

Families kept apart: Parent accommodation on the neonatal unit in England

infant
focus

Bliss, the charity for babies born premature or sick, has launched a campaign to highlight just how important it is for parents with a baby receiving neonatal care that they are able to stay with them overnight. Despite the importance of parental accommodation being acknowledged by policymakers, for example in the *Getting It Right First Time* report and the NHS long-term plan, challenges persist.

Maya Parkin Campaigns and Policy Officer, Bliss, mayaparkin@bliss.org.uk.

Bliss published research in England revealing that not enough parents have the opportunity to consistently stay overnight with their baby in neonatal care. This is a barrier to family integrated care (FICare), as parents cannot be true partners in care if they cannot be on the unit 24 hours a day every day.

In this article, we set out our findings and recommendations for national policymaking and share practical advice for services to support parents to stay overnight on the neonatal unit in order to maximise their involvement in care. This article focuses on our first policy briefing for England; further briefings addressing the needs and recommendations specifically for Wales and Scotland will be published later in 2024.

Why should parents have routine access to overnight accommodation?

Bliss research from 2022 showed the barriers that parents face in being involved with their baby's neonatal care. In our survey, 87% of parents said that the lack of accommodation on units stopped them from being involved in their baby's care, at least sometimes.¹ Three-quarters of parents said they did not have access to overnight accommodation when their baby was critically ill. These findings highlight that neonatal services are not currently providing the basic facilities parents need to be partners in their baby's care.

"It was torture and the most heartbreaking time leaving our baby each night ... we were offered one night of accommodation in the hospital." Mum to a baby born at 33 weeks.

Many parents tell us that being able to comfort or feed their baby during the night is a crucial part of being meaningfully involved in their care. Moreover, evidence shows the numerous

benefits to babies of receiving a family integrated model of neonatal care. Parents supported to be with their baby for prolonged periods report increased parental confidence and reduced stress and anxiety scores.² Providing direct, hands-on care allows parents to feel like parents – which evidence shows is key for their perceptions of attachment to their baby – and physical and emotional closeness is crucial for forming strong parent-infant bonds. Research also underscores the positive outcomes of FICare for babies, including improved infant reflexes at term and better gross motor development at four to five years.³ Inadequate accommodation hinders the delivery of this model, while provision of suitable parent accommodation on or near the unit allows parents to play a full hands-on role in their baby's care.

"Being in the flat [in the NICU] meant I could spend as much time as I possibly could with Alice ... finding every small way possible to bond and be her mum". Katherine, mum to Alice born at 39⁺ weeks.

Previous Bliss research has also found a huge additional financial cost to the parents of having a baby in neonatal care, which we estimate to be £405 per week above usual expenditure.⁴ The largest proportion of this additional cost was daily travel to and from neonatal units. Parents being able to stay overnight could relieve some financial burden alongside enabling parents to be more involved in their baby's care.

What does accommodation provision look like in England?

To understand what facilities neonatal units currently provide for parents and what barriers they may be facing to improve these, we conducted a survey of Neonatal Operational Delivery Networks

For further information: Sign up for the FREE accommodation webinar, taking place in September.

Access resources and learn more about FICare by visiting www.bliss.org.uk/health-professionals/family-integrated-care.

Bliss' Baby Charter also provides a clear set of standards to support parental involvement in care:

www.bliss.org.uk/health-professionals/bliss-baby-charter

The website also provides a wealth of information for parents about all aspects of their baby's neonatal journey:

www.bliss.org.uk/parents/support

between November 2023 and January 2024.

In the responses to our survey, across the neonatal units, 350 rooms were identified where both parents can stay on the unit. Out of 2,778 reported cots across 140 units, this is only 13 per cent of babies who can have both parents stay in a room overnight on the unit. This means that 87% of babies cannot have their parents stay in a room overnight on the unit – that is nearly nine in 10. It was welcome to note that the number of parent bedrooms where both can stay overnight (350) did not differ significantly from those where only one parent can stay (371).

Disaggregating the number of parent bedrooms by designation shows that only 9% of babies on a NICU can have both parents stay in a room overnight, compared to 15% and 16% in local neonatal units and special care units respectively.

A third (34%) of units reported having access to rooms for parents nearby but outside the neonatal unit. These rooms may be on another ward or provided by a charity.

Just over half (56%) of units had temporary beds such as reclining armchairs or fold-out beds next to at least one cot. Therefore, the short-term accommodation options are also limited.

Only 17% of units allow siblings to stay overnight, but health-care professionals told us this is usually only permitted in exceptional circumstances. However, having space for siblings to stay over the weekend, for example, is important for family bonding and eases the logistical challenges of childcare that parents tell us are barriers to spending time with their baby in neonatal care.

What are the barriers to improving accommodation?

We asked respondents to tell us about the barriers their units face to providing parents somewhere to stay overnight. Those completing the survey were asked to select the biggest barriers from a list of options. All respondents said that the biggest barriers to providing parents somewhere to stay overnight were:

- lack of capital investment to build overnight accommodation for parents;
 - lack of physical space on the unit and on the Trust estate to build overnight accommodation for parents;
 - lack of physical space on the unit for temporary beds.
- We also asked respondents to list three priorities for spending to improve accommodation. The most common priorities, identified using thematic analysis were:
- access to capital funding for increasing unit footprint;
 - access to grants to upgrade existing facilities, ie laundry, kitchen and dining, counselling areas, bathrooms, sitting rooms and sibling play areas;
 - financial support for all families for things like meals, travel, and parking.

The final question asked for any further comments on the issue of accommodation. Topics raised that are not already reflected above include:

- current standards for the provision of accommodation are not fit for purpose and do not encourage investment in facilities to support FICare;
- policies about who can stay cot-side include risk assessments and eligibility criteria, which may exclude vulnerable families with safeguarding issues, reducing equality and access to care;
- infection prevention and control guidance is not consistent between Trusts, so purchasing furniture for overnight accommodation for parents is difficult.



A lack of accommodation on units stops parents from being involved in their baby's care.

What is the urgency for improving accommodation?

We asked respondents to tell us if there are plans to reconfigure, renovate or rebuild in their network and found that around one-third of units already have plans for future works.

Respondents shared whether they think their units will be able to fully support an increase in parental presence following the introduction of new Neonatal Care Leave and Pay entitlements in April 2025. While we very much welcome, and have campaigned for, this new entitlement, 67% of survey respondents do not believe they have this capacity with their current facilities.

Recommendations for policymakers

The issue of a lack of overnight accommodation is not an easy or cheap fix, but the need is pressing. We would like long-term investment from the Government to address these problems and create an NHS estate that ensures that babies can have their parents with them throughout their neonatal stay. We recommend:

- 1) NHS England should update the guidance in the Health Building Note that units should have one parent bedroom per intensive care cot and ensure that Trusts are held to account to provide accommodation in line with the guidance.
 - 2) NHS England should develop a small grants programme so that Trusts can apply for funding immediately to buy new furniture or equipment to improve the neonatal environment and provide parents with the facilities to support them being partners in their baby's care, including the purchase of pull-out beds, comfy chairs or privacy screens.
 - 3) The Government must identify the capital investment required to bring all parent accommodation up to a minimum standard on neonatal units.
- "There are so many little things that would benefit parents ... things like access to parent toilets on the ward so we don't have to wait to be buzzed in and out."* Jessica, mum to a baby boy born at 31⁴⁵ weeks.

How can parents be better supported?

While a lack of funding persists, there are ways that neonatal units could support parents.

1) Communicate accommodation options with parents when they arrive on the unit

Parents often tell us that they aren't aware of what accommodation options are available to them until later in their baby's stay in hospital, and this is sometimes only from talking to other

parents on the unit. Being able to stay overnight on the unit from the moment their baby is admitted can be transformative for parents' involvement in care.

"I had to leave my baby daily to go home even though there were empty rooms, because I lived close. It was only when I complained about my son's care I was allowed to stay." Tasha, mum to Teddy born at 26⁺ weeks.

We hear from some healthcare professionals that they lack confidence to offer accommodation to parents, knowing that they may have to ask them to leave after a couple of nights. Acknowledging this challenge, we strongly recommend the nurse in charge has a conversation with parents when they arrive, about their individual needs and what accommodation is available on or near the unit.

Families who live further away from the hospital or whose baby has a long stay may prefer accommodation outside of the unit, in a hospital-owned flat or a charity-run building. These may be more spacious with well-equipped facilities, like kitchens and showers, and allow siblings to stay for the weekend. Other parents, particularly those whose babies are critically ill, may want to stay on the unit, for example in reclining chairs or pull-out beds.

As well as discussing where parents can stay overnight, we recommend informing them of other ways to reduce their financial burden. For example, neonatal units may offer free meals and/or parking vouchers.

2) Championing FICare for all parents

From the moment they arrive on the unit, parents should know that they can be equal partners in their baby's care. The model of FICare enables and empowers parents to become confident, knowledgeable and independent primary caregivers.⁵ When the importance of being involved in their baby's hands-on care is clearly communicated, parents may be more likely to utilise available overnight accommodation.

Certain groups of parents are more likely to face challenges to being involved in their baby's care. For example, our research found that fathers do not receive the same level of training and information as mothers.⁶ Sometimes, even the basics like a chair for them to sit at cot-side are missing.

In 2022, Bliss research looking at the experiences of South Asian families with a baby in neonatal care found that cultural

assumptions may make it harder for fathers to participate in care; 50 per cent of survey respondents had to ask permission for skin-to-skin; and parents who did not speak English as a first language were more likely to report poor experiences.⁷

Neonatal units should routinely have conversations with parents, as early as is practical after admission, about barriers that might stop either or both parents being present on the unit. They should work with parents to ensure they can be as involved as they want to be. Units need to develop clear strategies for supporting groups of parents who may typically struggle to engage.

Summary

Parents being fully involved in their baby's hands-on care and decision-making improves outcomes for babies born premature or sick. However, parents face a significant obstacle of not being routinely provided somewhere to stay overnight on the neonatal unit. There have been clear national commitments to make improvements in this area, but these are yet to be delivered on. We are urging the Government and NHS England to act to ensure that parents are not forced to endure the trauma of having to leave their newborn overnight. Neonatal services, and the staff who work in them, can also support parents by communicating what accommodation is available when parents arrive on the unit, and by empowering parents to be partners in their baby's care.

References

1. **Bliss.** Families kept apart: Parent accommodation on the neonatal unit in England (2024) online at: www.bliss.org.uk
2. **O'Brien K, Robson K, Bracht M et al.** FICare Study Group and FICare Parent Advisory Board. Effectiveness of family integrated care in neonatal intensive care units on infant and parent outcomes: a multicentre, multinational, cluster-randomised controlled trial. *Lancet Child Adolesc Health* 2018;2:245-54.
3. **Treherne SC, Feeley N, Charbonneau L, Axelin A.** Parents' perspectives of closeness and separation with their preterm infants in the NICU. *J Obstet Gynecol Neonatal Nurs* 2017;46:737-47.
4. **Bliss.** Bliss Briefing: Impact of cost-of-living crisis in neonatal care. 2022 online at: www.bliss.org.uk
5. **BAPM.** Family Integrated Care: A BAPM Framework for Practice. 2021 online at: https://hubble-live-assets.s3.eu-west-1.amazonaws.com/bapm/file_asset/file/793/BAPM_FICare_Framework_November_2021.pdf
6. **Bliss.** Fathers' experiences of neonatal care briefing. 2024. Online at: www.bliss.org.uk
7. **Bliss.** South Asian families' experiences of neonatal care. 2022. Online at: www.bliss.org.uk



infant

**Keep up-to-date with advances in neonatal care:
Sign up for our free email newsletter at
www.infantjournal.co.uk/bulletin.html**

The **essential** journal for neonatal and paediatric healthcare professionals