HCA) should be assigned to them until they are able to do it themselves. Newborn babies feed frequently, little and often, and latching a crying baby is difficult.[3] Preserving the contact between parent and baby should be a priority.

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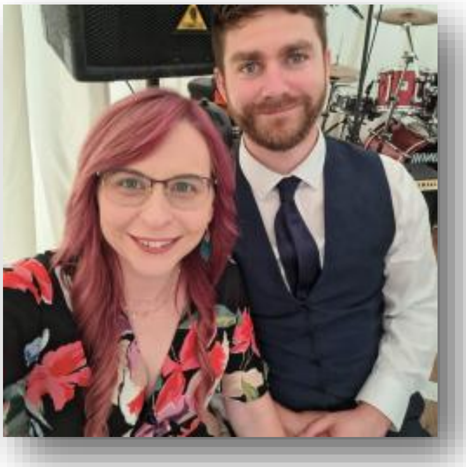
Generalised hypermobility: Emma’s story

by Emma Dickinson



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

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.

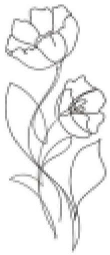
The whole time we were in that room Evie seemed quite content. She just was laying there quite happily asleep. I was trying to breastfeed and kept saying, “is this working? I don't know”, but she didn't really feed on me much at all. She just slept.

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.
- 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.

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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.

Type 1 diabetes - given my time again: Victoria’s story

By Victoria Rixon

Author Bio: Victoria Rixon is an ex-NHS midwife with type 1 diabetes. Founder of the With Woman Movement, she is striving for change and safer maternity.

In 2019, at 26 weeks pregnant, I was admitted to hospital with sickness, headache, raised blood pressure and glucosuria (glucose in the urine). I was placed on fluids, sent to a bay on the antenatal ward and booked for a glucose tolerance test in two days time.

As a qualified midwife of two years, the ward was familiar to me. I settled in, being cared for by my amazing colleagues. I was brought flowers, treats and cards encouraging a speedy recovery.

My denial of, and inexperience in, diabetes made it hard to accept what was soon to become the most traumatic experience of my life. My other pregnancies and births, including a home birth in 2011, had been so empowering. I had always felt heard and supported and these positive experiences were the reason why I eventually became a midwife. However, I was now acutely aware that I was a high risk patient and was being robbed of all the freedom I’d previously had. Quite frankly I was petrified.

With very little family support around me I attended my first consultant appointment alone. I can still remember what I wore, how I felt and who was there. Etched into my mind, it was an event that will stay with me forever.

My obstetrician, an endocrinologist, two diabetes midwives, three junior doctors and a student nurse, all came to the ‘show’. They had never come across someone like me before, they wanted a piece of the action for their portfolios, to talk about in an essay perhaps. One vital piece was missing however - my consent and my voice as I sat there frozen in fear. Then I heard the words, “you have type one diabetes”. I believe I said, “not me surely?" A fit, young, healthy mum of three, running frequently and with a normal BMI; they must have the bloods mixed up with some poor other diabetic.

I can't remember much thereafter, but I know they checked my finger nails and skin and whispered between each other. I was a puppet, in their exciting show, not a vulnerable pregnant woman. They failed to understand I was no longer there in the capacity of a professional midwife. The only word I remember taking home from this appointment… *stillbirth*.

I was sent home on oral medication, as I refused insulin. Insulin was for the really sick people not me, or so my understanding and education led me to believe. A few days later I became symptomatic of hyperglycaemia and I admitted it; they were right and I was wrong. I needed insulin after all. I was back at work by then and, during a shift on the labour ward caring for a patient in labour, the diabetes nurse sat me down in my scrubs, gave me a brief explanation and showed me how to set up my insulin pen and how to administer the dose, and then off she went.

I can't recall much between then and around 36 weeks. I slipped into some strange blur, having daily glucose highs and lows, worrying that if I didn't keep my numbers normal my baby was going to die. I did all they asked, "don't eat this, don't eat that, exercise daily, don't eat bread, cut down on carbs, but enjoy your pregnancy, don't panic, but call us if your numbers go over 7.5 more than 3 times". That was daily for me.

What I know now is that it is common for people with type one diabetes to have a wider range of levels throughout the day but you are made to feel a bad person for that happening. I didn't attach to my baby, in fact I knew he was going to die so why bother. I developed *hypo anxiety*,[1] not leaving the house or driving, or walking the dog even. I was a broken, sad, pathetic mess and no one, not even my team, nor my employer seemed to notice or care.

I was told I wouldn't be allowed to go past 37 weeks as per NICE guidelines.[2] At 33 weeks my obstetrician informed me I now had type 2 diabetes. The test for antibodies was negative and I would now need to wait for induction until 38 weeks. To be told I had another week trying to keep my baby alive simply destroyed me beyond words. Fast forward to my 36 week appointment and my obstetrician informs me that I am now a gestational diabetic and won't be induced until 39 weeks, and that I would not require insulin following delivery. I have never had a panic attack previously but, on reflection, I had one that day. My baby wasn't coming out alive, I simply couldn't cope for three more weeks like this. Forgetting all I do for other women - empowering them to feel safe, loved and supported, the very essence of being a strong woman able to birth babies - all of that had long gone from my mind.

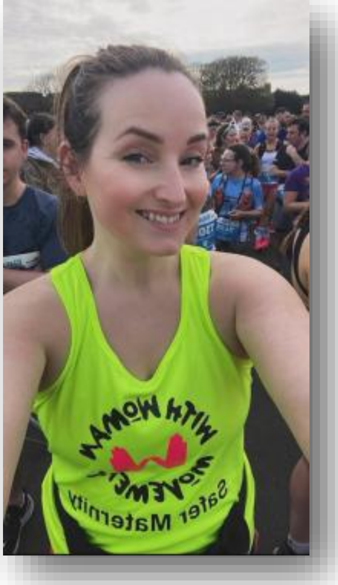
I took a second opinion, I demanded an induction at 37 weeks. I got it; induction of labour for anxiety. I feel angry when I look back at that even now. Wouldn't you? I had detached myself from associating with being pregnant, self preservation and protection from what I knew was coming, either I was going to die, he was going to die or we both were.

My induction was absolutely horrific, hyper-stimulating on the propess,[3] so many vaginal examinations that I was red raw and screaming, my husband crying in fear that I was genuinely dying. I was taken to the labour ward, the artificial rupture of membranes helped soothe the hormones, and my smallest baby at 6lb 14oz was born … ALIVE!

The morning I delivered, my obstetrician was on shift. As I had taken a second opinion against her advice she made derogatory comments about me to colleagues that were later fed back to me. I let her know what I thought, felt and hoped would be different for others.

I was sent home, with no insulin, but a live baby. That oxytocin bubble is incredible and I felt on top of the world. I was relieved I could leave this all behind and begin to rebuild my life. Months later I was diagnosed with type one diabetes and the journey since then, now five years, has not been easy. Given my time again, I would have had my home birth, even as a diabetic, as I believed somewhere that all was going to be fine. But sadly I allowed myself to be lost in the world of doctors' opinions and their 'evidence' and lost complete control of mine.

I am no longer a midwife, I suffered trauma as a result of my pregnancy, and disability discrimination, and have stepped away completely and de-registered from the NMC.



[1] Editor's note: Hypo anxiety, also known as hypoglycemia anxiety, is when you're worried your blood glucose level (blood sugars) will go too low.

[2] Editor's note: NICE guidelines are guidance - not the law. They always stress that options must also be offered and the patient's decision respected.

[3] Editor's note: Propess is a form of a hormone called prostaglandin. It is administered vaginally in a small removable 'bag' with the intention of softening the cervix in preparation for the next stage of induction. Occasionally it will trigger the labour without further steps being required. Sometimes it causes contractions that are too strong (hyperstimulation).

Pre-eclampsia: Eliza's birth story

by Catharine Hart

Author Bio: Catharine Hart studied biology at the University of York and later trained as a midwife at the University of East Anglia. She is an AIMS volunteer and a member of the Campaigns Team. She lives with her family in Suffolk. Email: catharine.hart@aims.org.uk

Our first daughter was born 13 years ago at only 32 weeks. She is now a tall high school student, one of the tallest in her year. You would never guess that she weighed only 3lb 3oz (1.44 kg) when she was born. This is her birth story. Although I am sure hospital practices will have changed since this time, I hope it is still of interest to AIMS readers.

Being pregnant as a final-year student midwife was both daunting and exciting at the same time. My husband, family and midwifery lecturers were really supportive, although some of my fellow students seemed a little shocked. One comment was, “Why couldn’t you just have waited?” This from a group of students who were supposed to be regularly reflecting on being non-judgemental and supportive to pregnant women and people in all circumstances.

All seemed well as I excitedly started my pregnancy journey. I even got through the nauseous first trimester without our lodger noticing too much. I remember still feeling quite nauseous at 16 weeks when my sister got married, but pleased that I was still able to wear the 1950s-style dress my sister had chosen alongside the other bridesmaids! All went well as I settled into my second trimester and began my final year as a student midwife, however, the thought that I could develop pre-eclampsia[1] was never far from the back of my mind, as this condition runs in my family. My Mum developed it when pregnant with both my sister and I. She often enjoys recounting the story of my birth when during labour her blood pressure was apparently so high it was ‘off the chart’. Shortly after I was born she was given diazepam (Valium) directly into her bloodstream and rendered unconscious for 24 hours. Thank goodness we have better preventative treatments today.

Because of this, my husband and I were regularly checking my blood pressure at home. When I was just under 32 weeks pregnant we found it had gone up after quite a stressful final shift in my midwifery placement. A day later it still remained high, although, apart from the usual tiredness, I didn’t seem to have any other symptoms. As my next midwifery appointment wasn’t for a few weeks, I rang my community midwifery team and asked if they could fit me in at a clinic “just to check my blood pressure”. I was trying to sound casual, still hoping that with rest and deep breathing my blood pressure readings might go down. However, knowing how quickly things can move in these situations, I quickly packed an overnight bag. I hadn’t previously met the community midwife who was checking my blood pressure, but with a reading of around 170/110 mmHg (the normal level is usually less than 140/90) it was definitely enough for her to act.

She didn’t quite fall off her chair, but she immediately asked if we’d *please* be happy to go into hospital - now! I had a sense that this was the beginning of a series of events which was going to be important, although the idea that our precious daughter could actually be born so soon still hadn’t really occurred to me.

I was still hoping at this point that I could just be given some medication for high blood pressure and sent home. I definitely don’t recall anything like making an informed decision about starting an induction of labour. I really wanted an in-depth discussion about what the actual consequences of going ahead or not could be. I wanted and expected to be treated as an adult, told the actual risks and then to make my own decisions. There was a lot of skirting around the issue and one midwife just barked at me “You have to be realistic”, which definitely left me with more questions than answers.

If I could have the situation again, being treated respectfully, being given full rather than partial information, being trusted to make decisions, and being treated as an adult rather than being infantilised with less than honest information, is what I would want. No matter that I was a student healthcare professional, I was just at sea and experiencing the same emotions as any other parent in this situation. Eventually, however, I agreed to go ahead with induction of labour and the staff (some of whom were familiar to me) were then very compassionate about the situation, even humouring my attempts to bounce on a birthing ball to get labour going.

Things were fine initially, but soon after my waters were broken, Eliza's heartbeat started to show signs of foetal distress on the monitor, a situation which I was all too familiar with as a student midwife. At this time, the staff responded quickly and professionally and explained clearly to me that an emergency caesarean section was now on the cards; I certainly consented this time. It was clearly a well-rehearsed scenario and I always felt the team were keeping Eliza and I safe. Everything happened very quickly, I remember being given a spinal anaesthetic which meant I could no longer feel the cramps of early labour and was able to stay awake for the operation. My cervix had now dilated to 3cm, which I was very proud of. I was also glad to have experienced something of labour - although now I have actually experienced full-blown labour, I feel this was more like 'paddling in the shallow end of a swimming pool'!

Our 'belly birth'[2] was a success. Eliza's cry came through loud and clear and I felt strongly from then on that everything was going to be ok. We had a small cuddle, although not skin-to-skin. It was one of the best minutes of my life, shortly to be followed by one of the hardest; I knew that Eliza would have to be taken away from us. With an incubator at the ready, off she was whisked to the neonatal intensive care unit. In those days incubators were thought to always be better 'heaters' than Mum's and Dad's chests. Thank goodness we know better now[3] that this isn't always the case, even for premature babies.[4]

The first moment I was able to meet my daughter, all the more precious because I knew it would not be for long.

One episode which still makes my blood boil was my first ever visit to the neonatal unit to see my newborn daughter, less than 24 hours after her birth. I understand it is common for neonatal units to be described as 'co-located' with maternity wards if they are fairly near each other. It certainly doesn't feel very 'co-located' when you have to travel down two public corridors to see your newborn baby. I was so excited to finally see our daughter again, but I was met at the door and simply told, "there is a ward round on at the moment - can you come back later?". I still find it quite unbelievable and infuriating that this happened.

Of course there is a need for confidentiality during ward rounds. But all parents should be given access to their own children in neonatal units; for 24 hours a day, unless there is a very good reason. I am glad to see the latest National Institute for Health and Care Excellence (NICE) guidance now recommends that parents *should* attend ward rounds and be involved in discussing their own children's care.[5] Dr Nils Bergman, an international expert in neonatal care and skin-to-skin contact, writes, "Parental absence has been strictly enforced in neonatal care units for many reasons and could lead to toxic stress".[6] It felt that parents had been excluded intentionally or 'by design' from the unit - shouldn't every incubator or cot have a chair nearby for parents or caregivers as standard, for example? Nearly all the adult beds in the hospital do, yet for the youngest 'patients' this seems to be forgotten.

Eliza in intensive care

I found the noise and bustle of the postnatal ward an unwelcome distraction from recovery. We lived very near the hospital, and I was very thankful to be allowed home after only a few days. I soon learnt that many of the other parents visiting the unit were undertaking much, much longer journeys to see their babies, often daily. The tiny milk expressing room on the unit had been designed with no windows (one-way glass, anyone?), presumably to give women privacy. To me it felt like being trapped and tears certainly flowed more easily than milk at this stage. I was given odd looks when I tried instead to sit next to Eliza's incubator holding a colostrum syringe, desperately trying to hand express a few drops of colostrum. Now, having breastfed four children, I would be much more forthcoming in this kind of situation, and know that expressing or breastfeeding often needs little more than a baggy T-shirt and a dose of confidence![7]

Another thing which sticks in my mind from this time were the continual, loud noises of the baby monitor machines "Beep beep, beep beep, beep beep beep BOING". These sounds would constantly remain echoing in my head later in quiet moments, after I had returned home.

Our daily visits to the neonatal unit were punctuated by my attempts to express breastmilk, with the added pressure that Eliza had to be given infant formula because I wasn't able to express enough breastmilk for her 'requirements'. We weren't lucky enough to be at one of the neonatal units in the UK with an onsite donor milk bank.[8] I was given good support to express milk, but it was always a struggle for me at this time. This led to Eliza being given a mixture of infant formula and my expressed milk.

Unfortunately, when she was three weeks old, Eliza developed the dreaded necrotising enterocolitis (NEC), potentially a really serious condition. My Mum, who had just retired from work, met me at the hospital and I immediately burst into tears. This was probably the most worrying time of our whole premature baby experience. We were very lucky though; after some antibiotics and 24 hours of 'starvation' with only a dummy to comfort her, everything seemed to settle and her very swollen tummy started to return to a more normal size.

After this bump in the road, however, Eliza didn't look back. There were three rooms in the unit and she was moved from the highest intensity room into the middle room, then finally to the last room, where she had an open cot instead of an incubator.

What were the highlights of our care? Moments of humour definitely helped. The nurse who joked to me that little premature babies "look like scrawny chickens" made me laugh and spawned a new nickname for our daughter – "Lyzee chicken" – which stuck for several years afterwards!!! One nurse, who I will call A, really stood out for having the kindest attitude. She was there when I stayed overnight in the unit, a few days before we were due to finally bring Eliza home. It was strange that having longed so much to have our baby girl back home, when the time actually came, the idea of being fully responsible for her seemed in some ways quite intimidating. My entire experience of parenthood, up until then, had involved hospital visits, other people caring for our daughter, expressing milk, and me getting over 6 hours of sleep a night! This nurse, A, brought Eliza to me and, with a huge amount of patience, slowly explained to me how I would be able to care for her. No question felt too silly and I felt very reassured. We are lucky to have a friend who was a neonatal nurse on this unit, so I have been able to keep a connection with A and we have met a few times since. What she did for me and for us as a family, and what it meant and means to us, really goes beyond words; it still brings tears to my eyes to this day.

Other staff members, unfortunately, didn’t show quite the same attitude. They seemed more interested in themselves than what was happening around them. On Christmas day, the main priority of the nurse looking after our daughter was telling everyone how her husband always brought her a new second-hand car for Christmas and how she would be upgrading to a Mercedes this year!!

Cuddles on Christmas Day – Eliza came home the next day, complete with the feeding tube

Eliza was finally released from hospital on Boxing Day, complete with a feeding tube in her nose that she loved to pull out (we had to return to get it refitted!). After the second ‘pull-out’, five days after coming home, we were told that she was now gaining weight well enough that we could finally ditch the tube, which was a huge relief.

Lots and lots of skin-to-skin and breastfeeding followed and I finally felt that I could heal from what had happened. Looking back now, she seems so absolutely tiny, but at the time this seemed entirely normal, especially with her being my firstborn. Because she had been born so early we were totally unprepared with baby clothes or anywhere for her to sleep at first either. I was very relieved to be allowed to drive again after my postnatal check and my first mission was to seek out some of the tiniest of baby clothes for her. Friends and family also knitted some of the sweetest and tiniest cardigans I have ever seen, kept as precious mementos, and the unit also kindly donated to us anything which was hard to find.

Eliza may not remember much of her experience but she still has scars on her hands from needles that can be seen to this day. Having a premature baby is an experience I wouldn’t wish on anyone, but I can only hope, one day, that true ‘co-location’ or couplet care (where babies are cared for alongside their Mums or Dads 24 hours a day)[9, 10, 11] really happens for many more premature babies (yes, this might mean a complete redesign of neonatal units, but I remain idealistic!). I would love to hear from anyone with an interest in these issues.

Further Reading
I would recommend these books to anyone who has been through the premature birth experience, both are full of hope and positivity with lovely illustrations - and without too many wires!

Nolan, L (2015), *Peanut: A storybook for mighty preemie babies* (Omaha: Lindsay Nolan)
Watson, J (2016), *Soon* (USA: Four plus and Angel)

[1] Editor’s note: Pre-eclampsia is a potentially very serious condition of pregnancy that seems to originate in the placenta. https://action-on-pre-eclampsia.org.uk/public-area/what-is-pre-eclampsia/

[2] Tsai S (2018) Can Renaming C-Sections as “Belly Births” Impact the Birth Experience? Mothering https://www.mothering.com/threads/can-renaming-c-sections-as-%E2%80%9Cbelly-births%E2%80%9D-impact-the-birth-experience.1626549/

[3] World Health Organization (2022) WHO advises immediate skin to skin care for survival of small and preterm babies https://www.who.int/news/item/15-11-2022-who-advises-immediate-skin-to-skin-care-for-survival-of-small-and-preterm-babies

[4] Editor’s note: Many parents and their premature babies still experience unnecessary periods of separation and stress. Here are two good sources of guidance and support: Tommy’s list: www.tommys.org/pregnancy-information/premature-birth/organisations-support-around-premature-birth - and this AIMS article: www.aims.org.uk/journal/item/parent-empowerment-nicu

[5] NICE (2020) Specialist neonatal respiratory care for babies born preterm, ‘Quality statement 5: Involving parents and carers’: https://www.nice.org.uk/guidance/qs193/chapter/Quality-statement-5-Involving-parents-and-carers

[6] Bergman, N. J. (2019). Birth practices: Maternal-neonate separation as a source of toxic stress. *Birth defects research*, 111(15), 1087-1109.

[7] Editor’s note: For any reader with a baby in hospital, Catharine’s ‘dose of confidence’ is backed up by fellow AIMS writer Hannah Thomas who produced an inspiring, confidence-boosting guide for parents in this situation. www.aims.org.uk/journal/item/parent-empowerment-nicu

[8] Find a Milk Bank - https://ukamb.org/find-a-milk-bank

[9] Klemming S, Lilliesköld S, Westrup B. Mother-Newborn Couplet Care from theory to practice to ensure zero separation for all newborns. Acta Paediatr. 2021 Nov;110(11):2951-2957. doi: 10.1111/apa.15997. Epub 2021 Jul 1. PMID: 34146345. https://pubmed.ncbi.nlm.nih.gov/34146345

[10] Curley A, Jones LK, Staff L. Barriers to Couplet Care of the Infant Requiring Additional Care: Integrative Review. Healthcare (Basel). 2023 Mar 2;11(5):737. doi: 10.3390/healthcare11050737. PMID: 36900743; PMCID: PMC10001342. www.ncbi.nlm.nih.gov/pmc/articles/PMC10001342

[11] Klemming, S., Lilliesköld, S., Arwehed, S. *et al.* Mother-newborn couplet care: Nordic country experiences of organization, models and practice. *J Perinatol* **43** (Suppl 1), 17–25 (2023). https://doi.org/10.1038/s41372-023-01812-3

Pregnancy, Childbirth and Marfan Syndrome

by Victoria Hilton for the Marfan Trust

Author Bio: Victoria Hilton is the helpline and communications officer at the Marfan Trust, the only charity in the United Kingdom dedicated to improving and saving the lives of those with the condition.

Editor's note: In this very interesting article, Victoria Hilton from the Marfan Trust writes about the genetic condition Marfan Syndrome and explains how it may affect someone during their pregnancy. She includes two personal stories from women with this condition, the first of which may be distressing to read.

The promise of a new life brings new hope but also apprehension and worry. Pregnancy is a life-changing event, driven by shifting emotions and physiological change. Childbirth is a journey like no other, an intense rollercoaster of sensations and feelings, culminating in the most magnificent of physical achievements. All this becomes further heightened when a genetic illness is woven into the mix. Pregnancy with a lifelong disorder - one that can be passed on - adds a new dimension of worry to an already-stressful situation.

Marfan syndrome (MFS) is a genetic condition which carries a 50% chance of transmission to each offspring. It is a disorder of the body's connective tissue with implications for the eyes, skeleton, and, most dangerously, the heart. Pregnancy can exacerbate an underlying weakness caused by MFS and should be carefully planned from beginning to end, together with an obstetrician and a cardiologist.

Connective tissue helps provide structure to our body, binding skin to muscle and muscle to bone. It is made of fine fibres and 'glue' including a protein called fibrillin. This tissue provides the stretchy strength of tendons and ligaments around joints and in blood vessel walls. It also supports the internal organs. In MFS, a change in the fibrillin-producing gene, fibrillin-1, means that this protein is deficient in connective tissue throughout the body, creating an unusual stretchiness and weakness of tissues. This has far-reaching ramifications and can affect the eyes, lungs, gut, nervous system, skeleton and, potentially fatally, the cardiovascular system.

Our body's fist-sized motor engine, the heart, is where magic happens. It beats approximately 100,000 times a day, pumping blood around the body to keep us alive. Pregnancy adds to its workload, with the cardiovascular system making significant adaptations to nourish and accommodate the growing baby. For instance, blood volume increases between 30% and 50%. The body's largest artery, the aorta, is responsible for carrying the oxygen-rich blood from the heart to the rest of the body and it can become imperilled in Marfan syndrome. The stretchiness that is characteristic of the syndrome can affect the aorta which, if untreated, may dangerously widen and fatally tear. This is known as an aortic dissection and the risk rises with pregnancy as hormonal changes affect vessel walls and the volume of blood circulating increases. Another cardiovascular symptom of Marfan is a leaking heart valve (particularly the mitral valve) which can billow backwards and allow blood to flow in the wrong direction, making the heart work even harder. Again, pregnancy compounds the situation.

Ideally, Marfan syndrome should be diagnosed at an early age whereupon a medical plan is put in place to manage the often complex and multi-faceted manifestations. Any aortic problems are treated with medication - beta-blockers and angiotensin receptor blockers – which slow down the aortic widening. However, as a rare condition in which the signs and symptoms vary greatly from person to person, MFS is sometimes missed and goes dangerously undiagnosed until a crisis occurs. This was Julie's experience, during her 39th week of pregnancy.

Some first hear the words Marfan syndrome across the consulting table. Others grow up knowing them. A select few first encounter the words when recovering from emergency surgery, like Julie.

Julie's Story

In July 2010 I returned from a shopping trip, and slumped on the sofa, feeling exhausted. My tiredness was no surprise, I was in my 39th week of pregnancy and I had been out panic-buying baby vests. Just me worrying, in my final trimester, that the 50 tiny little vests, already washed and ironed in the drawer, were not enough!

After mustering up the energy to put the kettle on, I knew something wasn't right as I stood up. I felt light-headed with a heaviness in my chest that I hadn't had before. Telling my partner I was going to lie down, I reached the bed and as soon my head hit the pillow, *I felt the most intense pain in my chest. It was so strong that I sat bolt upright – not easy at 39 weeks pregnant! I knew I had to get to hospital.*

My partner and I walked to the car but during the journey, my condition deteriorated. Just when I thought the pain in my chest couldn't get any worse, it intensified. My back stiffened and stuck in an arched position. I couldn't feel my legs. "Something's not right", I repeated, over and over. I was cold all over. The traffic near the hospital was gridlocked. We went to drive around it and a police car appeared. An officer got out to speak to my partner and on seeing something was wrong, he jumped in our car and drove it, following his colleague in the police car ahead, into the Accident & Emergency Department at St George's Hospital in Tooting.

A porter arrived and opened my door, getting me onto a wheelchair as I still couldn't feel my legs. I looked up and saw the ceiling lights whizzing past me one by one. That is the last thing I remember until I woke up in the Cardiothoracic Intensive Care Unit at St Georges Hospital several days later.

On arriving at the hospital, I had been taken to the maternity ward and treated as a 'woman in labour'. I was monitored overnight but no one seemed to know what was wrong. A chest X-ray was ordered, and I was given pain relief. The following morning, one of the nurses struggled to get a blood sample from me, and the Senior Midwife arrived on shift. ***I credit her with saving my life****. She now says that she took one look at me and knew my problem was not baby-related. She humbly puts her efforts down to a fresh pair of eyes arriving on shift. An alarm was sounded, and staff rushed to the unit to assist.*

Initially, I was treated as septic. I was put to sleep and taken for an emergency C-Section as the doctors were worried that I was infecting my baby, or vice versa. When my condition deteriorated after the C-Section, a chest scan was ordered. It was then that the issue was highlighted. I had suffered a Type A Aortic dissection. I was prepared for theatre and underwent 9 hours of open-heart surgery to replace my aortic valve and aortic root. My family sat in the family room waiting for updates. They were told I was the sickest person in the hospital with one doctor suggesting they say their goodbyes, as there was not much hope. Thankfully, I had other ideas!

Waking up in intensive care with no idea what had happened to me, was the strangest feeling in the world. Lying there with a tube helping me breathe, unable to talk and vials of drugs at each side of my bed, I felt like a pair of eyes. My partner and my siblings stood at the foot of my bed, giving me thumbs up, telling me I was doing well. I didn't know what I was doing well, but they seemed pleased enough!

My ICU Nurse showed me a photo of a beautiful baby girl, with knowing brown eyes, olive skin and lovely brown hair. My eyes darted around as memories of my pregnancy *came back to me. My sister began telling me how my baby was in the Neonatal Unit being cared for by the staff. It all felt like so much to take in and I still didn't understand why I was there. As the days went by, I recovered well and was moved on to a ward, however, a week after my heart surgery, I suffered an ischemic bowel and was rushed to theatre for an ileostomy.*[1] *Thankfully it was reversed a year later.*

I spent three weeks in hospital and during that time I was visited by a member of the Cardiology Team. He discussed my progress and mentioned something that would feature in the rest of my life, Marfan Syndrome. No one in my family had ever heard of it, let alone been diagnosed. We had no one tall in our family and the only clue was that my brother had scoliosis when he was a teenager.

As time went on, the rest of my family were tested. We discovered that my dad, my brother, my new baby, and my brother's two children, all carried the gene. I thought my own diagnosis was hard to take but hearing that I had passed the gene on to my baby, knocked me sideways. I felt so guilty every time I looked at her and I worried constantly about things she was doing, and things she may never get to do. Over time I came to realise that there is a huge benefit to her being diagnosed early on. She is already taking Losartan and this will help her immensely. Medicine moves at such a fast pace and the Marfan Trust do such great research work – who knows what they will discover in years to come!

Julie suffered a Type A dissection, meaning a tear developed in the ascending section of her aorta, just as it emerges from the heart. This is a major symptom of Marfan syndrome, and yet Julie had remained dangerously undiagnosed because she didn't display the visible hallmarks which characterise the condition such as excessive height and elongated limbs.

As Julie's story testifies, Marfan syndrome is a family affair. With Julie's diagnosis came that of other family members including her new-born daughter. Should Julie's daughter choose to have children of her own, she will be offered careful monitoring with pre-conception counselling and, perhaps, a discussion of pre-implantation diagnosis (PGD). Any child of a Marfan parent has a 50% chance of inheriting the gene and so prospective parents have the opportunity to undergo IVF and test their embryos prior to implantation to determine whether they have the gene change that causes MFS. An unaffected pre-embryo can be selected,and implanted in the mother's womb. The parents then know their baby should not have MFS.

As a happy side-note, Julie and her family remain in close contact with our Marfan Trust, with her son recently volunteering at one of our conferences.

In contrast to Julie, Claudia was diagnosed with Marfan syndrome as a small child and entered pregnancy with knowledge of her condition, albeit with worries about how it would all unfold. Claudia approached the Marfan Trust, newly arrived in England from Italy and in her 32nd week of pregnancy. She shares her story, below:

By Claudia

I worried when I fell pregnant because I didn't know enough about my condition. I didn't know my Marfan gene wasn't the most serious manifestation and I didn't know that I could transfer only that gene to my child. I worried that my baby would develop a more severe manifestation of Marfan.

In Italy, my doctor was the one I'd had since I was a child and so she has followed me since I was little. Arriving in London I felt lost. What helped me most was speaking to my Italian doctor who put me in touch with Dr Anne Child, Medical Director of the Marfan Trust. Speaking to Anne was so reassuring, especially when she explained to me that my gene was not the most severe but a milder variant of Marfan syndrome. The NHS only seemed to know of the most severe cases of Marfan syndrome and they treated me accordingly, as though I was very ill, which I found very stressful.

During my pregnancy, my NHS doctor monitored me very closely and it all went well. In fact, it felt like private treatment. I was given regular echocardiograms as the doctors kept an eye on my aorta. But I would have preferred to be referred to a Marfan pregnancy specialist, and see someone who was an expert in the syndrome. Ideally none of my questions would have been left lingering.

Throughout my pregnancy I called the Marfan Trust for advice and someone was always there to answer my questions. This was very comforting for me.

I hoped for a natural childbirth and my NHS doctor was happy for me to have one. In Italy, it is normal for Marfan patients to have C-Sections. If there is aortic dilatation during pregnancy, then this is what is advised. I was relieved that, in England, I was allowed a vaginal delivery. My aortic measurements were all compatible with trying for a natural childbirth. [2] *I was told that I was allowed a maximum of 30 minutes pushing so as not to stress my heart.*

Childbirth went well and, as I was considered a high-risk patient, I was kept in hospital for longer than usual and the maternity care was very good. The obstetrician even called me after I was sent home which I thought was very considerate.

In retrospect and although everything went well, I wish my doctor had been an expert in Marfan. I would also have liked to have seen all the medical reports relating to my pregnancy. Not everything was given to me by the doctor. I would also have liked a 24-hour helpline to speak to about my aorta. The Marfan Trust were there for me always and never failed to pick up the phone. I think this is what every pregnant Marfan woman needs.

Claudia has since delivered two more beautiful babies into the world and loves being a mother.

Marfan syndrome is a complex condition that can complicate pregnancy, but with medical guidance and careful planning from pre-conception to post-birth and breastfeeding, a successful outcome can be assured.

For further information on pregnancy and childbirth with Marfan syndrome, please click here. Meanwhile, the Marfan Trust can be reached on 0333 011 5256 / info@marfantrust.org / www.marfantrust.org

Marfan Trust
Supporting Research into Inherited Aortic and Related Disorders

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[1] Editor's note: An ileostomy is a surgical procedure that brings the end or loop of the small intestine to an opening created in the surface skin of the abdomen. Bowel ischaemia occurs when blood flow to the bowel is blocked or severely reduced.

[2] Editor's note: AIMS reminds the reader that it is the mother who makes the decision (or does the allowing), even when there are strong reasons (as in Claudia's case) to have a medical care plan in place.

Epilepsy and pregnancy

by Kim Morley

Kim Morley is a nurse and midwife with advanced qualifications who has been instrumental in providing specialised care for women with epilepsy since 2000. Her service uniquely supports women from their teenage years through motherhood, ensuring continuity and specialised care.

Kim's initiatives include establishing two further hospital and community-focused epilepsy services, enhancing accessibility and tailored healthcare support. Academically and professionally, she prioritises safety and aims to reduce avoidable harm, which is evident in her involvement with MBRRACE-UK. This organisation plays a critical role in improving maternal and newborn health outcomes through research and information dissemination.

Moreover, Kim's advisory role with the MHRA (The Medicines and Healthcare products Regulatory Agency) highlights her expertise in the safe use of medications like valproate during pregnancy, an area of significant concern. Kim's dedication extends beyond direct healthcare; she actively contributes to epilepsy charities and delivers lectures both nationally and internationally, specifically targeting low and middle-income countries.

In this article, Kim describes the maternity epilepsy toolkit (www.womenwithepilepsy.co.uk). This is her own creation and a testament to her commitment to empowering women with epilepsy and healthcare professionals along the maternity pathway.

The maternity epilepsy toolkit

The maternity epilepsy toolkit is a crucial resource for expectant mothers with epilepsy and their healthcare providers, aimed at improving epilepsy management from conception to childbirth. It offers a personalised, informed care approach, incorporating detailed records of medical history, medication plans, seizure management, and risk assessment and prevention strategies. Additionally, the toolkit includes access to a website that provides the latest research and guidelines to ensure care consistency and align with best practices for supporting maternal and newborn health. Empowering women with epilepsy to have ownership of the toolkit, and sharing it with all members of their team, helps develop trusted health partnerships.

Developing trusted healthcare partnerships

Developing professional trust in healthcare, particularly in areas like pregnancy and chronic conditions such as epilepsy, hinges on several foundational principles and strategies. Key among these is active listening and empathy.

Active listening and empathy allows healthcare providers to fully understand and appreciate the woman's perspective, fostering a trusting relationship. Personalised and informed care is crucial, with treatment plans tailored to each woman's unique health needs and based on current evidence, ensuring relevance and sensitivity. Consistency in care from a dedicated team prevents the woman from having to repeatedly share her story, deepening understanding and trust over time. Education and continuous professional development for healthcare providers about conditions like epilepsy are essential for offering expert, non-stigmatising advice. A collaborative approach, involving a spectrum of healthcare professionals, ensures effective communication and management of the condition, placing the woman at the centre of care provision. Such strategies not only improve health outcomes but also enhance the overall care experience, making women feel respected, heard, and valued, while reducing risks associated with non-disclosure and non-adherence of treatment regimes.

So what is epilepsy?

Epilepsy is a complex neurological condition characterised primarily by the occurrence of seizures, which are the result of abnormal electrical activity in the brain. This condition is diverse in its presentation and varies significantly from one person to another, both in symptoms and in the severity of seizures.

Seizures are categorised mainly into three types: Generalised, Focal, and Unclassified. Generalised seizures affect the entire cortex from the start, displaying widespread electrical activity across both brain hemispheres. This category includes various forms such as tonic-clonic seizures and absence seizures, which manifest as sudden muscle control loss or brief attention lapses. Focal seizures originate in a specific brain area and may spread, leading to sensory disturbances like unusual smells or involuntary muscle jerks, and potentially impacting awareness. Lastly, Unclassified seizures are those that defy categorisation as generalised or focal, often reflecting limitations in diagnostic precision regarding the location or nature of brain activity during the seizure onset.

The pre-conception journey

> ***Having a proactive approach to support ensures that women and girls with epilepsy receive the best possible care through their childbearing years, particularly when planning and during pregnancy.***

While most women with epilepsy have a healthy baby after a normal pregnancy and labour, it is crucial to plan pregnancy carefully to minimise risks. Anti-seizure medicines (ASM), for example, can increase the risk of birth defects to varying degrees. Further information is available from: https://uktis.org/, a website that provides evidence-based safety information about medication, vaccine, chemical and radiological exposures in pregnancy.

The level of risk from ASM depends on the number, type and dosage. The use of sodium valproate particularly (Brand names: Epilim, Epilim Chrono, Epilim Chronosphere, Episenta, Epival, Depakote, Convulex, Kentlim, Syonell, Valpal & Belvo) in pregnancy is associated with a significantly higher risk of birth defects and *fetal valproate spectrum disorder* characterised by developmental and intellectual disabilities. Women of childbearing potential who are taking valproate must undergo an annual risk assessment by specialists to ensure adherence to a pregnancy prevention plan.

Utilising long-acting reversible contraception that does not interact with their ASM is crucial to prevent unplanned pregnancies and is a mandatory component of the pregnancy prevention plan.[1] Contemplating the change of treatment presents multiple dilemmas:

- Valproate may be the only anti-seizure medication (ASM) that effectively controls their seizures, yet its use necessitates strong advisories against conception due to significant risks to the baby.

- Switching to a safer ASM to take in pregnancy, such as lamotrigine or levetiracetam, is a slow process.

- During the switch, they are advised to stop driving and continue to avoid driving for six months post change. If a seizure occurs they will not be permitted to drive for 12 months

- Side effects from the added ASM can be unpleasant and include life-threatening rashes and the possibility of seizure recurrence.

- If a woman conceives during the ASM transition, the risk of birth defects in the baby markedly increases.

- If valproate needs to be reintroduced to regain seizure control, it may not be as effective as before.

Clearly, it is important that all women have the opportunity of discussing how epilepsy and their medications could affect pregnancy and vice versa. Talking to epilepsy specialists about the best time and way to plan a pregnancy is optimal for good health outcomes. Epilepsy support groups, counselling, and educational resources specifically designed for women with epilepsy can help empower and inform women in this process.

The provision of pre-conception care also helps identify personal seizure triggers and lifestyle behaviours that may be affecting seizure control. Mothers-to-be can help improve their health through eating a balanced diet, taking regular exercise, avoiding cigarettes, vapes, illicit substances and managing sleep and stress effectively. If they are taking other prescribed medicines that could lead to harm of a developing baby, this is also a time for re-evaluation.

Before contraception is stopped, Folic Acid supplementation is recommended to start before conception and during the first 12 weeks of pregnancy to reduce the risk of birth defects, as advised by RCOG guidelines.

Managing epilepsy during pregnancy
This requires a nuanced approach that balances women’s health needs and those of their unborn child. Management involves a delicate balance between controlling maternal seizures and minimising potential adverse effects from ASM on the baby. Simply knowing that a pregnant woman has epilepsy doesn't provide full insight into the accuracy of her diagnosis, the appropriateness of the ASM for her seizure type or whether the dose is correct. It also doesn't reveal the characteristics of her seizures, her individual risk factors related to those seizures, or the overall impact of epilepsy and its treatment has had on her and her family's life.

Women’s individual healthcare needs are complex. Care should not just be about managing seizures and adjusting medications. It requires a personalised approach that considers the full narrative of the woman's experiences — her medical history, and the physical, mental, and the social impacts of her condition. Comprehensive, tailored care should address a woman’s personal concerns, and fears, ensuring a holistic approach to her support.

Here's a deeper look at the key components
When women with epilepsy become pregnant, specific guidelines and protocols are implemented to ensure their health and the safety of the baby. These protocols include:

- Immediate referral of pregnant women with epilepsy to specialised care pathways is advised to ensure they can access their designated epilepsy care team within two weeks. This enables timely interventions to prevent complications for both mother and baby.

- Urgently discuss women’s treatment options with epilepsy specialists. Abrupt changes in medication can be harmful, and specialist advice is essential to assess treatment whilst ensuring both maternal health and fetal safety.

- Rapid access to specialist care allows for timely interventions, which are critical in preventing complications both for the mother and the baby, especially if seizure control becomes an issue.

- Regular planned antenatal and neurology/epilepsy care and assessments to help monitor seizure risks, medication adherence (possibly compromised by vomiting or fear of taking ASM in pregnancy), and seizure frequency, crucial for managing health effectively during pregnancy.

- Educating women and families on first aid and risk prevention strategies including safety around water, safety inside and outside the home. Women are also educated on the importance of not discontinuing medication without medical advice, as doing so can increase seizure activity and risks like SUDEP (Sudden Unexpected Death in Epilepsy).

- Minimising the risk of SUDEP, a rare yet devastating event where an individual with epilepsy dies suddenly and unexpectedly, is crucial in epilepsy care. Although the exact causes of SUDEP are often unclear, key preventive measures include raising awareness, regular risk assessments, and continuous education and support. This care extends throughout pregnancy and postpartum, with a strong emphasis on medication adherence to prevent tonic-clonic seizures, which pose the highest SUDEP risk when occurring during sleep particularly if sleeping alone. If sleeping alone is necessary, risk mitigation strategies such as a social care assessment for home safety and arrangements to live with family or friends should be considered. Further information available from: https://sudep.org/

- If a woman discontinues ASM suddenly, primary care providers, midwifery and obstetric teams must act swiftly to ensure she receives specialist epilepsy care to prevent increased seizure frequency and potential risks to her and her baby's health. This comprehensive approach helps manage epilepsy in pregnancy safely and effectively, balancing the health needs of the mother and her unborn child.

Safety advice from women with epilepsy for maternity hospital admission

Acknowledging women’s concerns

It is important for healthcare professionals to understand and address any concerns that pregnant women with epilepsy may have regarding their condition and treatment. Addressing these concerns can lead to better adherence to medication regimes and, consequently, better outcomes for both the mother and the baby.

If monitoring of anti-seizure medication levels is carried out during pregnancy, the results should be discussed with the woman to inform choices about any necessary dose adjustments. Balanced discussions ensure that women feel supported and valued in their care decisions, enhancing trust and adherence to their prescribed treatment plans.

By prioritising women’s safety, informed decision-making, and collaborative care, healthcare providers can significantly reduce anxiety and fears and improve outcomes.

Giving Birth and Monitoring Protocols

Women with active epilepsy or those on epilepsy medication are advised to give birth in a consultant-led maternity unit.[2] Although the risk of seizures during labour is low, additional monitoring for both the mother and baby may be necessary. This also allows expert care and appropriate intervention should complications arise during labour, safeguarding both mother and child.

Normal Birth and Healthy Baby Outcomes

Most women with epilepsy can expect a normal birth and a healthy baby.

Only in extreme cases is epilepsy an indication for induction of labour or caesarean section.

This information provides reassurance to expectant mothers, helping to reduce anxiety about the potential impact of epilepsy on childbirth. It is essential they continue their ASM as prescribed during labour and avoid pethidine as it has the potential to lower seizure threshold. If they feel sick an anti-sickness injection can be administered. Further information, guidance, and checklists to help optimise the birth experience are available from: https://www.womenwithepilepsy.co.uk/labour-birth/

Postpartum Safety and Ongoing Care

Postpartum mother and baby safety advice, including strategies related to breastfeeding, potential worsening of seizures, and ongoing medication management, should be discussed thoroughly during both antenatal and postnatal phases. These discussions prepare women for the postpartum period, emphasising the continuation of care and vigilance required to manage their condition while caring for their newborn. The woman's epilepsy specialist team should be informed of the birth of the baby in order they can continue to guide medicine management and epilepsy support into the postnatal year.

Feeding and Medication Considerations

1. Babies exposed to ASM through breast milk should be monitored for adverse effects such as excessive sedation. Urgent medical advice is crucial if the baby shows signs of breathing difficulties, rash, excessive drowsiness, or poor feeding.

2. Breastfeeding is generally encouraged and considered safe with most epilepsy medications, but it is important to be aware of medications that might pose risks. Further information is available from LactMed, the drug and lactation database: https://www.ncbi.nlm.nih.gov/books/NBK501922/?report=classic

Safety and Support in the Hospital

1. Ensuring the postnatal medicine plan is followed. If the ASM have increased during pregnancy, there should be a plan in place to start reducing these, often as early as three days postnatal.

2. Continuing ASM as prescribed is essential to avoid seizures, which could be risky for both the mother and the baby.

3. If the mother is at risk of having unwitnessed seizures, staying alone in a single room is not advised. Hospital staff should be informed if additional support is required to optimise safety.

Advice from women with epilepsy to reduce postnatal risk

The Postnatal Year
To manage seizure risks postnatally, women with epilepsy should maintain their prescribed medication regimen, stay hydrated, eat healthily, and get enough sleep. It's critical to treat any infections like mastitis promptly since they can provoke seizures.

Changes in seizure patterns should be reported immediately. Sleep deprivation, common in new parents, can also trigger seizures; thus, establishing a routine for early night sleeping and sharing nighttime feeding duties can help.[3] Resources like the NHS guide on baby sleep offer further guidance. Ensuring the care team is informed post-birth and implementing risk assessments and avoidance strategies are essential to minimise the risk of seizures during the postnatal year.

Further resources and information to help support women through the pregnancy continuum are available from: www.womenwithepilepsy.co.uk

[1] Editor's note: Use of sodium valproate in people who can father children within the 3 months prior to conception may increase the risk of neurodevelopmental disorders in the child. www.medsafe.govt.nz/safety/Alerts/Sodium_valproate_Epilim_use_in_people_who_can_father_children.asp

[2] Editor's note: Some women with epilepsy may feel strongly about giving birth at home or in a midwife-led unit. They may feel that they are in better control in familiar surroundings. Determining the place of birth is a human right. This page from Epilepsy Action addresses this possibility. www.epilepsy.org.uk/living/having-a-baby/labour-birth-and-after-the-baby-is-born. The chance of having a seizure in labour is generally given as being 1-2%. https://www.rcog.org.uk/media/rzldnacf/gtg68_epilepsy.pdf

[3] Editor's note: Creating a strong support network seems important. Having good breastfeeding support will help avoid the extra stress of mastitis for example. Family support may reduce sleep deprivation, and engaging a postnatal doula, mother's help or overnight support would also help with sleep, if funds permit.

Pelvic floor health - “I wish I’d known this sooner”

by Lara Watson

Author Bio Lara Watson has worked as a Physiotherapist for over 25 years. Specialising in Womens’/Pelvic Health since 2012, Lara is the proud recipient of 2 NHS awards for ‘Excellence and Innovation” in the field of Womens’ Health. More recently, Lara opened ‘MyCorePhysio’ in North Wales, supporting feminine health through 1:1 physiotherapy appointments, as well as Womens’ Health-Hypopressives Workshops and Retreats.

“I wish I’d known this sooner” - A sentiment I often hear from women consulting me over intimate health issues. Closely followed by, “Is it too late for me to do anything about it?”

Working as a Womens’/Pelvic Health Physiotherapist, I help to treat a wide range of symptoms, many of which are linked to issues with the pelvic floor, or to use medical speak, pelvic floor dysfunctions (PFDs). I’m talking about problems like urinary incontinence (uncontrollable leaking of wee, with or without urgency), bowel incontinence (uncontrollable leakage of wind or poo, with or without urgency), and pelvic organ prolapse (where one or more of the organs within the pelvis, the bladder, womb or rectum, move down from their usual position, bulging into the vagina). We can also help with some PFDs, that are even less talked about, including things like coccydynia (tail-bone pain), diastasis rectus abdominis - DRA (separation of the muscles down the middle of the tummy), dyspareunia (painful sex), vaginismus (spasm of the muscles around the vagina), pelvic girdle dysfunction-PGD (pain, clicking or grinding caused by the pelvic joints), and pudendal neuralgia (pain or tingling in the genitals due to nerve injury or irritation).

Whatever the problems, generally speaking, my short answer to “Is it too late to do anything about it?”, is “no, it’s never too late”. But a fuller answer would be that treatment is most successful when difficulties are dealt with sooner rather than later, and undoubtedly, prevention is better than cure.

However, in order to prevent something, we first need an awareness of its potential to happen, and it's not just the women who've passed through my clinic doors that wish they'd had more information sooner. Studies around this subject highlight that knowledge about PFDs during pregnancy is low[1] and women would like more education, in particular a stronger emphasis on preventative measures around childbirth.[2]

During pregnancy and in the weeks following birth, around half of all women report having one or more PFD. Urinary incontinence, faecal incontinence, pelvic girdle pain, DRA and difficulties with sex are the most frequently described,[3,4,5] plus around a third of first-time mums will report symptomatic pelvic organ prolapse.[4] Although there can be natural improvements in the weeks following birth, it's not uncommon for symptoms to reappear within a year[6] and giving birth can predispose us to developing PFDs later in life.[7,8,9] In other words, we can't just ignore things and hope they'll go away, even though many of us do just that. I regularly meet women who have put up with things like bladder leaks, pelvic pain and tummy separation for years. Lack of awareness, embarrassment and stigma are the reasons given for many of us putting our PFD symptoms on the back burner.[2] But whatever the reasons, delaying means we miss sweet spots of opportunity for prevention and for treatments when our bodies are at their most adaptive and changeable.

So, whether we're trying to conceive, are already pregnant, or recently postpartum, heck, for all of us, it's worth being informed about these very common problems, with an understanding that 'common' does not translate to 'normal', and that options exist to safeguard us.

So why do PFDs happen? Everyone's case and experience is individual, but factors such as having a BMI over 25kg/m2, lack of exercise, constipation, chronic lung disease with a cough, and diabetes, have all been identified as increasing our probability of developing PFDs.[7] Additional risks specifically associated with pregnancy and childbirth are:[7]

- Being over 30 years when having a baby
- Baby's birth weight over 4kg (9lb)
- Having given birth before
- Assisted vaginal birth (forceps or vacuum)
- A vaginal birth where baby is lying face up (occipito-posterior)
- An active second stage of labour taking more than 1 hour
- Injury to the anal sphincter during birth

In the overview that follows, I've focused on some things we can do to help reduce the risks to our pelvic floor. Links have been included for more in-depth guidance along the way, although it's important to be aware that this information is generalised, and as always, you should follow individualised advice from your health care professionals.
I feel a good place to start is with some of the things we all could and should be doing, irrespective of pregnancy. Pelvic floor muscle training is recommended to help us prevent and treat PFDs.[7,10] But, however motivated we may be with pelvic floor exercises (sometimes known as Kegels exercise), they're only effective when performed correctly.

When assessing the pelvic floor, it's not unusual for me to find that womens' sensory awareness of what the muscles are doing is a little off. In fact, at least two-thirds of us have an incorrect perception of our pelvic floor, feeling we're tightening when we're not, and nearly half of us are actually bearing-down.[11,12] But it's also been found that understanding more about these mysterious internal muscles improves our inner mapping and awareness of them (proprioception), which in turn leads to better muscle function.[13] So take every opportunity, and be proactive in learning about your pelvic floor, because in this case, knowledge literally equals power. Make sure you're doing your Kegel exercises right, and if you're unsure, ask for a referral to a Specialist Womens'/Pelvic Health Physio, who can assess your muscles and show you how.

In terms of what to expect from a pelvic floor assessment, be prepared to answer questions about your lifestyle and general health, as well as any PFD symptoms. Your pelvic floor muscles can be assessed simply, using a lubricated, gloved finger-tip just inside the vagina or back-passage (no speculums like a smear test), allowing the muscles to be palpated for tone and stiffness, and checked for their ability to contract and relax, their power, speed, endurance, coordination and flexibility, in other words, the characteristics the muscles need to work well. Other assessments of posture, pelvic joints, movements and muscles that work alongside the pelvic floor (including the respiratory diaphragm, deep abdominal and spinal muscles) may also be carried out according to your individual needs.

It really is advisable to get on top of any niggles you may have, in particular, because if you go into pregnancy with any existing PFDs, it is likely that symptoms will worsen during pregnancy, and may persist this way afterwards.[7]

During pregnancy, if you haven't already gotten going with pelvic floor exercises, it's advisable to start. Doing so can prepare the muscles and tissues for the increased work-loads they will experience during pregnancy and birth, as well as lessen the likelihood of pelvic floor injury during childbirth, a strong risk factor for long-term PFDs.[7,14]

Another way to prepare and protect your pelvic floor from birthing injuries is to perform daily perineal massage from around 35 weeks onwards. Be sure to choose an unscented oil. It doesn't need to be special, olive oil will do the job nicely.
With regards to general activity, we're long past the days when pregnancy was considered a condition of confinement, the latest advice being to remain active. In addition to following general guidelines for physical activity during pregnancy, my advice is to know your own capabilities, and listen to your body, adapting to changes as your pregnancy progresses.

Throughout, try to be candid in conversations with your doctors and midwife so you can access support in dealing with any difficulties or symptoms arising.

Postnatally, take special care of your pelvic floor area as it is recovering following birth. Remember to keep an eye on staying well hydrated, particularly if you are breastfeeding, and to avoid constipation. And, whilst we're on the subject, take care of hydration down below too. Hormone fluctuations in the postnatal period can cause vaginal dryness and irritation which in turn, may impact on the pelvic floor muscles' ability to work comfortably and can make sexual intercourse difficult or painful. There are numerous over the counter lubricants and moisturisers to try, but I use and recommend products that are made with organic ingredients, are paraben[15] and glycerine free, supporting the natural pH of intimate areas.

You may resume your Kegel exercises as soon as you are comfortable, and should do so whether you've experienced a vaginal delivery or not.[7,10,16] However, don't over-do it, and avoid getting into the bad habit of gripping with the pelvic floor. Time after time, I see overly tight muscles being just as problematic as weak ones. Again, if you're unsure or experiencing persistent symptoms of PFD, request guidance. Specialists like myself are here to treat and guide you, and women say that physiotherapy helps to regain control over PFD symptoms, which enhances their life.[2] Women tell me they've often avoided asking for help for fear of being seen as a complainer. But by reaching out, not only will you access the help you need, but you will also be contributing to the data that helps to inform decisions around future health care provisions for others in similar situations.

As time goes on, you may wish to look at options, other than Kegels, for exercising your pelvic floor. My choice for a more engaging alternative is Hypopressive exercise, a relaxing whole-body technique combining specific rhythmical breathwork and postural flows. Initially developed in Europe in the 1980s, to promote womens' postnatal recovery, Hypopressive exercise is now practised by women of all ages. The exercise is effective,[17,18,19] rebalancing and retraining the pelvic floor and core muscles reflexively, whilst improving body image and overall sense of well-being.[18]

Finally, avoid rushing back to impact activities, and anticipate that you will need to make any return to sports gradually. Guidelines for physical activity from birth to twelve months, along with those for a structured return to running postnatally can help direct you.

So to sum up, exercising our pelvic floor should be part of our regular selfcare in preventing PFDs, especially around pregnancy and childbirth. Our future selves who might want to enjoy a Zumba class, a belly laugh with friends or dare to wear light coloured trousers without fear of leaks or embarrassment, will thank us for it. But remember it takes a combination of sound technique and consistency over time to see results. I believe it's important to find a type of pelvic floor exercise that we find enjoyable, in order for it to be sustainable, supporting our pelvic health long-term, and through different phases of life. But, if despite everything, you find yourself experiencing PFDs, you are not alone. There are many non-surgical treatment options that you can access through NHS or private healthcare providers, professionals like me whose purpose is to advise, treat, support and guide you.

Links used in this text

Accessing specialist services within the NHS: www.nhs.uk/conditions/physiotherapy/accessing

Care of your pelvic floor following birth: www.nct.org.uk/labour-birth/after-your-baby-born/perineal-tears-recovery-and-care

General guidelines for physical activity during pregnancy: www.rcog.org.uk/for-the-public/browse-our-patient-information/physical-activity-and-pregnancy

Guidelines for physical activity for women after childbirth to twelve months: https://assets.publishing.service.gov.uk/media/620a2ff9d3bf7f4f0ec9b574/postpartum_infographic.pdf

Guidelines for returning to running postnatally: www.csp.org.uk/news/2020-06-03-physios-postnatal-running-guidance-recognised-aligned-government-advice

Pelvic floor exercises: https://thepogp.co.uk/patients/pelvic_health_advice/pelvic_floor_muscles.aspx

Perineal Massage: www.rcog.org.uk/for-the-public/perineal-tears-and-episiotomies-in-childbirth/reducing-your-risk-of-perineal-tears

Other useful resources

Bladder and Bowel Foundation (Information and support for bladder and bowel conditions): www.bladderandbowel.org

The Pelvic Partnership (for information and support for pelvic girdle pain in pregnancy): https://pelvicpartnership.org.u

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Doula UK online Conference 2024: Inspire & Connect

By Anne Glover

Author Bio Anne has been working as a doula for almost 9 years in Northern Ireland and has supported well over 150 women at some stage in their birthing journey. She currently volunteers on the AIMS Campaigns Team

This annual conference, held from the 22nd to the 24th of March, was as interesting and packed with pertinent topics as ever! The 3-day schedule was well thought out with quick breaks between talks and introductions presented by various leadership members. The theme this year was ‘Inspire and Connect’ and it was great to see collaboration with so many widely respected faces in the birthing world. The conference ran online from Friday afternoon until Sunday lunchtime, with 12 external presentations and introductions to the leadership team and sponsors. There were over 100 participants including Doula UK members and birth professionals from around the world attending the event.

The event covered a wide variety of topics including hypnobirthing, biomechanics, breastfeeding, postnatal support, neurodiversity, induction, high BMI, the ‘Born at Home’ film and a spiritual dimension of pregnancy in a secular world. Some of the talks were focused on the role of doulas supporting families, for example supporting neurodivergent birth and supporting families in sleep crisis, but anyone interested in birth and life with a newborn would have found these talks informative and inspirational.

Hot topics such as high BMI, neurodiversity, birth trauma and induction kept us all informed on the latest information accessible to doulas and parents. The collaboration between Doula UK and AIMS continues as Nadia Higson from AIMS shared her expertise on induction, engaging doulas about the latest evidence based information and sharing information on where to signpost clients to. This was based on the AIMS workshop 'Focusing on Induction of Labour' which has now been accredited for CPD by Doula UK, along with other topics. Buy tickets for AIMS workshops here.

Connecting with other attendees was limited to the chat box on Zoom, and there was also the opportunity to put questions to the presenters in the Q&A box which were addressed at the end of each presentation. The event ran smoothly from one presentation to the next with good time-keeping!

It was really useful to have the recording of the whole event available for 30 days after the conference, simply because there were so many interesting presentations and I certainly didn't want to miss any!

Over £4,000 was raised for the Doula Access Fund, which provides free doula support during pregnancy, labour and after the birth of a baby to those most vulnerable. Referrals can be made to Doula UK by a healthcare professional, social worker or charitable partner. Please see the website for more information.

Continuity of Carer Corner – April 2024

From the AIMS Continuity of Carer Campaign Group

Introduction

Every couple of months a small group of AIMS volunteers, who have an interest in the AIMS Continuity of Carer campaign, meet to discuss the various themes embedded in this model of maternity care, and to brainstorm different ideas and thinking.
Recent work includes:

- responding to a call of evidence - The House of Lords Preterm Birth Committee on how continuity of midwifery carer can help to reduce preterm births
- reviewing for update the AIMS Continuity of Carer position paper https://www.aims.org.uk/campaigning/item/positionpapers
- The annual review the previous year of this AIMS campaign should be available soon on the website
- reviewing the latest Cochcrane report: Are midwife continuity of care models versus other models of care for childbearing women better for women and their babies?

AIMS continues to play a leading role in supporting an effective Charities and Service Users Maternity Continuity Network.

We are also working to retain our status as a valued stakeholder for England policy implementation.

Part of our campaign work is keeping abreast of how the continuity model is being rolled out across the UK, looking at how we can influence political party manifestos, and commenting on midwifery professional development modules.
However we do know how important it is to hear from the women who experience continuity of midwifery care, and we therefore plan to bring their voices to this corner of the journal. So please catch up here with every edition of the journal!

AIMS Physiology-Informed Maternity Services (PIMS) - April 2024

Campaign Group Update

Introduction

A few members of the Campaigns Team meet regularly to focus on work related to the AIMS campaign for physiology-informed maternity services:

- Last year we put together three case studies to highlight good examples of physiology-informed care - optimal cord clamping, biomechanics and family centred caesarean birth. You can see the poster here.

- We have put together a new case study on Rebozo {link to follow} and are working on case studies on kangaroo mother care and skin-to-skin contact.

- We also included the need for a more physiology-informed approach in our evidence submission to the House of Lords evidence committee for preterm birth, including why several aspects of physiology-informed care such as optimal cord clamping and kangaroo mother care are vital for preterm babies.

- And we've been reviewing the AIMS Physiology-Informed Maternity Services position paper. Please let us know if you have any comments on this.

We will be recording for the Blossoming Midwife Podcast sometime at the beginning of June.

If you have other suggestions for case studies - whether it's something you do in your own practice or something you've heard about, please let us know.

Please email campaigns@aims.org.uk if you would like to be involved in either or both of these campaigns.

What has the AIMS Campaigns Team been up to this quarter?

by the AIMS Campaigns Team

Written outputs:

- 5th February: AIMS Submission to the Birth Trauma APPG
- 1st March: comments on

">BESt UK survey wording

- 6th March: Letter of support to Stella Creasy MP, who was referred to Children's Services by a online troll and was unable to get the referral removed.
- March: AIMS Submission to the House of Lords Preterm Birth Committee

Conferences and meetings attended:

- 2nd February: BESt UK information meeting, online
- 5th February & 18th March: RCM Research Prioritisation project steering group meeting, online
- 6th February: London Maternity & Midwifery Festival 2024
- 14th March: NHS-E Stakeholder Council away day
- 19th March: Bradford/Airedale MNVP meeting on women's experience of induction
- 20th March & 4th April: Plan-A Study PPI (Patient and Public Involvement) partners meeting
- 21st March: Continuity of Carer huddle: this is a sub-group of the AIMS Campaigns Team
- 22nd-24th March: Doula UK Conference
- 9th April: All-Ireland Maternity & Midwifery Festival 2024 in Dublin
- 12th-14th April: ENCA meeting online sessions
- 23rd April: Charities and Service Users Maternity Continuity Network meeting

Who we have been corresponding with:

- 25th March: Visiting midwives from Japan
- 17th April: Northern Ireland Nothing About Us Without Us (NAUWU) - Women's Health Strategy questionnaire
- 20th April: ENCA annual meeting blended session

What we've been reading:

- NICE guideline on twin and triplet pregnancy
- First 1001 Days Manifesto for Babies - A Manifesto for Babies is published by the First 1001 Days Movement – a coalition of over 200 charities and professionals who believe that babies' emotional wellbeing and development matters.

What we’ve been watching:

- Born at Home

Thanks to all the AIMS campaigns Volunteers who have made this work possible. We are very keen to expand our campaigns team work, so please do get in touch with campaigns@aims.org.uk if you’d like to help!