

Campaign for change: a move towards better facilities for parents

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Scotland
for babies born
premature or sick



It has been a year since the publication of the Bliss Scotland Baby Report *An Opportunity to Deliver Improvements in Neonatal Care*,¹ and of the Scottish Government's own report *The Best Start: A Five Year Forward Plan for Maternity and*

Neonatal Care in Scotland.² Both reports shone a light on the need for more resources, staff and facilities for families in neonatal services to ensure that babies born premature or sick have the best possible start in life.

A significant area of concern in our findings was the number of barriers stopping parents being able to spend as much time as possible with their babies on the unit. For babies and their families to have the best possible outcomes, it is essential that parents are able to be with their baby for long, uninterrupted periods of time in order to bond and take the lead in delivering their care.

There is a multitude of evidence to suggest that the outcomes for premature and sick babies improve when they are able to spend more time with their parents. Kaffashi et al concluded from their study monitoring sleep patterns between babies who received significant skin-to-skin care and those who did not, that those who did had far better sleep episodes and significantly better brain development as a result.³ Similarly, greater parental involvement in their baby's care has been shown by other studies to support brain development and improve cognition.⁴

For parents, being heavily involved with their baby's care also allows them to develop the skills and confidence they need to be able to take care of their child once they are home. Other benefits have also been shown to include:

- improved breastfeeding rates (mothers are more consistently supported on the unit, making it easier to establish breastfeeding)
- earlier discharge from hospital
- reduced re-admission rates.⁵

In order for parents to play this vital role in their baby's care, they need to be supported to be with their baby in hospital. However, the Bliss Scotland Baby Report revealed that most neonatal units across Scotland find it a challenge to provide sufficient overnight accommodation to meet the needs of families. Indeed, three of out of the 12 neonatal units that responded to this question in our survey have no dedicated accommodation for parents whatsoever. Worryingly, two of these units are level three neonatal intensive care units (NICUs). These units care for the sickest babies and it is likely that their parents will therefore encounter the longest and most financially difficult stays in neonatal care. Scotland's geography means parents can often travel a long way to be with their babies, incurring significant costs relating to travel, accommodation, food and drink, and childcare for other children at home (FIGURE 1).

One of the key recommendations of the Best Start report was: "Maternity and neonatal services should be redesigned to ensure mothers and babies stay together."² While this recommendation

supports the findings of our own work, facilities must be in place to enable parents to stay with and be at the centre of their baby's care.

As part of its acceptance of all the recommendations in the Best Start report, the Scottish Government pledged to undertake "an urgent review of the approach to expenses for families of babies in neonatal care... to develop a nationally agreed policy." In November 2017, Bliss launched a campaign asking supporters to email their Member of the Scottish Parliament asking them to write to Cabinet Secretary for Health and Sport Shona Robison to call for immediate investment into neonatal services, including facilities and support for families.

On 22 December 2017 the Scottish Government announced that this would start to be addressed with the creation of a new Family Fund, for which it has pledged £1.5 million to support parents of premature babies in neonatal care with travel and food expenses. In announcing the Fund, Shona Robison said: "Becoming a parent should be the best feeling in the world, but if a baby is born prematurely and needs neonatal care it's an

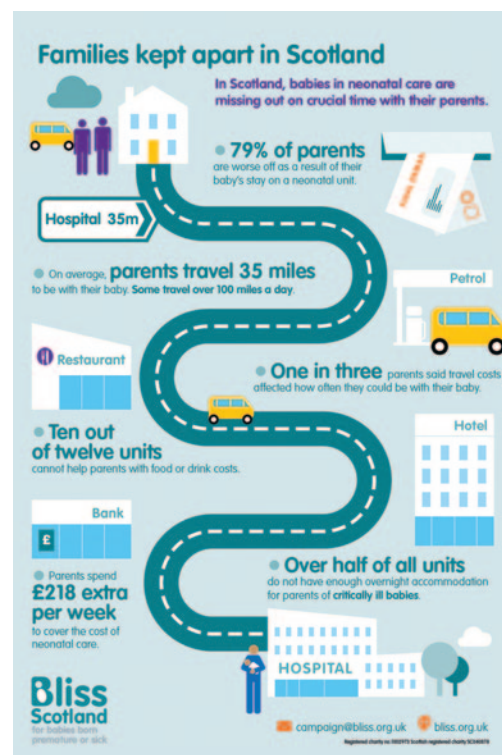


FIGURE 1
Parents can often travel a long way to be with their babies and incur significant costs.

anxious time. We also know that it can be expensive, so we have looked at the support available to parents. This new national Family Fund of at least £1.5 million will be available to parents regardless of income to ease money worries at a very difficult time.”⁶

At Bliss Scotland we have warmly welcomed this new Family Fund, which will go a significant way towards helping families who, until now, have had to shoulder the financial burden that comes with having a baby in neonatal care. Research published by Bliss Scotland has revealed that the average weekly cost of having a baby in neonatal care is £218 across Scotland. This includes:

- £61 on buying food and drink in and around the hospital
- £74 spent on travel
- £81 for childcare for older children.

Almost 80% of parents we surveyed said that having a baby in the neonatal unit had worsened their financial situation, with a third of parents saying the cost had affected their ability to be with their baby in hospital.

It should also be kept in mind that parents accessing neonatal services in Scotland may be from the most vulnerable families who will already be struggling with financial costs. Recent research by the Royal College of Paediatrics and Child Health and the Child Poverty Action Group noted that doctors in Scotland raised concerns about the impact of poverty, low incomes, housing issues and even homelessness on the health of infants and children.⁷

As we welcome this significant investment, Bliss will continue to work with the Scottish Government in 2018 to ensure the fund works in the best way for families. Over time we would like to see equitable provision made available for parents of full term but sick babies who require a lengthy stay in neonatal care. And we also want to see action taken to provide accommodation for parents on neonatal units, an area that is not covered by the new fund. This is an important step forward, however, and signals the Scottish Government’s ongoing commitment to improve support for families with a baby in neonatal care.

The bigger picture: facilities across the UK

Of course Scottish parents are not the only ones facing financial pressure while their babies are in neonatal care. In 2013 Bliss surveyed parents and neonatal units across the UK to investigate the financial impact of having a baby born premature or sick. This research formed the basis of our *It’s Not a Game: the Very Real Costs of Having a Premature or Sick Baby* report.⁸ The results were striking. Of those families who responded, their babies spent an average of eight weeks in neonatal care and during this time they spent an average of £282 on top of normal household expenses for every week their baby was receiving neonatal care, or £2,252 over the entirety of their baby’s stay.

In 2016, Bliss research found that one in seven neonatal units in England were unable to provide any, or only very limited, facilities or financial support for families. A staggering 40% of English neonatal units had no or very limited kitchen facilities and less than one in five NICUs had enough overnight rooms for parents of critically ill babies.⁹

In Wales, there is a similar picture with none of the country’s three NICUs having enough overnight accommodation for parents of critically ill babies to meet the All Wales Neonatal Standards requirement for one room per intensive care cot in 2016.¹⁰

Access to kitchen facilities and free meals varied across Wales and at some hospitals only breastfeeding mothers were entitled to free meals due to restrictive criteria. For mothers who are unable or not wanting to breastfeed, it can be distressing to be denied financial help for this reason.

Although in the year that has passed since the release of our findings there has been some change at a local level, on the whole there has been very little improvement. We know that NHS finances are tight, but we believe it is vital that the Department of Health in England and decision makers in Wales follow Scotland’s lead and make sure funding for facilities and financial support are not seen as an additional extra for services, but are instead factored in and funded as an essential component of a modern neonatal service.

Conclusion

The Scottish Government’s recent announcement of a new national fund to provide financial support for parents of premature babies in neonatal care is a welcome first step towards ensuring that parents are able to be with their babies in hospital as much as possible, which we know is best for babies and families. Bliss looks forward to continuing work with the Scottish Government on the implementation of the full suite of Best Start recommendations, and in particular the further action required to increase accommodation provision to enable parents to stay near their baby and play a full role in their care. This will become even more important in light of the planned reconfiguration of neonatal units in Scotland and must be planned into future service developments.

Bliss also wants to see equivalent action taken in the other nations across the UK following the example set by Scotland. In this way every parent with a baby born premature or sick and in neonatal care in the UK will be able to be with their baby as much as possible.

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