

Abigail Mason-Woods - Written evidence (PRT0026)

In late 2021, nothing could have prepared me for the cloak of vulnerability that fell upon myself, expecting Monochorionic/Diamniotic (Identical) twins. My career experience and qualifications as a Designated Safeguarding Lead and Family Support Worker in Education should have, 'on paper', helped me to navigate what was ahead of myself and my husband, as we tried to safely bring both our girls into the world. I quickly realised, life before NICU is mostly irrelevant when you find yourself stood, post-partum, next to your baby in an incubator, hoping and wishing that you make it out safely. And they survive. The vulnerability is beyond crippling.

I experienced a pre-term birth (missing the whole of my third trimester. And fourth.), complex health issues for myself as a result of their early arrival, and lengthy NICU stays for both babies (just under 150 nights), in hospitals that were 80 miles away from our home address. My birth story was not represented in the birth narratives told to society. This is how I became, an expert by lived experience of pre-term birth. The mother of 677g and 500g twins.

It was after those 150 nights, filled with life saving surgeries, mechanical ventilation, several episodes of sepsis, and too many blood transfusions to count, that I was then 'flung' back out into the world (time stops still in NICU!) and forced to navigate not only caring for newborn twins but also trying to navigate life after NICU. And most importantly, understand what we had been through and experienced. Society seems to know so little about Neonatal Care and the long-term effects. There was no support after.

Once I had reflected on my our own experiences of Pre-Term birth, I outlined several key areas that were pertinent to me:

- There has to be better Antenatal Education on Pre-Term birth and Neonatal Care. Education that doesn't exclude, but instead

empowers parents and caregivers with the knowledge, should their baby require Neonatal Care. It should be proportionate and appropriate, not overwhelming, but allows parents to be prepared should the unexpected happen. It saddens me that some still may think my daughters' photos from their hospital stays, should carry a 'trigger' warning. Or if pre-term births are discussed antenatally, we may make others manifest a 'negative' birth for themselves or even 'traumatise' pregnant women. In fact, not knowing enough about pre-term birth antenatally, traumatised me when I found myself experiencing it.

- We have to ask services to consider the current significant gap between Maternity and Neonatal Care. High risk pregnant women quickly become 'just' the parents of neonates in the critical post-partum period. Those giving birth often are left feeling the physical and emotional effects of a pre-term birth. It brings with it guilt for bringing your baby into the world too early, forced separation from your baby/ies, and even a sense of bereavement and grief for the path we thought we would all follow postnatally. The birth narrative portrayed by society is very different – chubby babies placed on a mother's chest immediately after birth, breastfeeding (without a pump in sight!) and taking your baby home after, with the statutory car seat photo walking out of the hospital. When you don't take your baby immediately home (or for some, very sadly, they never take their baby home), it feels like your birth is forgotten. Not counted.
- Recognising that for many, our story starts long before we walk through the doors of NICU. Remember we have given birth. We were once pregnant. This is too often forgotten and you are hurried to repair physically, whilst watching your baby fight for their life. I was asked once by a well-meaning Neonatal Consultant, who required bloods from parents for genetic testing, why I'd had a

blood transfusion. It was forgotten that I had given birth so recently, and experienced a significant haemorrhage. Never mind trying to recover from it whilst catching taxis in London from a hotel to the hospital. To spend hours stood next to incubators. There was no parent accommodation and I couldn't sit in the car for two hours to my home address at this time.

- Robust safety netting for those whose babies are admitted to Neonatal Care. Safety Netting that considers not only the trauma of parent and care-givers' own baby's journey through Neonatal Care, but also the vicarious trauma that is experienced beyond the bay your baby occupies on the ward. The Fourth Trimester is a critical time and support should be being offered universally. This is a life changing period of our lives. Why are we too often forgotten? If clinicians do not signpost to psychological support and recognise this is a highly challenging and frightening time, the effects of it can be minimised. Parents and care-givers can perceive this as 'I should be coping.'
- Parents and Care-givers always being viewed by clinicians as part of their child's plan and I believe, that we are crucial to our child's recovery. Equitable partners. Not knowing your child ever, beyond the hospital environment, can lead to a state of vulnerability and thinking you are inferior and entirely helpless, however, being part of the team, fully informed and held in high regard, empowers you as a parent and care-giver and can even lessen the gap you feel between yourself and your baby.
- There is a critical importance that those who are able to reflect on their own experiences of Pre-Term birth and Neonatal Care, are actively heard and thus, drive forward the planning of Maternity care, and Family Centred Care and Neonatal Family Engagement. Representation matters and currently, this area is fiercely under-represented and spoken about too little.

I always come back to, on paper, I should have had all of the resilience and skills to weather the pre-term birth of my children and their hospital stays. I didn't. I was vulnerable and fearful for all three of our lives during their birth, and for their lives, every hour of every day, of their hospital stay.

Birth happens every minute of every day across this country. It doesn't in our own lives. The birth of our children is remembered and carried with us for forever. To even begin to understand our path, I'd like the committee to consider,

'What if the day your child was born, was one of the worst and most frightening days of your lives?'

So let's reframe this. Allow those who have experienced pre-term births and navigating life after to be experts by lived experience. Allow us to shape more trauma informed, compassionate, and intuitive care for all. Allow us to tell you what we need and what our wishes are. Please don't assume this. Allow us to be equitable partners in our own maternity and post-natal care, and in our babies' care also. Make it always personalised. Allow us to also represent those who walked with us but whose babies came and didn't stay. Allow us to tell their story because they still don't feel they are able to. Allow us to have a platform to ensure more people do not have to endure what we have.

Please know the birth of my 677g and 500g babies will make a change. Their strength, determination and fire meant they survived every critical step. But as their mother I will always wish, they never had to fight. And I will always wish my body had never made them be born early.

In February 2024, The Patient Safety Hub kindly gave me a platform to discuss my views on the gap between Maternity and Neonatal Care, from the perspective of the high risk pregnant woman. I have summarised parts of this within the body of this letter, and I have also attached the full article (my own content) and where it can be accessed on the

internet, as an Appendix to this letter. I believe every word of this article is relevant evidence for the committee too, as I make clear recommendations from my perspective.

Appendix

Article published on Patient Safety Learning – The Hub 19th February 2024

(<https://www.pslhub.org/learn/patient-safety-in-health-and-care/high-risk-areas/maternity/women-who-experience-high-risk-pregnancies-are-too-often-forgotten-when-their-babies-are-born-r10974/>)

Women who experience high-risk pregnancies are too often forgotten when their babies are born

Intro

In this long-read article, Abbie Mason-Woods talks about her experience of having a high-risk pregnancy, pre-term birth and two baby girls in a Neonatal Intensive Care Unit (NICU).

Abbie shares her deep insights as a patient and parent, highlighting the importance of trauma-informed, person-centred care throughout the care pathway, and the risk in forgetting the mother.

Main content

I'm Abbie Mason-Woods and in late 2021/2022, I experienced a high-risk pregnancy with my identical twin girls. The girls were born at only 27 weeks plus 5 days gestation, weighing in at just 677g and 500g, and spent twenty weeks in a Neonatal Intensive Care Unit (NICU).

On paper, I had my career as a Designated Safeguarding Lead and qualified Family Worker in Education, a First-Class degree in Childhood

Studies, and a confidence to always advocate for the right support, at the right time for families. The cloak of vulnerability that fell upon me however, when I found myself pregnant with twins and navigating a high-risk pregnancy, pre-term birth and twenty weeks in NICU, was beyond paralysing.

Beginning to process and reflect

Clarity.

The journey to bringing home my pre-term twins had in fact started long before I walked through the NICU doors for the very first time, as their mother. I realised I had once been the patient too. A 'high risk' pregnant woman who had been told at 22 weeks pregnant that it was very possible my pregnancy could end in stillbirth because of its complications and difficulties. Weeks followed of careful considerations about options and expectant management of the pregnancy, the tertiary care miles from our local hospital, multiple scans, and too many bloods and blood pressure checks to count.

Pre-eclampsia led to pre-term birth and early delivery at 27 weeks with an emergency caesarean section, a blood transfusion, a week's stay in hospital, and my babies now separated and in two different hospitals. Only one remaining in the same hospital as myself. Quite the list of events.

And then I was discharged.

From patient to 'NICU mum'

I took up watch now at the side of my girls' incubators instead. It was all I could do as a 'NICU Mum'. Watch on as between them they endured extended periods of mechanical ventilation, emergency, and planned surgeries, including lifesaving surgery for a bowel perforation, a stoma

reversal, laser eye surgery for retinopathy of prematurity (ROP), blood and platelet transfusions, episodes of sepsis and many other clinical events. They now were the high-risk patient, and I was simply the patients' mother. Helpless as they fought for their lives.

I'd never 'mothered' before. As a first-time Mum, I wasn't acutely aware at this time of how different all of our 'firsts' were in those first few months, but I did feel like I had been mis-sold 'motherhood' somewhat. I hadn't had a term baby, who had been placed immediately upon my chest, no car seat photo as we all left the hospital together within a few days, no family being able to rally round us in a 'baby bubble', as we soaked up newborn snuggles. NICU was my third and my fourth trimester. It certainly didn't feature in a leaflet in an antenatal clinic. I spent many hours hoping they would live and eventually come home.

Forgotten but needing support

Disconnect.

I noticed that I had existed in two very different clinical systems and played two very different roles. Once I had been the patient and then I became the person giving consent for the patient to receive care and treatment. Maternity and neonatal existed in isolation from each other. Maybe partly due to my babies being in the NICU that wasn't at the hospital I gave birth in, or maybe each thinking the other would 'catch' us, there was a striking realisation that there was no connectedness between the two.

I was in a transitional state. I wasn't ready to be discharged and become 'just' the parent. It became clear to me that the overwhelming feeling of paralysis as I stepped through NICU with the girls for twenty weeks was because the cortisol rushing through my body had long run out. The fight or flight mode I was in was exhausting and the lethargy I felt entirely overwhelming. My body trying to repair after major surgery and a

complicated pregnancy, whilst travelling miles to my babies, expressing breast milk, remembering to eat and drink, and watch on as they fought for their lives. Navigating the twists and turns of NICU with very small neonates, the future was entirely unknown.

Each hour unpredictable. It all cumulatively took its toll. Whilst my mind was often still trying to process the clinical decisions that I needed to make at just 22 weeks pregnant, my body stood next to my baby being mechanically ventilated and requiring 1:1 nursing.

So, was this abandonment intentional? No. Each clinician, from the tertiary Hospital I gave birth in to the NICU did their absolute very best to ensure I gave birth safely and our girls made it home. Nobody intended to 'forget' about me; however, systemically, I had been forgotten. Complicated paths such as this can lead to cumulative trauma and to mitigate this a support must be built in in at each stage of the pathway.

Supporting women who spend their post-partum period in NICU

Safety netting for high-risk pregnant women, through birth and beyond must be robust and rigorous. These are life changing moments for parents, carried with us forever. Without considerate and informed care and support, patient safety can be compromised both physically, mentally and emotionally.

The specific needs of women whose post-partum period is spent in the NICU must be considered. For example, care for the physical aftereffects of birth, such as checking stitches or blood pressure, often means having to walk back into a maternity unit surrounded by pregnant women and women who are able to take their baby home immediately. This can be incredibly painful emotionally which could prevent some women going back. They may also not wish to leave their baby while they receive aftercare.

My GP surgery at home had no understanding of what was happening in the Level 3 Surgical NICU unit my daughters were in. Despite receiving my discharge paperwork from the hospital I gave birth in, when they called to arrange our '6 week check-up', a receptionist advised me that if the babies were home it would be with a GP. They repeatedly asked me when the babies were going to be discharged. When I said I didn't know, trying to swallow the lump in my throat, the receptionist had to ask a colleague and told me that if there were no babies to check it would be a healthcare assistant 'to check your stitches.' Thus, demonstrating the lack of connectedness and understanding between the settings and assuming each post-partum woman fitted into a one-size-fits-all care plan.

Cumulative trauma builds at a significant moment in our lives and diagnoses of an array of maternal mental health conditions, such as postpartum depression or post-traumatic stress disorder, may follow. It is important to consider not only the experiences parents and caregivers have with their own baby, but also vicarious trauma, from the other events you witness and experience during time spent on NICU. Parents who have experienced time on a NICU Unit are 50% more likely to experience psychological distress, than parents who haven't - [Is it common for parents to struggle with their mental health? | Bliss](#)).

The care provided should ensure that protective steps of support are in place universally to minimise the effects of this.

Embedding protective factors

Universal but tailored support

I don't think there can be an 'ideal' as such. Each situation and circumstances are different. We as individuals differ too, notably my husband's experience of NICU and his feelings differ greatly to mine. Care is required to be personalised, trauma informed and intuitive. There are multiple contact opportunities with high-risk pregnant women owing to

care and appointments being more frequent. These should provide support, signpost to appropriate information and, ultimately, 'catch' the patient.

I think it is important that we acknowledge that support should be universal here, not just for those who may have been identified as 'vulnerable' because of a particular factor, such as a previous mental health condition. Universally providing support means that the patient feels empowered with knowledge. There is also great comfort in knowing that clinicians recognise that medical events or experiences can be challenging physically and/or mentally, and that there is support for you if you need it. Without this, patient experience is minimised, and clinicians can appear de-sensitised. The patient can be left feeling that they should be coping and that this is the shared expectation.

Kind and compassionate communication

For parents who experience NICU there is a continued need for these opportunities and offers of support throughout their child's stay. Kind and compassionate language, care that is sensitive to a family's needs and pathway to the 'here and now', opportunities to ask questions or gain a deeper understanding of what your child needs or is experiencing, collaboration and involvement in your child's care, and decision-making opportunities. All examples of protective factors that can be implemented and that also offer the parents some control back within an uncontrollable situation. A shared understanding between clinicians and families of the feelings associated with spending a third and/or fourth trimester in a NICU is important too. Fear, helplessness and guilt are some of the 'normal' feelings associated with experiencing a NICU stay. There is definitely a feeling of safety knowing what you are experiencing is 'normal' for the situation you are in.

Primary post-partum care

Beyond hospital care, primary care has its role to play too. Navigating trauma and its after-effects does not always happen immediately and this needs to be recognised. Trauma-informed care throughout all settings means that appropriate support can be provided at a time that is right for the individual; it is never too late to be given the choice to receive support. This will demonstrate that the experience is not simply compartmentalised within each setting but that the pathway is connected throughout. This pathway should also include robust follow up for post-partum physical care.

Using patient insight for change

I think that too often, patients can feel that if they provide feedback and reflection on what they wished for, or needed but didn't receive, during their care, it may lessen the gratitude towards clinicians. It doesn't. Our insight can shape care for the better, making it more efficient and safer. Patients should be telling their story just once and the pathway actively listening, responding to patient choice, working collaboratively and intuitively based upon individual needs and wishes. This will empower patients and their families. Universal, unconditional, trauma-informed care and connectedness provides universal safety.

26 March 2024