

Bliss briefing: Impact of cost-of-living crisis in neonatal care

September 2022



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 average additional cost that parents who answered our survey had to pay was **£405 per week** while their baby was in hospital
- These costs arise from parents paying for travel to and from neonatal units daily, relying on high-cost food and drink available on site at hospitals, paying additional unaffordable childcare costs, and losing around £3000 in lost income during their baby's stay
- Parents are an essential part of their baby's care-team, but these costs have a clear impact on their ability to be involved in their baby's care, this is particularly true for parents already on a low income
- More than half of parents said that their finances impacted their ability to be as involved as they wanted to be (in early 2022) and the rising cost of living in the UK is increasing the financial pressure on parents with a baby in neonatal care
- Parents whose babies have been discharged from neonatal care recently, are concerned about keeping their homes warm to keep their baby healthy, and about how they will pay for the additional electricity they need to run their child's essential at-home medical equipment
- The Government and NHS Bodies must act to ensure that parents do not need to choose between debt or being with their baby *and* to ensure no family is pushed into poverty by the rising cost of living

The hidden costs of having a baby in neonatal 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.¹

While NHS services are free at the point of use, this does not mean that there are no financial implications of accessing services. Neonatal care for babies born premature or sick 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.

¹ Method: self-selecting survey disseminated through Bliss social media and email newsletters, and via partner organisations in February and March 2022. 1928 respondents. Two focus groups conducted in March 2022 with a) dads (n=9) and b) parents who were on a low income/struggled significantly with finances during their baby's neonatal stay (n=5).

We asked parents what the additional cost to their household was of having a baby or babies in neonatal care. The average cost reported by parents who answered our survey **£405 per week**.

We asked parents what impact this cost has on their access to care. More than half (52%) of respondents to our survey said that finances had an impact on their ability to be involved in their baby's care, with 18% saying that finances impacted their ability to be involved "*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, kangaroo-care (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.

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.

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. Those using a car spent £101 per week on average, in comparison to £119 for those using public transport.

Despite spending more on travel, parents using public transport to see their baby are more likely to be in lower income brackets². This is in keeping with car ownership in the wider UK population, where households in the lowest income bracket are far less likely to have access to a car³.

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, including 23% who said access to transport "*always*" stopped them being as involved in their baby's care.

➤ 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.

² Household income under £25,000

³ Department for Transport, NTS0703: [Household car availability by household income quintile: England](#) (ODS, 25.4 KB)

Despite standards⁴ requiring space for siblings in neonatal units, few units have adequate facilities. As a legacy of harsh 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

The cost of food and drink at hospitals is notoriously high. 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 quality⁵.

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 £2994 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 7 in 10 families with a significant neonatal stay, at least one parent (usually dads and non-birthing parents) return to work while their baby is still sick in hospital.

While the Government are 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 (expected at least 18 months after Royal Assent). Once it is available, many parents will not qualify (self-employed and workers) and will continue to receive no support to reduce the impact on their income.

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. 1 in 4 families had to borrow money or increase their debt because of their baby's neonatal stay.

⁴ Department of Health (2009) Toolkit for High-Quality Neonatal Services

⁵ NHS England (2022) Neonatology GIRFT Programme National Specialty Report

Emergency support needed: Impact of the rising cost of living in Autumn 2022

To understand the impact of the increasing cost of living crisis in the UK 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 year⁶.

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 mortgage; 84% said it had impacted their ability to pay for travel to and from the hospital; and 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.

Babies who have been discharged from neonatal care in the last year are more vulnerable than other babies. They are at an increased risk of respiratory conditions and viruses, including Respiratory Syncytial Virus (RSV).

Post discharge

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.

Families caring for a child with a disability use more energy on average as a result of their child's disability – with energy for equipment and/or heating being a key factor in this⁷. As has been noted elsewhere⁸, there is a serious risk to the health of anyone who uses at home medical equipment if they have to reduce their use of electricity in their home, or if they can't keep up payments for energy.

Some babies born premature or sick who need more help with their breathing will go home on oxygen. This means their breathing will be supported by additional oxygen from a tank which is given to them through a tube in their nose. This equipment requires an electricity connection.

Concerningly, 2 of the 24 respondents whose babies were currently using at home medical equipment that required electricity to run 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.

⁶ Method: Self-selecting sample disseminated through Bliss social media. 168 respondents, 32 with a baby currently in neonatal care, 127 with a baby who was discharged in the last year, 7 disqualified (discharged longer than a year ago)

⁷ Contact, Out of Energy Survey results March 2022 <https://contact.org.uk/wp-content/uploads/2022/04/Out-of-Energy-Survey-ResultsFINAL-March-2022.pdf>

⁸ HSJ (2nd September 2022) 'Life threatening' risk to clinically vulnerable after firms disconnect energy supply, warns NHS chief <https://www.hsj.co.uk/north-east/life-threatening-risk-to-clinically-vulnerable-after-firms-disconnect-energy-supply-warns-nhs-chief/7033112.article>

Recommendations

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.

The cost of travel and subsistence for families of babies born premature or sick are high and these costs are prohibitive to some families being involved in their baby's care. Families, particularly those on low incomes, face an unfathomable choice between being fully involved in their baby's care and getting into debt.

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. Through the 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 as a result of being able to claim

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 2 years of age to keep their homes warm this winter.

In the months and years after discharge from a neonatal unit, babies who were born premature or sick are at a higher risk from viruses such as Respiratory Syncytial Virus (RSV). This year, high rates of RSV have been seen in the population much earlier than previous years (since July)⁹. To ensure vulnerable children are given the best chance of staying healthy in their early years, it is essential that their parents can keep their homes warm through the winter months, when these viruses are in circulation.

Some babies born premature or sick who need more help with their breathing will go home on oxygen. This means their breathing will be supported by additional oxygen from a tank which is given to them through a tube in their nose. It is essential that parents with a child who requires at home medical equipment can pay for the additional electricity needed to run this equipment. While we know parents will prioritise this, some will not be able to keep electricity supply for equipment, others will be pushed into debt to keep their child healthy.

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.

⁹ CAS Alert <https://www.cas.mhra.gov.uk/ViewandAcknowledgment/ViewAlert.aspx?AlertID=103210>

Parents are an integral part of their baby's care. However, they are currently not given the same support with travel expenses that NHS patients are given when attending hospital for their, or their child's, hospital appointments.

The Government and NHS acknowledged the vital part that parents play in their baby's neonatal care during the COVID pandemic, stating that *"parents of babies on neonatal units are not considered to be visitors and should not be treated as such"* requiring Trusts to *"facilitate unrestricted access for parents of babies on neonatal unit"*¹⁰.

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 hospital¹¹.

4) No family to go without essential energy connection

We are calling on the Government and Ofgem to ensure energy companies cannot disconnect domestic energy support for households which 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. As a result, parents find themselves with increased debt, reduced savings and family budget and many struggle to pay essential bills like rent, mortgage and utilities. In the years after their baby is discharged from hospital they require more, not less, energy and are therefore unable to reduce use of heating etc.

It is unfathomable that families could face having their homes disconnected with a vulnerable child who requires medical equipment.

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.

Contact

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¹⁰ NHS England (December 2020), Supporting pregnant women using maternity services during the coronavirus pandemic: Actions for NHS providers, accessed online at: <https://www.england.nhs.uk/coronavirus/wpcontent/uploads/sites/52/2020/12/C0961-Supporting-pregnant-women-using-maternity-services-during-the-coronaviruspandemic-actions-for-NHS-provi.pdf>

¹¹ <https://www.nhs.uk/nhs-services/help-with-health-costs/healthcare-travel-costs-scheme-htcs/>