



# It's not a game:

the very real costs of having  
a premature or  
sick baby in  
Northern Ireland

**Bliss**  
for babies born too soon,  
too small, too sick

**Tiny  
Life.**

## Need to talk?

Our helpline is open Monday to Friday 9am to 9pm.

# 0500 618140

RNID typetalk 018001 0500 618140

Or email Bliss at [hello@bliss.org.uk](mailto:hello@bliss.org.uk) anytime and we'll get back to you as soon as possible.

### About Bliss

Bliss is the UK charity dedicated to ensuring that the 80,000 premature and sick babies born each year survive and go on to have the best possible quality of life. We provide practical and emotional support to families, work with doctors and nurses to ensure the very best care is given to babies, and campaign for essential change within government and the NHS.

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Or email TinyLife [info@tinylife.org.uk](mailto:info@tinylife.org.uk)

### About TinyLife

TinyLife is the premature baby charity for Northern Ireland, dedicated to reducing premature birth, illness, disability and death in babies. TinyLife provides a range of family support services within neonatal units, at home and in local community settings, which meet the growing needs of families with premature and ill babies in Northern Ireland. TinyLife also funds medical research and provides a program of training and information seminars for professionals and parents.

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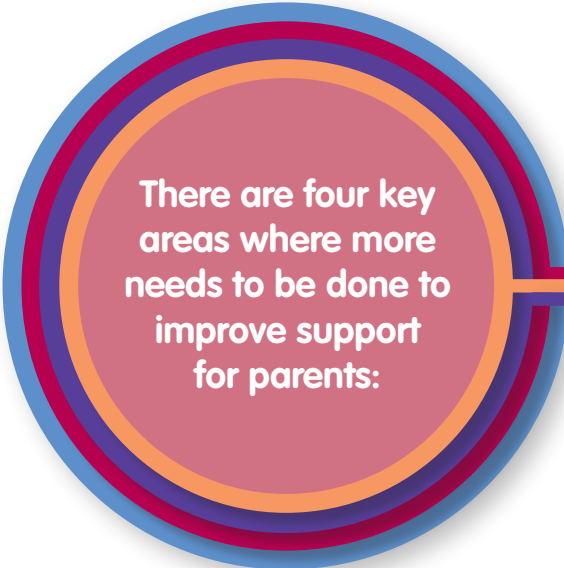
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## Executive summary

There are around 1,900 babies born too soon, too small or too sick and admitted to neonatal care in Northern Ireland each year. Alongside the fear and anxiety felt by their parents is the reality of a hospital stay that can stretch from weeks into months and the financial strain this places on families.

For the parents responding to our survey, these additional costs averaged **£229** a week, or **£1,374** over the course of their baby's stay in hospital.

This report is based on the survey responses of 192 parents and the 6 hospitals who responded to our survey.



There are four key areas where more needs to be done to improve support for parents:

## Time to be with your baby

Prolonged hospital stays are denying mums the chance to bond with their baby once they come home. While for dads, many have to go back to work while their baby is still in hospital. **Maternity leave** (which will soon be available to both parents as shared parental leave) **needs to be extended for the parents of premature or sick babies who face a hospital stay of two weeks or more.**

## Staying with your baby

Only three of the units who responded offered some free accommodation on site. This means that hundreds of parents have to leave their baby each night to travel back home. Day-to-day costs add up as well; for those parents having to buy food and drink while at the hospital this came to £65 a week. **Parents need to be offered free accommodation near their baby and access to free meals and drinks.**

## Travelling to the hospital

Bus and train fares, petrol and parking all quickly add up. For those parents who faced these extra costs, they totalled an average of over £100 a week. Where not already the case, **parents of premature and sick babies need access to free parking and help with travel costs.**

## Supporting families

It is important that parents are aware of the support that is available to them. There needs to be **a welcome pack available to every parent upon arrival at the unit** and a designated person they can speak to about any concerns. Extra support is also needed for those parents who already have children, with free supervised childcare to enable them to bring older brothers and sisters with them to the hospital.

Meeting these needs will not make having a premature or sick baby any less scary, or remove the worry and anxiety for parents. But it will mean that parents are able to focus on the one thing that matters – their baby.



### Family care standards cards

The Bliss Baby Charter<sup>1</sup> sets out guiding standards and principles in non-clinical neonatal care, and what should be offered to parents of premature and sick babies to ensure that families are at the centre of care delivered.

The support  
that should  
and can be  
provided



### Best practice cards

Some hospitals and employers are leading by example, doing everything they can to support parents to be with their baby.

# Introduction

Following the birth of their child, most parents expect a hospital stay of a few hours or possibly a day or two before going home with their baby. However, things are very different for the parents of the 1,900 babies admitted to neonatal care in Northern Ireland every year.

For these parents, their babies face a hospital stay that in many cases stretches from weeks into months. What should be one of the happiest times of any family's life becomes the most traumatic.

Adding to this stress are the significant unexpected financial costs parents of premature and sick babies face. Everyone knows it's expensive to have a baby, but these costs spiral when a baby is born premature or sick. On top of all the usual costs of clothes, cots and buggies, parents face daily travel costs to hospital, parking, food and drink, childcare for any other children, and loss of earnings. For the parents responding to our survey, this worked out on average as an extra £229 a week, or £1,374 over their baby's entire stay in hospital.

***"Apart from watching my baby really struggle to stay alive, I was struggling to keep the family above water on my own. In the end I had to stop eating to be able to afford to feed the children."***

Families face  
unexpected  
costs of  
£229 a week

## Methodology

This report is based on the real stories of 192 parents from across Northern Ireland who responded to our 2014 survey, all of whom had a baby admitted to neonatal care in the last 5 years. While the survey received 275 responses in total, a cut off was established to ensure the information used is as current as possible. Some quotes in the report are from our UK wide research as well as our specific Northern Ireland parent survey.

We carried out a further online survey across the UK to explore parents' experience of maternity and paternity leave in greater depth. This received 289 responses. This is referred to as our 'parental leave survey' to distinguish it from our initial research.

A separate survey was also sent to all hospitals providing neonatal care in Northern Ireland with 6 out of 7 responding.



# Having a premature or sick baby

When babies are born premature or sick, their parents start on an unexpected rollercoaster ride of hope and fear for their baby's future. A baby may need specialist hospital care if they are born premature (before 37 weeks) or born full term with a low birth weight or a medical condition that needs treatment. These babies will require some form of hospital care provided in neonatal units at three levels:

- **Special Care** – A baby's breathing and heart rate is monitored, they might receive light therapy for jaundice and are likely to need help with their feeding or be given extra oxygen.
- **High Dependency Care** – More specialist care for babies weighing less than 1000g or needing more intensive help with their breathing or feeding.
- **Intensive Care** – For babies who are very small or sick who will normally be on a ventilator and receiving constant care to keep them alive.

## How long does each baby need to stay in hospital?

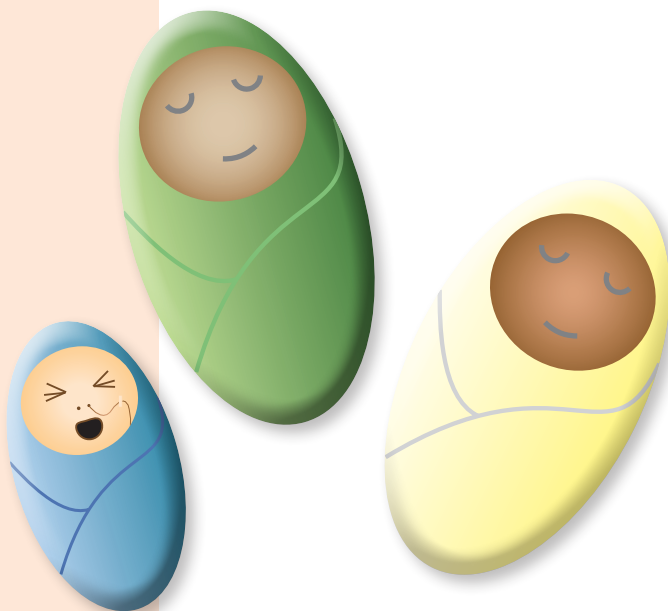
How long a baby will stay in neonatal care can vary, from days, to weeks or months. The smallest and sickest babies will have to stay longest, and premature babies will usually stay in hospital until they reach their expected due date.

A neonatal unit can be a scary place with a steady chorus of beeps and flashes

## What is a neonatal unit like?

A neonatal unit can be a scary place. There are usually four or more babies to a room, each attached to monitors and equipment emitting a steady chorus of beeps and flashes. Some of the babies will have been born full term, others will be tiny and fragile. Many of the babies will be on their own for much of their time in hospital due to the barriers faced by parents such as work, travel costs and the care of other children. This report and its recommendations aim to tackle these barriers so that all mums and dads can be with their baby at this crucial time.

*"I was constantly on edge, worrying my daughter was fighting for her life and potentially dying while I wasn't there. It was terrible. The worst time of our lives."*



# The role of mums and dads

**F**amily-centred care puts the physical, psychological and social needs of both a baby and their family at the heart of all care given. This approach is key to best practice and associated with positive outcomes for both parents and their baby.

Spending quality time at the hospital is essential for the health of parents and their baby in a number of ways:

## Breastfeeding

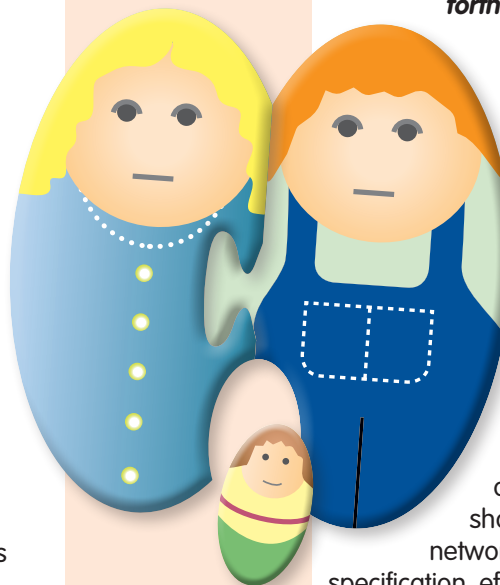
All mums should be supported to establish breastfeeding or express their milk, as it provides vital nutrients for babies and improves their immunity against infections. However, being away from their baby can mean parents missing feeding times.

***"I was unable to breastfeed due to not being able to spend all my time with my daughter."***

## Bonding

When parents are at the hospital, nurses can support parents to hold their baby, change their nappy, bathe them, feed them, or comfort them when they are having painful treatments. These all help establish that early bond between parents and their child.

***"My partner was unable to bond with our baby because we couldn't afford for him to take unpaid leave from work. He could hardly visit the hospital."***



## Parents' health

Not being able to be with their baby can also negatively affect parents' mental health.

***"I developed postnatal depression; I believe this was because I couldn't bond properly with my twins. I didn't have the time to do so, nor the energy from traveling back and forth."***

## Family-centred care

We believe that every baby in Northern Ireland deserves the very best care and all families in Northern Ireland should expect the same support as elsewhere in the UK.

The recent Paediatric Review in Northern Ireland recommended that the Health and Social Care Board and Public Health Agency, should work with the neonatal network to develop a neonatal service specification, effectively a set of standards for neonatal care.<sup>2</sup> Principles of family-centred care should be central to these new standards.

## Recommendation

- A new Northern Ireland Neonatal Care Service Specification should include a comprehensive set of measures to support families while their baby is in neonatal care.

# Time to be with your baby

The average stay in neonatal care for the babies of those parents who responded to our survey was six weeks. For some, this was a matter of days, but one-in-six faced stays of 12 weeks or more and some experienced stays of 20 weeks or longer. For mums, this involves starting their maternity leave earlier than expected and for dads the need to take additional time off work in order to be with their baby while they are in hospital.

It is important that parents are with their baby, carrying out the day-to-day tasks most parents take for granted, like changing nappies and bathing their baby. For those mums who are breastfeeding or expressing milk to be

**Over half of mums say maternity leave is not long enough for the parents of premature or sick babies**

given to their baby, they need to be within a short distance of the neonatal unit so their baby can have all their feeds.

Many parents told us that work commitments affected how much time they could spend at the hospital with their babies. For example, 46 per cent of dads reported that they had no choice but to return to work while their baby was still in hospital.

## Mums

Mums are entitled to take up to 52 weeks maternity leave.<sup>4</sup> This means they have time to spend with their baby on the unit when they are born. However, there can be problems with starting maternity leave early and all mums then face a reduced maternity leave once they take their baby home. Of those parents responding to our parental leave survey, 59 per cent felt that maternity leave was not long enough for the mums of premature or sick babies.

***"I lost three months while he was in hospital. Using maternity leave to visit him while he was 50 miles away every single day felt like a kick in the teeth. I wanted to spend more time with my baby at home."***

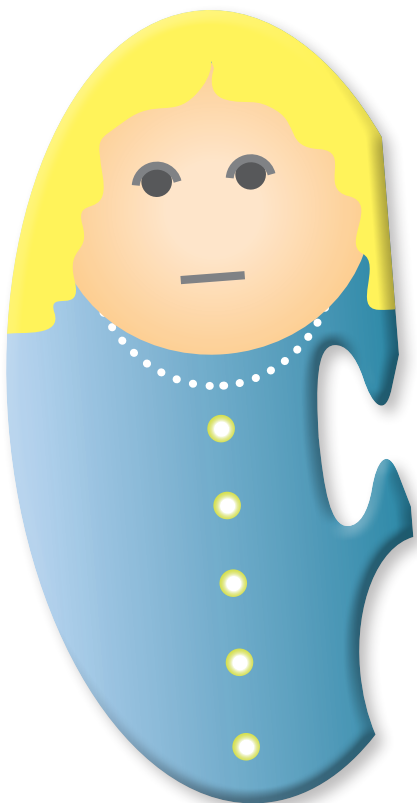
All mums have to notify their employer of their due date using a form called the MAT B1 in order to claim maternity pay. When a baby arrives early, this form must be resubmitted confirming their baby's arrival date. Some mums reported being chased for this form by HR departments, placing them under extra pressure in the days immediately after their baby's arrival.

## FAMILY CARE STANDARDS

Parents are informed, guided and supported to help them feel confident and involved in their babies care. Breast milk expression and breastfeeding are actively promoted.<sup>3</sup>

Keep this card until you need to play it





***"As I didn't have a MAT B1, my employer refused to pay me. I had to discharge myself from hospital and see my GP to arrange an emergency one."***

Mums also reported problems with employers pressuring them to complete work and handover while they were at the hospital with their baby. This seemed to result from a lack of awareness among employers of the impact of having a premature or sick baby on parents.

***"My employer kept trying to contact me while I was in hospital requesting that I meet them to hand over work. I felt very pressurised."***

### **After two weeks, dads have to return to work**

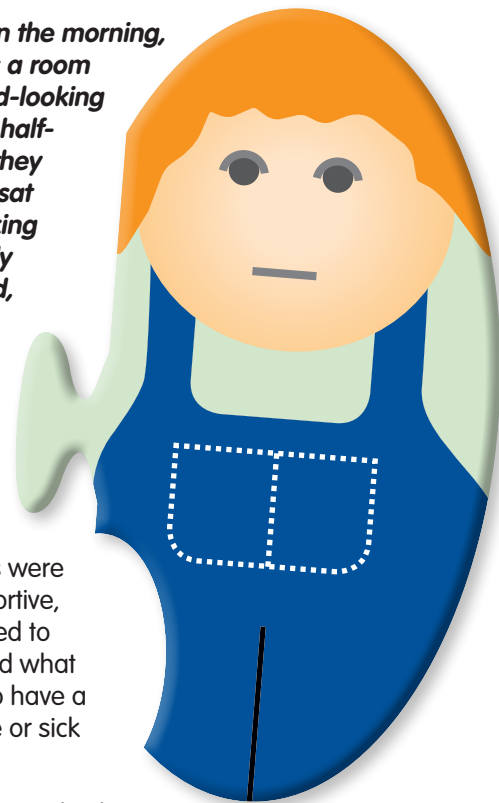
#### **Dads**

Currently dads are entitled to just two weeks paternity leave.<sup>5</sup> They are then faced with the alternatives of taking paid or unpaid leave, signing-off sick or leaving their job if they want to continue to be with their baby. Some have no choice but to return to work while their baby is still in hospital.

***"At 6:30 in the morning, there was a room full of tired-looking dads. For half-an-hour, they were just sat there looking completely exhausted, before and after work."***

Dads also reported that while some employers were very supportive, others failed to understand what it meant to have a premature or sick baby.

***"My employer had no sympathy for our situation, actually stating at a meeting 'I don't care whose kids are in hospital'."***



The planned future introduction of shared parental leave means that parents will be able to share maternity leave entitlement.<sup>6</sup> While this will offer welcome flexibility for many parents of premature or sick babies, taking the average six week stay experienced by our parents would mean using a total of 12 weeks leave before their baby even comes home.

***"I felt that I had been robbed of time with my baby due to having to start my leave early. I lost out on time with my son once he was home and well."***

## Parents of premature or sick babies need an extension in maternity leave

## Recommendations

- Extend maternity leave and statutory maternity pay for the parents of premature or sick babies facing a hospital stay of two weeks or more to reflect their total hospital stay.
- MAT B1 forms to be available on the neonatal unit.
- The Northern Ireland Executive to publish advice for all employers on supporting the parents of premature or sick babies.
- Larger employers to have a policy in place for supporting the parents of premature or sick babies.



# Staying with your baby

Any new parent wants to be with their baby, but while this is often the norm for the parents of older children in hospital, it is not always possible for the parents of premature and sick babies.<sup>7</sup>

Only three units who responded to our survey offer some level of free accommodation onsite to parents. One of these units also provides some further subsidised accommodation. Two of the three units that provide accommodation report that it is sometimes oversubscribed, and they have to prioritise which parents can stay with their baby. Not being able to stay nearby affects mums' ability to breastfeed and can make it harder for parents to bond with their baby.

***"It's just knowing that if anything happens in the middle of the night, or if anything happens when you're on a bit of downtime, you can get there in three seconds flat. It just makes the difference."***

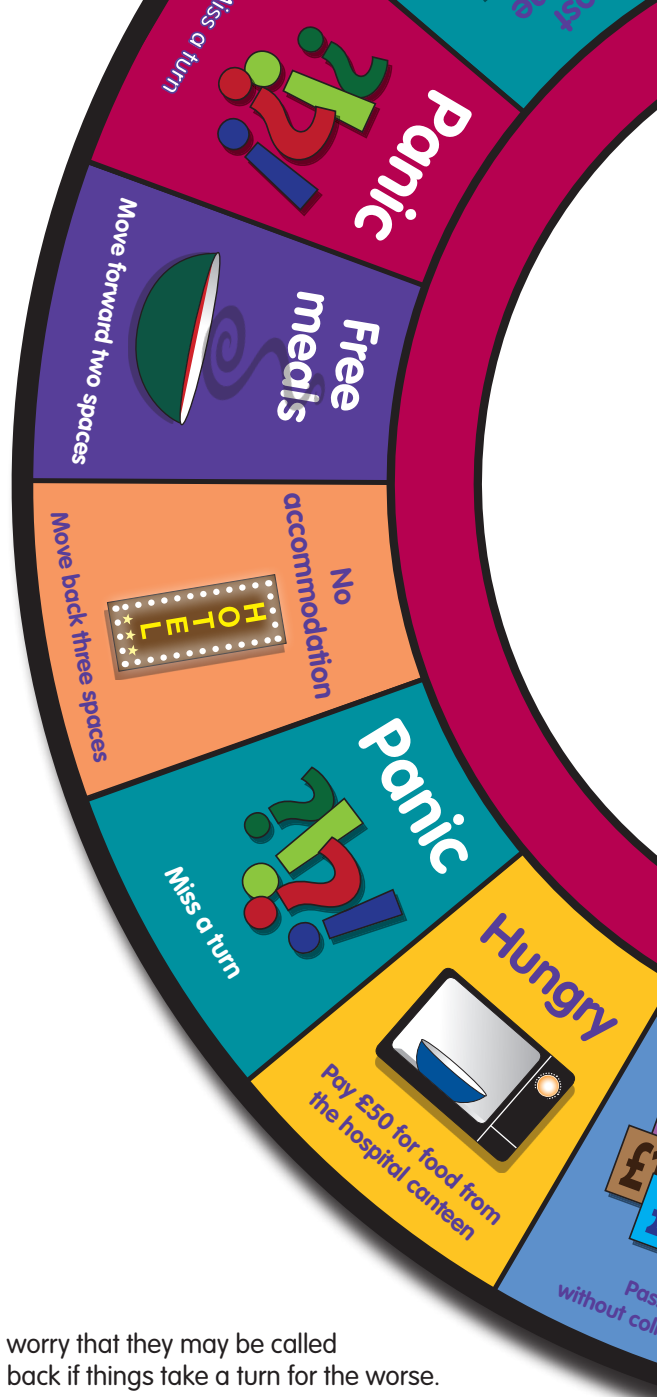
Not being able to stay close to their baby can be heart-breaking for parents. Instead, they are left having to go home, sometimes many miles away, with the

**It can be heartbreaking for parents unable to stay close to their baby**

## FAMILY CARE STANDARDS

Parents of babies on the neonatal unit should be able to access overnight accommodation with bathroom facilities, as close as possible to their baby and without cost.<sup>8</sup>

Keep this card until you need to play it



worry that they may be called back if things take a turn for the worse.

***"I felt exhausted traveling up and down to hospital, but I couldn't afford to stay nearby."***

## Food and drink

Spending many hours on the unit, parents become reliant on the hospital canteen or expensive franchises; the mums and dads responding to our survey who had to pay for food and drink reported that this cost on average £65 a week.

***"For me that was the biggest expense; every single cup of coffee, every single sandwich, from first thing in the morning to last thing at night."***

Some hospitals provide kitchen facilities where parents can make teas and coffees or reheat food from home, but this is on an ad hoc and often limited basis.

Only one of the units responding to our survey said that they provide parents with all their meals free of charge. One further unit helps by providing reduced meal costs from the hospital canteen.

**All parents of babies in neonatal care need to be offered free accommodation**

## Recommendations

- All parents of babies in neonatal care to be offered free accommodation.
- Parent facilities to include an area for making drinks and preparing simple meals.<sup>9</sup>
- Parents to be provided with meal vouchers or free hospital meals.

### BEST PRACTICE

"Parents are offered free hospital dinners and staff are also happy to make them breakfast if staying overnight, so they do not have to leave their baby for meals."

*Neonatal unit*

Take an extra turn



we forward four spaces

Pay £70

Weekly travel ticket

# Travelling to the hospital

Those parents unable to stay with their baby face a daily commute to and from the hospital. The average return journey for the parents taking part in our survey was 32 miles. Within this there were parents whose baby was staying at their local hospital. However, 12 per cent of families faced journeys of 75 miles or more and there were parents facing a 100 mile round trip on a daily basis just to be with their baby.

Many parents have to rely on public transport to visit their baby (particularly mums recovering from a

**Families face weekly travel costs of over £60 a week**

caesarean section who are not allowed to drive). For parents having to meet travel costs, these worked out on average as £65 a week, including both petrol and public transport. All the units responding to our survey suggested that parents could get free parking at the hospital. Despite this over a quarter of parents reported having to pay for parking and this worked out on average as an extra £37 a week.

Some parents reported spending hundreds of pounds each week just to travel to see their baby. 43 per cent of parents reported that travel costs affected their ability to visit their baby.

*"We could only visit our baby two days a week as we were unable to afford the train fare every day."*



### BEST PRACTICE

"As soon as we arrived on the unit, we had an explanation of what was happening with our baby, and we were brought a form to sign for the parking permit."

*Dad of baby boy born at 25 weeks*

Move directly to  
free parking



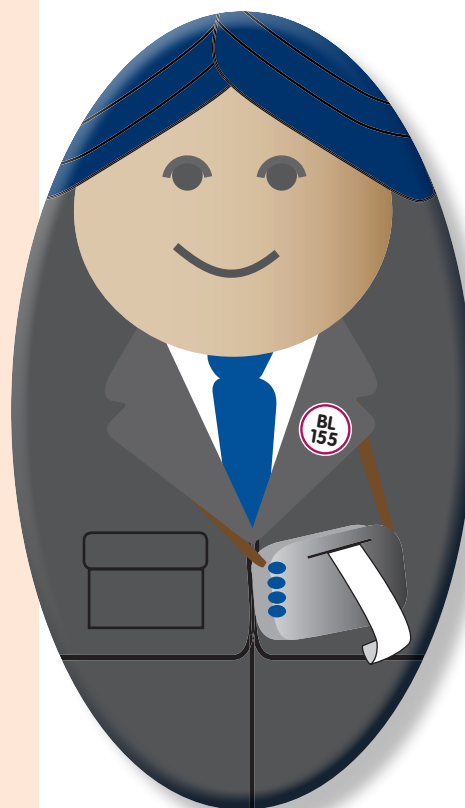
Parents who are on certain benefits, or on a low income (less £15,277), may be eligible for support through the NHS hospital travel cost scheme. However, for others there is little or no support and many face difficult and expensive journeys to see their baby.

***"I had to get taxis there and back. Then, the days that I didn't have any money to do that, I would have to get a bus that took about an hour, and I was there 12 hours each day because I was breastfeeding as well."***

**Many parents are not made aware of free parking, paying an extra £37 a week as a result**

### Recommendations

- All parents of babies on the neonatal unit are to be made aware of free parking.
- Parents travelling 20 miles or more to visit their baby to have their costs reimbursed.



# Supporting families

Parents need to be given the right support and information so they can manage their finances and existing caring responsibilities during their baby's time in hospital. One-in-three parents responding to our survey reported that their mental health had worsened as a result of the pressure caused by additional financial costs.

## Information

The parents responding to our survey faced costs amounting to an extra £229 a week, or £1,374 over their baby's entire hospital stay. These extra costs meant that 91 per cent of parents reported that their family finances were worse as a result. One-in-five said it affected their ability to pay household bills, and a further one-in-ten said it affected their ability to pay the rent or mortgage. Some families resorted to payday loans in order to make ends meet.

Despite this, 44 per cent of parents responding to our survey said they had not been offered any information about the financial support available while their baby was in hospital. For example, of the hospitals responding to our survey all said they provide free parking for the parents of premature or sick babies. However, many parents reported that they paid for parking, clearly unaware that they could access it for free or at a reduced rate.

Nearly half of parents received no information about financial support on offer



## FAMILY CARE STANDARDS

Parents should be given information on useful websites with information, advice and support on financial matters."

Keep this card until you need to play it



## BEST PRACTICE

"I visit the unit every week and offer support directly to the whole family."

*TinyLife Support Worker*

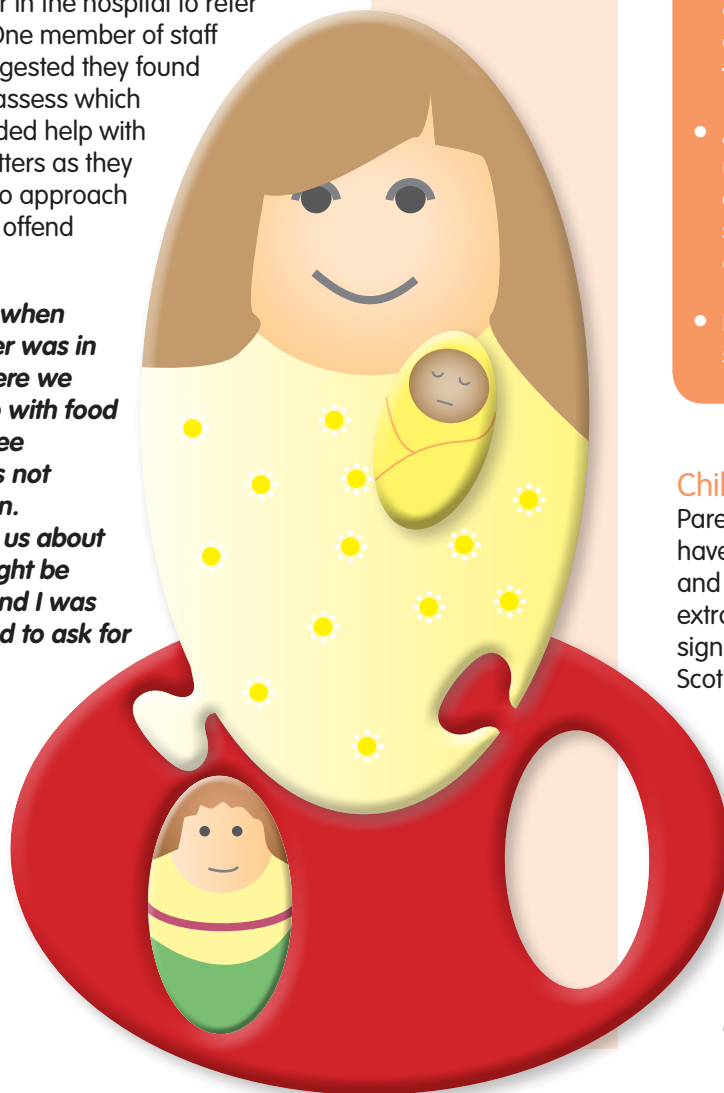
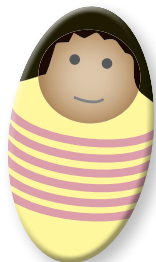
Move directly to free parking



***"When my baby was transferred the hospital never mentioned anything about a parking permit. Only because I knew about it from my previous hospital did I ask."***

None of the hospitals who responded had a dedicated member of staff on the unit responsible for making sure parents are aware of the financial support available. Two of the units did have a social worker in the hospital to refer parents to. One member of staff at a unit suggested they found it difficult to assess which parents needed help with financial matters as they didn't want to approach parents and offend them.

***"At no time when our daughter was in neonatal were we offered help with food costs and free parking was not always given. No-one told us about what we might be entitled to and I was embarrassed to ask for help."***



## Recommendations

- Parents to be provided with a welcome pack upon arrival at the neonatal unit including information on the support available with accommodation, free parking, transport and food.
- A designated person on each neonatal unit responsible for ensuring parents understand the support available and are able to access this.
- Parents to have access to free supervised childcare at the hospital.

## Childcare

Parents with older children to care for have to juggle arranging help from family and friends or paying for childcare, with extra costs totalling £110 a week. This is significantly more than parents in England, Scotland or Wales reported paying.

***"My husband was still going to work during the day and trying to cover the care of our other child at home. The nurses on the unit used to laugh at him because they thought he was on shift work. He would go at midnight or one o'clock in the morning to visit the baby because that was the only way he could fit it into his day."***

# Conclusion

The parents of premature and sick babies are no different to any other parent in their desire to be with their baby. However, inadequate leave entitlement can mean dads having to head back to work while their baby is still in hospital. A lack of accommodation can also mean parents are unable to stay with their baby. Costs at the hospital can leave parents struggling to meet essential bills and a lack of information can mean parents are left feeling they are on their own.

Having a baby in neonatal care will always be a stressful and difficult time for families. Simple steps to help with the financial costs parents face can at least relieve some of these pressures and enable parents to focus on their baby.

At the most basic level it is making sure parents are aware of the support available, simplifying the process of claiming maternity pay and educating employers about what it means to have a premature or sick baby.

Hospitals need to look at what more they can do to support parents, providing food and drink and helping with travel costs. In the longer term, investment in accommodation is needed so parents aren't forced to leave their baby each night.

Finally, to give parents the freedom to be at the hospital with their baby, maternity leave needs to be extended for the

**For the  
parents of  
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It's real life  
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mums of premature or sick babies. It needs to reflect the extra weeks families face in hospital and to be paid as statutory maternity pay. This will help remove the worry of making ends meet or running out of leave.

We have all played games with paper money, but for the parents of premature and sick babies it's not a game. It's real life and it's their baby's life. There are many things parents will worry about when their baby is admitted to neonatal care, whether they can afford to be there shouldn't be one of them.



# Recommendations

## For the Northern Ireland Executive

- Extend maternity leave and statutory maternity pay for the parents of premature or sick babies facing a hospital stay of two weeks or more to reflect their total hospital stay.
- MAT B1 forms to be available on the neonatal unit.
- To publish advice for all employers on supporting the parents of premature or sick babies.

## For employers

- Larger employers to have a policy in place for supporting the parents of premature or sick babies.

## For the NHS

- A new Northern Ireland Neonatal Care Service Specification should include a comprehensive set of measures to support families while their baby is in neonatal care.
- Parents travelling 20 miles or more to visit their baby to have their costs reimbursed.

## For hospitals

- All parents of babies in neonatal care to be offered free accommodation.
- Parent facilities to include an area for making drinks and preparing simple meals.
- Parents to be provided with meal vouchers or free hospital meals.
- Parents to be provided with a welcome pack upon arrival at the neonatal unit including information on the support available with accommodation, free parking, transport and food.
- A designated person on each neonatal unit responsible for ensuring parents understand the support available and are able to access this.
- Parents to have access to free supervised childcare at the hospital.

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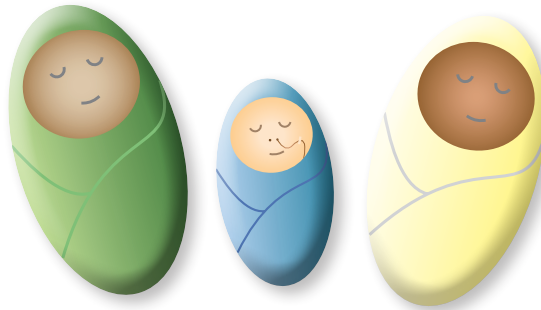
# Make your voice heard

Sign up to call for better support for all parents of premature and sick babies.

Join our campaign at

**[bliss.org.uk/campaigns](http://bliss.org.uk/campaigns)**

**[tinylife.org.uk](http://tinylife.org.uk)**



Join the conversation

@Blisscharity

@TinyLifeCharity

#notagame

# Bliss

for babies born too soon,  
too small, too sick

# Tiny Life.