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# The hidden costs for families in neonatal care

**B**liss, the charity for babies born premature or sick, has published new research about the impact of the hidden costs associated with having a baby in neonatal care, alongside several recommendations for Government and NHS services. These changes are needed to minimise the impact that the soaring cost of living is having on families with a baby in neonatal care, or who has recently been discharged from hospital.

## The hidden costs of having a baby in neonatal care

While NHS services are free at the point of use, this does not mean that there are no financial implications of accessing services. As our findings show, neonatal care is no exception. These hidden costs introduce inequity in family experience and in the care that babies receive, as they are unable to receive the same level of parent-led care.

The costs associated with having a baby in neonatal care are high and prevent parents being with their babies. Bliss has conducted research looking at the financial toll that having a baby in neonatal care can have on families and the impact this can have on them as a family.

## Bliss research

The findings in this article are based on two surveys conducted by Bliss with parents of babies born premature or sick. The first was conducted

in February and March 2022, with a self-selecting sample of 1,928 parents recruited through Bliss social media, email newsletter and via partner organisations. As part of this phase of evidence gathering, we also conducted two focus groups in March 2022 with dads (n=9) and parents who were on a low income/struggled significantly with finances during their baby's neonatal stay (n=5).

The second survey was conducted in September 2022, with a self-selecting sample of 159 parents. 32 respondents currently had a baby in neonatal care and 127 had a baby who had been discharged from neonatal care in the previous 12 months. Respondents were recruited through Bliss social media.

## Findings

In the survey conducted by Bliss in early 2022, the average reported cost was £405 per week on top of usual expenditure.

In the more recent survey, half of parents with a baby currently in neonatal care said that the rising cost of living was impacting their ability to pay rent, bills, or a mortgage. More than half of survey respondents said that finances had an impact on their ability to be by their baby's side, with around one in five saying that finances impacted their ability to be involved in their care 'significantly'.

It is essential that parents can be involved in their baby's care. Babies have the best developmental outcomes when their parents can deliver hands-on care. This includes: feeding, skin-to-skin contact, administration of some medications, changing, bathing and comfort-holding their baby. Evidence shows long periods of direct care, lead to increased weight gain, improved breastfeeding rates, improved infant reflexes at term and better gross motor development at 4-5 years, and reduced pain during invasive procedures.<sup>1,2</sup>

Involvement in care and decision-making is also critically important to parents and contributes to improved family well-being and cohesion. Physical and emotional closeness is crucial for forming strong parent-infant bonds – evidence demonstrates that parents who can be with their babies for long periods of time report increased parental confidence, have reduced stress and anxiety scores. They also report feeling like parents, which may be key for their own perceptions of attachment to their babies.<sup>3</sup>



The soaring cost of living in the UK is increasing the financial pressure on parents with a baby in neonatal care.

## What are families paying for?

### Travel

Travel is the biggest cost, on average, for parents. Respondents to our survey spent £109 per week on average on getting to and from the neonatal unit. Parents using public transport to get to the hospital spent more than those using their own car. Despite spending more on travel, parents using public transport to see their baby are more likely to be in lower income brackets (household income under £25,000). The unaffordable cost of travelling to and from the neonatal unit has a tangible impact on how involved parents can be in their baby's care. 84% of those who used public transport said that access to transport stopped them being as involved as they wanted to be.

### Cost of childcare

While not every parent of a baby receiving neonatal care has older children at home, for those who do the cost of childcare is prohibitively high, stopping those who have older children from spending as much time with their sick baby as they want to.

Despite standards requiring space for siblings in neonatal units,<sup>4</sup> few units have adequate facilities. As a legacy of restrictions to access introduced on neonatal units during the COVID-19 pandemic, facilities for siblings have worsened over the last three years and in some areas, siblings are still not given access to the unit at all.

The average additional childcare costs for those with other children at home was £122 per week. 76% of parents with caring responsibilities outside of the hospital said that this stopped them going to the unit when they wanted to and 83% said that caring responsibilities stopped them being as involved in their baby's care as they wanted to be.

### Food and drink

Parents have little choice over where to buy food and drink while at the hospital and are reliant on expensive hospital canteens and franchises rather than being able to prepare food from scratch or shop around. The lack of choice is exacerbated by limited facilities on neonatal units. The recent Getting It Right First Time (GIRFT) report found more than a quarter (27%) of neonatal units do not provide a parent kitchen, and where facilities are available these are often poor quality.<sup>5</sup> Parents that responded to our survey spent £96 above their usual food budget while their baby was in neonatal care.

### Loss of income

A key challenge for families when their babies are born premature or sick is the loss of income when one or both parents take additional time off work to care for their baby. This loss of income compounds the financial issues of families.

57% of respondents to our survey said that their household lost income during their baby's neonatal stay because someone had to take unpaid time away from work or took on less work during this period. On average, households lost £2,994 in income over the time that their baby was in neonatal care. Many families cannot afford to lose this level of earnings and as a result, in seven in 10 families with a significant neonatal stay, at least one parent (usually dads and non-birthing parents) returns to work while their baby is still sick in hospital.

While the Government is taking action to support employed

parents with this by backing the Neonatal Care (Leave and Pay) Bill currently making its way through Parliament, this will not be in place for some time and, once it is available, many parents will not qualify (eg the self-employed).

### Long-term financial implications

The hidden costs associated with neonatal care in the UK can lead to reductions in the family budget of babies born premature or sick, sometimes pushing families into debt and struggling to pay essential bills like rent or mortgage. One in four families had to borrow money or increase their debt because of their baby's neonatal stay.

### Understanding the impact of the cost-of-living crisis

In autumn 2022 Bliss conducted research into the specific impact of the cost-of-living crisis on families of babies born premature or sick – including looking at how rising energy prices are impacting families whose baby is vulnerable, having been discharged from hospital in the last year.

#### In hospital

- 52% of parents whose baby was still receiving neonatal care said that the rising cost of living was impacting their ability to pay rent, bills or a mortgage
- 84% said it had impacted their ability to pay for travel to and from the hospital
- 87% said it impacted their ability to pay for food and drink when at the hospital with their baby.

In the same survey, parents told us that the cost of travel to the hospital to see their baby stopped them seeing their baby (23%); impacted their family budget (94%); increased their debt (45%); and concerningly, 77% said that the cost associated with going to the hospital was having a negative impact on their mental health.

#### Post-discharge

The problem doesn't end when babies are discharged from hospital. Families caring for a child or a baby who is reliant on medical equipment – such as home oxygen – will use more energy on average to keep their equipment running. There is a serious risk to the health of anyone who uses at-home medical equipment if they must reduce how much energy they are using, or if they can't keep up with costs.

Concerningly, two of the 24 respondents whose babies were currently using medical equipment requiring electricity at home said that the rising cost of energy prices had stopped them using the medical equipment that their baby needed. 47% said they were concerned that the cost of energy may impact their ability to run this equipment in the future.

Babies who have been discharged from neonatal care in the last year are more vulnerable than other babies to serious complications from common colds or viruses, like respiratory syncytial virus (RSV). To help keep babies well it is important that parents can keep their homes warm through the winter months when these viruses are in circulation, yet 74% of parents with a baby who had been discharged in the last year said they were concerned that it was 'somewhat' or 'very likely' that the rising cost of energy could stop them keeping their home warm this winter.

## Recommendations for the Government

### 1) Introduce an emergency neonatal family fund

Bliss calls on the Government to introduce an emergency fund for parents of babies in hospital in England to cover food and drink, travel, parking, accommodation and childcare costs associated with having a baby in neonatal care.

Acknowledging that some parents find it challenging to afford to attend the neonatal unit as much as they need to because of their finances, in 2018 the Scottish Government introduced a Neonatal Expenses Fund (now Young Patients Family Fund). Parents of babies who are inpatients in hospital can apply to have their travel and subsistence costs reimbursed by the scheme. Some parents can access help with accommodation costs in certain circumstances. An evaluation of the scheme in Scotland found that parents reported that the fund relieved financial anxieties during a very stressful period, and helped them spend more time with their babies in the neonatal unit.

### 2) Introduce an emergency energy fund

Bliss calls on the Government to introduce a fund to offer payments to cover additional energy costs to cover any additional electricity needed to run at-home medical equipment and for all families with a baby born premature or sick who is under two years of age to keep their homes warm this winter.

### 3) Make an immediate change to the Healthcare Travel Costs Scheme

Bliss is calling on the Government and NHS Business Services Authority to expand the NHS Healthcare Travel Costs Scheme to give parents access to reimbursement for travel expenses to be with their baby in hospital if they are receiving certain benefits.

Parents are an integral part of their baby's care. However, while parents can claim expenses back for travelling to and from hospital for their own treatment, and to accompany their child if they need treatment, parents of babies in neonatal care cannot currently claim for their travel to be with their baby in the hospital.

### 4) No family to go without essential energy

We are calling on the Government and Ofgem to ensure energy companies cannot disconnect domestic energy support for households that include a vulnerable baby, including those with a baby who needs to power an at-home medical device.

As we have shown, families with a baby born premature or sick face considerable costs/loss of income as a result of accessing the services they need for their baby to have the best chance of survival and quality of life.

## Recommendations for NHS trusts and neonatal units

### 1) Appropriate sign posting

Families report receiving much of their support and signposting from staff on a neonatal unit. Neonatal unit staff should therefore be familiar with community services in their area to support

families on low incomes including baby banks, food banks, the wider financial support available to new families and financial support provided by the hospital (eg hardship grants). The Bliss website has some information about this ([www.bliss.org.uk/parents/support/financial-information-and-support-for-families](http://www.bliss.org.uk/parents/support/financial-information-and-support-for-families)).

### 2) Early conversations with parents

Neonatal units should routinely have conversations as early as practical in the baby's stay about what financial support families might need during their stay and at discharge. Highlighting any needs that are likely to be present post-discharge will ensure early intervention, eg cost of running equipment or taking clothes and blankets home.

### 3) Consider financial support by the trust or health board

NHS trusts and health boards should revisit the support they provide to families. This should include financial support with parking and public transport costs, meals for all families, accommodation provision, etc. Neonatal teams should work with other departments in the hospital, where appropriate (eg accommodation facilities).

### 4) Assess the impact of sibling access policies this winter

Extra childcare for older siblings can cause significant financial strain on families. Neonatal units should review their existing access arrangements for siblings, balancing the risk of infections with the risk that parents may be prohibited from being with their baby if they cannot afford additional childcare.

## Summary

Parents being partners in care delivery and decision making improves outcomes for babies born premature or sick, but the costs associated with having a baby in neonatal care are high and prevent families from being involved as much as they need to be. The Government and NHS bodies must act to ensure that parents do not need to choose between debt or being with their baby and that no family is stopped from being with their baby in hospital by the rising cost of living. Bliss is urging the Government to act now to provide financial support to parents who need it, to ensure all babies get the best start in life, regardless of their parents' financial position.

## References

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