

Bliss briefing: Co-ordination between maternity and neonatal care



March 2024

Summary

- Fifty per cent of inpatient mothers said they weren't as involved in their baby's care as they wanted to be while they were in postnatal care.
- **Twenty per cent of mothers said they couldn't see their baby** whenever they wanted, even once they were well enough.
- The most frequent barriers to physically being able to be on the neonatal unit with their baby was a lack of physical assistance getting to the neonatal unit and the need to be physically on the postnatal ward for meals and medication.
- Mothers **rely on their partners or other friends/ family members** to take them to the neonatal unit, usually in a wheelchair – this is not a sustainable solution when partners/support people cannot be at the hospital all the time.
- A lack of co-ordination of care between the postnatal ward and neonatal unit can be a barrier to seeing their baby, even when they are well enough, and some mothers compromise their own care to be with their baby.
- Communication while an inpatient was really important to the experience and involvement of parents.
- 16% of inpatient mothers told us they were **"never" kept informed** about their baby's condition.
- There was **no protocol on the postnatal or neonatal wards for relaying information** between NICU and postnatal ward.
- Being on the postnatal ward without your baby can have a serious mental health impact
- While sometimes unavoidable, if a baby is transferred without the mother, this can be a very traumatic time.

About Bliss

Bliss is the UK charity that champions the right of every baby born premature or sick to receive the best care. We achieve this by empowering families, influencing policy and practice, and enabling life-changing research.

About Neonatal Care

1 in 7 babies born in the UK is admitted to neonatal care. Neonatal care is the type of hospital care a baby receives if they are unwell in the first 28 days of life. Babies are admitted to neonatal care shortly after birth, either because they have been born prematurely (before 37 weeks of

pregnancy) or at full term but sick. For example, they might have an infection, difficulty breathing or a genetic condition.

These babies are among the most vulnerable patients cared for in the NHS: they may spend days, weeks, and in some cases months in hospital, and sadly some never make it home. For parents of these babies, the experience is life-changing. Rather than taking their baby or babies home shortly after birth, they are admitted to a specialist hospital unit to receive care which ensures they have the best possible chance of survival and quality of life.

Co-ordination of maternity and neonatal care- survey

Method: In February and March 2022, we conducted a survey with parents of babies who spent time in neonatal care. This was promoted through Bliss social media/newsletters and other charity organisations supporting parents of babies born premature or sick. The overall sample size was 1930 with 986 respondents identifying themselves as a birth-giving parent who spent time in postnatal care while their baby was in neonatal care.

Note on language used in this document: Throughout this document we use the term “Mother” to refer to a group of almost 1000 respondents to a survey who identified themselves as being the birthing parent of a baby who received neonatal care (having been born premature or sick) who told us that they received inpatient postnatal care after the birth of their baby. We sometimes use “inpatient mother”, “parent” or “birthing parent” – we are describing the same group of respondents.

Findings:

Fifty per cent of inpatient mothers said they weren’t as involved in their baby’s care as they wanted to be while they were in postnatal care. From the data we have gathered the reasons for this are myriad. Some, understandably, were too unwell to be involved in their baby’s care post-birth. Others were not able to access the support they needed to physically attend the neonatal unit, despite being an inpatient in the same hospital, and many also found that their and their baby’s care was arranged in a way that acted as a barrier to them being involved in their baby’s care.

Twenty per cent said they couldn’t see their baby whenever they wanted, even once they were well enough. The most frequent barriers to physically being able to be on the neonatal unit with their baby was a lack of physical assistance getting to the neonatal unit and the need to be physically on the postnatal ward for meals and medication even if the mother is well enough to go to the neonatal unit.

Physical barriers to involvement in care

Mothers **rely on their partners or other friends/ family members** to take them to the neonatal unit, usually in a wheelchair. This is not a sustainable solution to keep parents involved in their baby’s care. Partners and other support people may only be allowed in during visiting times and may have other commitments outside of the hospital including work and looking after older children. A reliance on partners to physically move mothers around the hospital can also discriminate against single mothers. Alternative help was often not available.

When inpatient mothers could leave the postnatal ward, many physically struggle to get to the neonatal unit unaided and reported that help was often not available. Parents told us:

"I had a section so was in pain and my husband was at home with our other child so I didn't have anyone to take me down to neonatal to see my baby until I was well enough to walk down there myself."

"I couldn't walk far following a c section. I would have to wait for a porter to take me to the unit which took a long time. Then I couldn't move around the unit as the porter would leave but my babies were in different rooms. I ended up just walking even though I was in pain."

"I had a c section so found it difficult to walk around as much as I'd liked to have been there. I had to wait for a nurse to be free to take me in a wheelchair and sometimes I'd be waiting up to an hour."

"Couldn't see him for nearly 24 hours as husband needed to leave overnight and there was no porter available to take me there in a wheelchair (unstable blood pressure and dizziness)."

Without any planning for parents who can't stand, mothers report that it can be difficult to be physically involved while recovering from birth – even if they are able to get to the unit.

This was a theme for able-bodied women post-birth but is also concerning for mothers who are already in a wheelchair or cannot stand for long periods, regardless of whether they are an inpatient at the hospital or not, in being able to be involved in their baby's care more broadly.

"Due to having an emergency c section I was unable to walk to the unit and be able to stand long enough without being uncomfortable or in pain, therefore I was unable to be as involved as I couldn't reach into the incubator or change their nappies."

"I had cannulas in the crook of my arms so couldn't hold my son, also had a c section so couldn't get up and down plus picked up an infection."

"I was in a wheelchair and not able to stand well so I could only sit and watch for about 1 week. I had to stand to put my hand in which was hard."

Co-ordination of care as a barrier to involvement

A lack of co-ordination of care between the postnatal ward and neonatal unit can be a barrier to seeing their baby, even when they are well enough. For example, they must be on the postnatal ward for ward rounds, medication, and food – timings of which cannot always be predicted and therefore can take mothers away from the neonatal unit for many hours during the day.

"I had raised blood pressure and was on set times medication. I was always waiting for the nurses to give me the medication before I could go to my baby and then had to go back down when they were due again. The nurses would never come up to the neonatal unit to give these to me so I didn't lose time with her."

"I was readmitted with retained products. I spent days waiting for a scan, the day/time was never confirmed so it was time I was sat on a ward when I could have been with my baby. I was always going back for doses of IV antibiotics and observations. I spent another day waiting for an operation. I wasn't given a time so I had to wait all day until almost 5pm. Again, it was another day I could have spent with my baby. Better communication about time slots for scans/theatre would have been appreciated so I could come back to the ward for these things and not miss them or time with my baby."

Mothers therefore face a choice between **compromising their own care** or not being with their sick baby in hospital.

"I just had to power through with no help and not much pain relief. There was never anyone to take me from post-natal to the unit so less than 24 hours after a C-section I was walking myself up there. Taking my expressed milk, being on the unit meant I often missed drug rounds and would then wait a long time for pain relief."

"When I was visiting the neonatal ward I kept missing the round of my painkillers so was in a lot of pain."

"I had a c section and wasn't able to walk the distance to the NICU however the midwives were too busy to take me in a wheelchair so I had to wait for my husband to be allowed in in visiting hours to wheel me over. After the second day I walked to and from the wards causing myself immense pain and slowing my recovery because all I wanted to do was to see him and be by his side."

"I neglected my own health and pushed myself too hard as I had to get up and walk to the NICU myself due to short staffing. Being in the NICU all the time also meant that I kept missing all my meds and meals as I wasn't in my bed in transitional ward."

Communication

Communication while an inpatient was significant to the experience and involvement of parents. 16% of inpatient mothers told us they were **"never" kept informed** about their baby's condition and 23% of inpatient mothers were only "sometimes" kept informed about their baby's condition.

Often it seems there was **no protocol on the postnatal or neonatal wards to relaying information** between NICU and postnatal ward – mothers describe needing to repeatedly ask for information about their baby's condition, and generally, it appears that their partner or other family member would be their only source of information. This support can be inconsistent, their partner or support person is unlikely to be able to be at the hospital all the time, particularly if they have older children or if restrictions on visiting are in place.

Parents overwhelmingly felt that they did not receive adequate communication about their baby while they are unable to be with them in the neonatal unit.

"There was no communication. I was stuck in a bed unable to move. It was like I hadn't had a baby!"

"Due to having covid I wasn't allowed to see my baby for 7 days, which in itself was very traumatic [...]. I also felt very uninvolved, and nobody actually communicated or explained anything to me about what was happening with my baby except for my partner. I was just given a breast pump and told to provide milk, I was offered no support or information about what was happening."

"I had no idea where in the hospital he was. Nothing was explained to me. I wasn't taken to the post-natal ward so I didn't know how to get to him to see him."

"Couldn't always get there. Would ask them to ring and see how he was. Barely got a response."

"When they took my baby from the delivery room I had no idea of his health, where he had gone or when I would see him next. Eventually, I could go to see him but was required to be back at certain times for check-ups/monitoring. No updates on my baby were available to me when I was on the postnatal ward."

"I did not see my baby for the 1st 48 hrs of life which was very hard, and no updates were given."

"I was on a different ward, and it seemed the ward I was on and the Neonatal weren't in contact. If I asked how my son was the nurses weren't aware."

Mental health impact

The mental health impact of being left on the postnatal ward while your baby is in neonatal care can be severe. Parents told us:

"My baby was not by my side which affected bonding and mental health. I had to hang around for midwife checks and in turn missed important doctors rounds for my daughter."

"I felt like I was left after the birth and no communication about the baby. I had to find NICU myself no one offered to help me it was quite traumatic."

"Physical health needed to be monitored as I was at high risk of blood clots and developed some large clots from the placenta. This meant time away from the babies. My mental health suffered while in hospital as I was processing a lot of guilt from the early birth. Also, I couldn't be next to my babies like other mothers on the recovery ward so that affected my mental health."

Transfers

While it can be unavoidable but extremely traumatic when a baby is transferred to a different hospital than the one where the mother is being treated. Respondents told us about being desperate to be transferred so they could see their baby, wanting to be discharged so they could be with their baby at another hospital and discharging themselves – with detriment to their treatment and health – if they couldn't be transferred.

"I begged the nurses to transfer me to where my baby was, but they "couldn't" do it. No one kept me informed about how he was doing. No one asked me how I was coping after having a baby at 24 weeks. I mentally shut off from the fact I had just had a baby and just focussed on getting myself in a condition to be discharged so I could get to him...[I] had to sign off on donor milk at first as no one even asked me or helped me to express straight after the birth. I was first given a pump a day after the birth."

"As my baby was moved so soon after birth I was discharged within 5 hours of having her. Having to travel to another hospital impacting my ability to heal probably as I had an episiotomy and there weren't any toilets in the neonatal unit and it was a long walk to the nearest ones."

"I was told I couldn't be moved hospitals to be with my baby so I said I would discharge myself so they instead transferred me to the same hospital as the baby and admitted me to the ward there."