AIMS For a better birth...

What I wish I'd known about NICU: Raising awareness in antenatal education

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By Hannah Thomas

I used to think that special care was just for premature babies - but the majority of babies who receive neonatal care are actually born full term. 60% of babies[1] in NICU are full term (after 37 weeks) and may need support due to infection, issues with breathing, feeding, jaundice or lack of oxygen to the brain.

Around 1 in 7 babies born in the UK are admitted to a neonatal unit. Having an awareness of what to expect and how to feel empowered would help parents cope and lessen their trauma if their baby does need medical care, so I am urging antenatal teachers to include special care in their conversations with birthing families - as 1 in 7 of those babies will need it.

NICU isn't just for premature babies

I really enjoyed being pregnant. Right from the beginning, I felt fulfilled in a way that I'd always longed for. It felt as if I was living my purpose - that I was doing what I am on earth to do. But mixed with that certainty, was a lot of self-doubt, deep wounding and unhelpful conditioning from my childhood, that I wasn't aware of at the time.

I threw myself into learning about positive pregnancy and physiological birth. I had one-on-one hypnobirthing sessions, I read stacks of books, joined groups online, created a vision board, painted affirmation posters, wrote our own hypnobirthing script, practised prenatal yoga at classes and at home, stuck affirmation cards all round my desk at work; we engaged enthusiastically in our antenatal classes and doula sessions, went to breathing and visualisation classes, did pregnancy meditations, had acupuncture, and listened to pregnancy and birth podcasts every day.

Until I became pregnant, I had the same conditioned view of birth as most women in the developed world (as a painful, terrifying, medical event) - and everything I learnt to the contrary was wonderful and enlightening and amazing. I felt so excited and blessed to be the kind of person who seeks to educate myself so that my baby could have the kind of beginning every child deserves.

But as it turned out, the Universe had other plans. After a healthy 'low-risk' pregnancy, labour started spontaneously during my 42nd week. After 36 hours of relentless back-to-back labour at home, there were concerns about her heart rate and we were transferred to hospital where, after an emergency forceps birth, my baby daughter ended up in NICU for 10 days with Meconium Aspiration Syndrome.



It was three days until we had confirmation from a doctor that she would definitely come home. Three days where we didn't know if she'd live. It was three days until I could hold her, still attached to loads of wires. Five days until I could try to breastfeed her. I will always wonder whether, if we'd asked to speak to a different doctor at first - a more sensitive communicator - we'd have had better understanding and avoided those three days of terror, not knowing whether or not she would survive.

The hospital let my husband stay for five days on the maternity ward with me, and he wheeled me

around. I could barely care for myself and my carefully-prepared postpartum plan with holistic rest and recovery went out the window. My wound from an episiotomy and 3rd degree tear became painfully infected, but when I was examined they said they couldn't see any signs of infection. I persisted and it took three different courses of antibiotics before the infection eased and I was no longer in searing pain.

After the five days we had to travel back and forth to the hospital, but I refused to go home without her, so we stayed at my mother's instead. Leaving her there overnight, not being in the same building, was unbearable. It was like living in a nightmare. On the outside I looked calm, but inside I was screaming, one long drawn-out anguished wail. I had to shut down in order to keep going, and in the process I now realise I had to shut her out too. I've done everything I can in the four years since to help us heal from the trauma, and since the day we brought her home we've never been apart - bedsharing, breastfeeding, babywearing and bonding with skin-to-skin.



Feeling powerless contributed to our trauma

A lot of the trauma I still carry is about her experience in NICU - knowing the fear and pain she would have felt and feeling powerless to help her. Looking back, I can see that not knowing straight away that we were 'allowed' to do certain things for her and with her added to our trauma. We felt helpless, shocked and totally disempowered as her parents.

If NICU had been discussed in our antenatal classes so I'd had an idea of what I could still do, and how I was still the parent and the one in charge, and what to expect - then it would have made the experience less traumatic for her and me. And if our doula had had the tools to help guide and empower us in NICU, it would have made a difference to our experience. I needn't have felt so helpless.



Not being told until two days in that our baby wouldn't like the way we'd been stroking her gently, not being told straight away that I could have been using my expressed colostrum for mouth care to help seed her microbiome, not being told that we could bring in our own blankets for her incubator, not being told that I could have been the one washing her and changing her. There's many more. If antenatal teachers, doulas, hypnobirthing teachers and midwives always addressed the potential for NICU before birth, perhaps I could have known how to still feel empowered and like I was doing everything I could for her even though I couldn't hold her or feed her.



Finding the things you can control

As I was laying alone in the recovery area, surrounded by mothers and their babies, waiting for the epidural to wear off so I could be wheeled down to see my baby for the first time in a box - I took the initiative to start expressing colostrum myself as I knew it was crucial to do so as soon as possible after birth. I may not have got the birth and the golden hour or gentle postpartum period I wanted for us - so I was even more determined to make breastfeeding a success. I pumped religiously every two hours, including through the night, to establish my supply until she was ready to nurse. But when we tried she couldn't latch, and we later had a tongue tie division. Thankfully, nipple shields were suggested and they helped us to breastfeed for two months until we could finally nurse on our own. I feel so proud that I kept pushing to get the support we needed and managed to exclusively breastfeed her despite our difficult start, and went on to feed her until she was three.



What I wish others could know about NICU

1. **You are still the parent - you are in charge**

- In a scary situation it can be hard to remember, but it's so important to know that parents are not visitors - they are partners alongside doctors and nurses - and are still the decision-makers even though their baby needs medical support.
- You can ask for another doctor or a second opinion[2] if you don't feel heard or understood. Make notes during doctor's rounds, and don't be afraid to 'be a bother' - ask as many questions - as many times - as you need to feel you are making informed decisions. Use B.R.A.I.N. (Benefits, Risks, Alternatives, Instinct, Nothing) to make empowered choices for your baby.
- Know that you can call anytime you want an update on your baby and trust your instincts if something doesn't feel right.

2. **You can make a difference to your baby's experience**

- There are ways you can reduce the stress and over-stimulation of the NICU environment for your baby. Even if you can't hold them, you can place still, resting hands at their head and feet to help them feel contained. This is better than soft, feathery stroking movements which may feel irritating and overstimulating.
- You can minimise over-stimulation from noise, lights and smells, and improve baby's environment in other ways such as:
    - partially-covering the incubator with a blanket
    - allowing your baby time to recover after tiring or stressful procedures
    - warming hands and speaking before touching baby
    - not wearing perfume or deodorant so baby can recognise your smell
    - talking, reading and singing to your baby as much as you can to soothe them with familiar sounds
    - providing comfort with breastfeeding or skin-to-skin during procedures if possible
    - bringing in your own things to look after baby like nappies, hat, gloves, and personalising your baby's sleeping space with your own blankets and keepsakes
    - helping to provide comfort to your baby when you have to go by leaving them a soft toy or cloth that you've had against your skin.

3. **You can feel empowered by taking the lead with baby's care**

Don't wait to be offered the opportunity to do things for your baby. Don't assume that you can't do something like hold them, clean them or change them because the nurses haven't offered. Take charge of your baby's care, and be proactive (and pushy!) in asking for support so you can:

• have as much skin-to-skin as possible

• give kangaroo care in a sling or wrap

• understand your baby's condition, needs, medications and treatments

• change nappies

• change bedding and remake the 'nest' to help baby feel contained

• give mouth and eye care with colostrum

• express breastmilk regularly and establish breastfeeding

• manage tube feeding

• be there to support your baby during procedures.



Increasing awareness to lessen trauma

Despite my birth trauma, my passion and belief in physiological birth was not dented, and during my second pregnancy I started creating pregnancy and birth art, which led to making birth education downloads for antenatal teachers, doulas and hypnobirthing teachers to use with birthing families. I'd

love to help lessen the potential trauma for other parents by spreading awareness about why a baby might need special care after birth, and the ways that they can still feel empowered even when their baby is poorly. I've created some free handouts that birth workers can download with a licence to print and share with birthing families, and use as teaching tools to have conversations about NICU antenatally - or to help them support families at the time they are in NICU.

A breastfeeding support lead who runs a NICU parents' support group at North Middlesex University Hospital. recently told me that:

> "The number one subject that comes up in the support group is that people had no idea about NICU beforehand. They all agree that having an understanding of what would happen if their baby was born early or sick would have made their journey easier and less stressful."

I agree it's important to focus on the best case scenario, and to picture positive outcomes and a healthy birth - but I don't feel talking about NICU has to be scary or negative. When the message we're putting across is one of how to be prepared and empowered - no matter how birth goes - then it can only be a good thing. So I urge antenatal teachers (anyone providing childbirth preparation - including midwives) to make it a priority to include awareness of special care in their conversations with birthing families - as 1 in 7 of those families will need it.



Author Bio: In between consciously-parenting two toddlers and healing her own inner child, stay-at-home mother Hannah Thomas creates handmade pregnancy, birth and postpartum education downloads and art for doulas, midwives, antenatal and hypnobirthing teachers to print and share with clients - as well as original watercolour artwork and gifts.

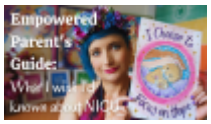
Hannah's aim is to make illustrations, handouts and posters that are easy for other non-medical people to understand, and focus on the physiology of birth and holistic comfort measures rather than the common medical view of pregnancy and birth - to help empower others and spread good news about the magical journey from womb to world.

Find her @wombtoworldart on Instagram and Facebook andwww.wombtoworldart.com

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Editor's Note: Hannah has also created a wonderfully empowering video in which she shares ways in which parents can be intimately involved with their baby's care from the first day.

https://www.wombtoworldart.com/products/-c153181718



For those of you who may be wondering about the high number of babies that spend time in NICU and are concerned about the harms done by unnecessary separation of the mother and her baby, one NHS source says the admission of term babies to NICU could be reduced by 20%. https://www.england.nhs.uk/mat-transformation/reducing-admission-of-full-term-babies-to-neonatal-units/).

Other admissions of term babies may be iatrogenic (the result of medical treatment). Caesarean births, and induced or accelerated labours, increase admissions to the NICU (especially in early-term babies born before 39 weeks), even when these procedures were not medically indicated.

https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8074312/;
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC7268653/;
https://obgyn.onlinelibrary.wiley.com/doi/full/10.1111/aogs.13511;
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6207096/

1 Bliss (accessed 2023) Statistics about neonatal care

https://www.bliss.org.uk/research-campaigns/neonatal-care-statistics/statistics-about-neonatal-care

2 Editor's note: "Doctors guidelines say they must respect your right to seek a second opinion. But you don't have a legal right to one." https://www.cancerresearchuk.org/about-cancer/treatment/access-to-

treatment/different-doctor-second-opinion