



Families kept apart: barriers to parents' involvement in their baby's hospital care

Bliss
for babies born
premature or sick



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This report was written by Josie Anderson, edited by Sadie Constable and designed by Chris Beardsall.



Foreword



Every year, tens of thousands of babies in England are born premature or sick. These fragile newborns are the NHS' smallest and most vulnerable patients; sadly, not all of them will make it home.

While clinical intervention is essential for survival, for babies to have the best possible chance of good long-term health outcomes, parents must be able to take the lead in caring for them. Skin-to-skin contact, breastfeeding and comfort holding are just some of the things parents need to be supported to do for their baby. High levels of parental involvement also improves bonding and gives babies the best start in life. This has been recognised by many academic studies and national standards for safe high-quality care.

Parents need to be with their baby as much as possible to fully participate in their baby's care. While national standards outline the facilities which should be available to all families to enable this to happen, such as accommodation and kitchens, this report shows that many units lack these basic resources – keeping babies and their parents apart as a result.

Daily trips to the hospital and long hospital stays for their baby are costly for families and it is disheartening to see that financial assistance is not more widely available. This creates another barrier for parents visiting their baby. The link between economic deprivation and higher rates of premature birth and infant mortality is well established, meaning the burden of costs is felt most acutely by the poorest in society – the people least likely to be able to cope with the dramatic hikes in expenditure which parents face when their baby is in hospital.

The findings of this report show how crucial it is for babies to have their parents with them, caring for them, comforting them and protecting them - just as every new parent wants to do. NHS Trusts, hospitals, commissioners and the government must take action to enable this to happen for every family, to give every baby born premature or sick the best chance of survival and quality of life.

A handwritten signature in black ink, appearing to read 'Caroline Davey'.

Caroline Davey
Chief Executive

Summary of findings

For premature and sick babies to have the best possible chance of survival and good long-term health, it is vital that parents are there to support their recovery. Hospitals providing neonatal services must have the necessary infrastructure in place to enable parents to care for their babies in this way. We have gathered evidence from neonatal units and parents across England, providing a clear picture of the facilities and support that is in place to support parents being actively involved in their baby's care - and also where gaps exist.

While there has been welcome improvement since 2013 in the number of units with facilities for families and financial support mechanisms in place, this has not been a straightforward increase. Many units have also lost existing support over this time. There is huge variation in provision across the country, and many financial schemes are vulnerable to being discontinued. This means that not every baby will be able to be fully cared for by their parents, because their parents are not sufficiently supported to be with them.

- One in seven (15 out of 99) neonatal units told us they are unable to provide any, or only very limited, facilities or financial support for families

A lack of facilities on or close to the neonatal unit, such as overnight accommodation or basic food preparation areas, is a substantial barrier to parents spending as much time with their baby as they would like, as they will regularly need to leave the unit to eat or sleep.

- More than one in three hospitals do not have dedicated accommodation for families of critically ill babies
- Only five out of 29 neonatal intensive care units had enough overnight accommodation for parents to meet national standards
- However there has been some welcome progress in this area, with around one in five units (11 out of 50) able to provide more parent accommodation than they were in 2013
- Over 40 per cent of units (30 out of 71) have no, or very limited kitchen facilities for parents to prepare food or hot drinks

Inadequate facilities have a huge impact on family expenditure as travel, food and accommodation costs for parents mount up quickly. However, the availability of any additional help that units can provide to parents is very variable.

- A third of hospitals (29 out of 86) offer parents no support with meal costs while their baby is being cared for in hospital
- There has been an overall increase of 10 more units now able to offer support to parents for food and drink costs
- However, we found that 10 units which provided this support to parents in 2013 to help cover meals are now not able to

Babies are frequently cared for in neonatal units far from home. The daily cost of car parking is prohibitive to parents staying at the unit for as long as they would like, or even being able to visit their baby every day. Despite the government having issued guidance to Trusts in 2014 to offer free or reduced parking to anyone visiting critically ill or long-stay patients, our findings show that the costs that parents of babies in neonatal care face has, in many cases, actually increased in recent years.

- 49 per cent of Trusts (62 out of 126) with a neonatal unit have increased either their hourly or all day parking rate in the last three years
- A third of hospitals (16 out of 48) where parents could park for free in 2013 now charge parents for parking
- 27 per cent (16 out of 60) of hospitals have increased the cost of their concessionary charges for parents between 2013 and 2016

Bliss is calling for urgent action from hospitals, NHS Trusts, commissioners and the government to make sure facilities and support are in place to enable parents to participate fully in the care of their baby.

One in seven hospitals offers no, or only very limited, facilities or financial support to parents of premature and sick babies





Introduction

Over 84,000 babies are admitted to neonatal care in England every year because they have been born premature or sick. Many of these babies will face a hospital stay stretching into weeks and months, and will need highly specialist care to survive and thrive – a life-changing and traumatic time for parents desperate for their baby to recover and come home.

Despite the need for often very intensive clinical intervention to help them survive, just like with any newborn baby their mother and father are the most important people to them. The direct, hands-on involvement of parents in their babies' care throughout their time in hospital is vital: it is linked to improved bonding and better long-term outcomes for both babies and families (see page 11).

For parents whose baby sadly dies, good facilities enable them to spend as much precious time as they can with their baby and give parents a safe, supportive environment to grieve.

At what may well be one of the most distressing times of their life, the last thing any parent with a baby in neonatal care needs is to worry about whether they can afford to be with their baby. Yet, our research shows this is the situation thousands of families find themselves in every year.

Despite national standards requiring neonatal units to support parents to be with their baby, insufficient facilities, such as a lack of overnight accommodation or kitchen space, and an absence of practical support to help manage costs, are significant barriers to parents being able to participate fully in their babies' care. Neonatal staff work incredibly hard to ensure every parent is supported to care for their baby, but without the right facilities and financial support in place, they are restricted in what they can offer.

This report also demonstrates that there have been some changes to the provision of facilities and support for families in recent years. In the two-year period between our 2013 survey and our research for this report there have been some welcome improvements in the number of units with facilities and support in place for families, but there is still wide variation between what different units can offer. All too few units are able to provide the facilities and support that national standards say they should, and one in seven are unable to offer parents any, or only very limited, support at all.



Supporting parents with hands-on care

Supporting and encouraging parents to be actively involved in delivering care improves babies' long-term outcomes. It is vital for bonding between babies and their parents, reduces the length of the baby's stay in hospital, and empowers parents.^{2,3} A high level of parental involvement reduces the baby's stress levels and supports better development. It has also been shown to reduce the likelihood of mothers suffering from post-natal mental health conditions, which are much more prevalent among mothers whose baby has had a neonatal stay.^{4,5,6}

Due to the specialist nature of neonatal services, units – especially those looking after the smallest and sickest babies – can be located many miles from the babies' home. These distances physically separate parents from their baby and make it challenging for families to be kept together. This can directly impact on outcomes for babies. Not being able to be at the hospital for long, uninterrupted visits is a barrier to establishing breastfeeding, engaging in skin-to-skin contact and other bonding activities like comfort holding; all of which are essential for the baby to develop as well as they possibly can.⁷

Family-centred care, which is embedded in national standards for safe, high-quality services,⁸ places the baby firmly in the context of the family and acknowledges that the family is the most important and constant influence on a baby's development. It encourages health professionals to consider how it feels to be the parent of a very sick baby, and then to work to improve the parental experience and involvement, which in turn improves care and outcomes for babies.⁹ The recent report from the National Maternity Review reiterates the importance of keeping premature and sick babies together with their parents and ensuring parents are actively encouraged to participate in their baby's care.¹⁰

Facilities for families, like free overnight accommodation and basic kitchen equipment, as well as support with additional costs, are essential for effective family-centred care. Needing to leave the unit to travel home for sleep or meal times is a significant barrier to parents being with their baby as regularly, and for as long, as they would like.

Neonatal staff across the country work incredibly hard to support parents to care for their baby. They teach them how to comfort hold, support mums to breastfeed and teach parents how to confidently respond to their baby's cues and do their daily cares like changing, bathing and feeding. But they cannot support parents in isolation. Good facilities are essential to enabling staff to support parents as fully as possible to take the lead in their baby's care.

There is also evidence to suggest that facilitating parents to take the lead in providing their baby's every day care while in the neonatal unit can free up staff time to focus on other tasks.^{11,12} As shown in *the Bliss baby report 2015: hanging in the balance*, many neonatal units in England are chronically understaffed, so providing the infrastructure parents need for better family-centred care could allow staff more time to dedicate to more complex clinical duties.

What should parents be offered?

What facilities and support parents should be offered¹³

Principle 3 of the *Toolkit for High-Quality Neonatal Services* sets out the minimum facilities units should have to facilitate family-centred care, including accommodation, kitchen equipment, parent rooms and changing facilities for older siblings.

This principle states that parents should receive written information on admission to the unit which tells them about travel, parking, support groups and other sources of support on offer at the unit looking after their baby.

National standards are clear about what units should be able to provide to parents, but what units can *actually* provide varies wildly. The wide variation in the facilities and support available at different hospitals, has resulted in a postcode lottery whereby neonatal units - even those within the same network - often have vastly different provision for parents. While the majority of units are able to provide some support for parents, most lack the resources to support every parent who needs it.

Although building new accommodation and kitchen space can be costly and difficult to plan, NHS Trusts have an obligation to ensure that they are available. Where they are not currently in place, Trusts must be actively developing long term plans to address these service shortfalls, as well as immediately sourcing interim solutions to make sure families can be kept together. Family facilities are not 'nice-to-haves'. They are an essential requirement of national standards and are central to high-quality care.

With health services under increasing pressure to curb spending and make savings, schemes to help regular visitors with costs, such as parking concessions or meal vouchers, are often the first to be cut. However, parents are not just 'visitors'. Mothers and fathers need to be at the hospital every day and often for very long periods of time, so they can parent and care for their vulnerable baby. Their presence on the unit and delivery of hands-on care for their baby is integral to their babies' long-term health and for strengthening family bonds. Financial support schemes can mean the difference between parents being with their baby every day or just once a week.

It is not uncommon for a baby to be transferred between different units during their recovery; it is a normal and essential part of neonatal care to ensure babies receive the appropriate level of care in the right setting for their needs. However, for their families, a transfer from a hospital which offers a lot of support to one which offers very little can be disconcerting, frustrating and stressful.¹⁴ An added distance between a baby and their parents coupled with a lack of facilities or support schemes can undo patterns of parental care which had been established in the previous unit, like breastfeeding or regular skin-to-skin contact.

Despite these challenges, the majority of neonatal units surveyed are able to provide some facilities and financial help for parents. However, **one in seven (15 out of 99) neonatal units told us they are unable to provide any or only very limited, facilities or financial support.** Worryingly, five of these units are Neonatal Intensive Care Units (NICUs) and the remaining ten are Local Neonatal Units (LNUs). These units care for babies with the most complex needs who have the longest stays.

The financial toll of having a baby in neonatal care

In 2013 Bliss surveyed parents and neonatal units across the UK to investigate the financial impact of having a child 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*.¹⁵ 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.

These average weekly costs included:

- **£53 on buying food and drink** in and around the hospital
- **£75 on travel**, either by car or public transport, to be with their baby every day
- **£32 on car parking**, on top of petrol
- **£60 on accommodation** to stay near their baby, if they were being cared for far away from home.

“ At the first hospital we were given overnight accommodation and I could stay over and be with my babies. I was expressing milk and hoping to breastfeed eventually. Unfortunately, when we were transferred to the second hospital, they didn't have any accommodation. I visited daily for as long as I could but they were being fed from a bottle when I had to go home and they simply wouldn't feed from me. I believe this is why I couldn't establish breastfeeding.”

Mother of twins born at 29 weeks

“ We could only visit our baby two days a week when she was being cared for in the NICU. This carried on for six weeks. We were simply unable to afford to travel there every day.”

Mother of a baby born at 27 weeks

Accommodation

Sufficient accommodation is the most important facility to keep parents with their baby. Due to the distances between homes and hospitals, parents who are unable to stay overnight may need to cut their visits short because they have long and tiring journeys back home. While there have been welcome improvements in the numbers of units able to offer more parents accommodation, very few are able to meet the levels set by national standards. This means hundreds of parents have to leave their vulnerable baby every day, missing out on valuable bonding time and adding to the stress and anxiety felt by both babies and their parents.

National standards for accommodation

The *Toolkit for High-Quality Neonatal Services* states that there must be one overnight room per intensive care cot, within a 10-15 minute walk from the unit. These rooms must all be free of charge and have bathroom facilities. They must be in addition to, not including, two dedicated 'rooming-in' rooms for parents to use to help them adjust to caring for their baby around the clock without the support of nurses and doctors prior to their baby being discharged home.

The *Bliss baby report 2015* highlighted the difficulty that units across England have with providing enough accommodation to meet demand. While the majority of units which responded to the survey (80 out of 91) do have some accommodation, over a quarter of units (24 out of 91) only have 'rooming-in' facilities. **More than one third of all units (35 out of 91) do not have dedicated accommodation for families whose baby is critically ill or being cared for many miles from home. And only five out of 29 neonatal intensive care units were able to meet the Toolkit standards of one room per intensive care cot.**¹⁶

This patchy provision for parents of sick babies is not the same for all parents of sick children. By direct contrast, all hospital children's departments now have some room for parents to stay overnight. In order to ensure parity for babies in neonatal care, who need their parents to care for and comfort them just as much as older children, it is vital that this inequality of provision is quickly addressed.

Staff have told us both in 2013 and 2015 they understand the difference it can make when parents are able to stay with their baby. Despite their best efforts to keep families together, the chronic shortage of rooms, means nurses regularly have to make difficult decisions about which parents get to stay with their baby, and which have to go home.

The National Maternity Review recommends that accommodation should be available to parents when their babies are transferred to another hospital.¹⁷ 44 per cent of all neonatal transfers occur because a baby needs to be cared for at a more specialist unit.¹⁸ However, these findings indicate that accommodation is unavailable for many of these families.

The lack of sufficient accommodation, particularly at intensive care units, is also concerning because, sadly, some babies will die before they have the chance to go home. When a baby dies it is important that parents have space to not only come to terms with the news and to express their initial sadness and grief in a safe environment, they also need a room so they can spend time with their baby after their death to say goodbye and to make their last memories. While some units have dedicated bereavement facilities, many units do not and rely on normal accommodation or quiet rooms. Not only can availability be an issue, which may impact on a family's privacy, but the time they want to spend with their precious baby may be cut short. Sufficient accommodation is an essential component of good bereavement facilities.

While progress has been made since 2013, with 22 per cent (11 out of 50) of units able to provide more accommodation to parents than they were two years previously,¹⁹ many units have been forced to 'double-up' their rooming-in facilities so they can be used as emergency accommodation for parents who live far away or have a very sick baby. This means the majority of parents with a baby being cared for in a NICU will not have the opportunity to stay with their baby for the duration of their stay as rooms are in such high demand.

The shortage of accommodation is one of the most significant barriers to parents actively caring for their child. Going home for the evening can be anxiety-inducing for parents, particularly for those with very sick babies who may fear what could happen while they are away. For parents who live far away from the hospital or whose baby is in a critical condition, the only option may be to stay overnight at a local hotel to be near their baby. This can be extremely costly and is not a long-term, practical solution for most families.

“ We were at a hospital a four-hour round trip away. We had to pay to stay in a doctor’s on-call room for the nine weeks our baby was being cared for. It was that or a four-hour round trip each day, which was just too much when my baby was so sick. We were lucky to have kind friends who could help us cover the costs but others aren’t so lucky.”

Mother of premature child



Fewer than one in five NICUs have enough overnight rooms for parents of critically ill babies



Best Practice Case Study

Barnet hospital: Starlight neonatal unit

In 2013 the special care baby unit at Chase Farm Hospital was merged with the Starlight neonatal unit in Barnet, requiring Starlight to increase their capacity by an extra ten cots. Staff were concerned that the extra patient load could create a chaotic, noisy environment which conflicted with their ethos of fostering a space for family-centred and developmental care.

Senior nurse Kathryn Eglinton says, *"we asked a lot from parents: to be able to feed, care and bond with their babies while not being with them 24 hours a day. That's why we chose to create ten Individualised Care Rooms (ICR) so that each baby, once medically stable, could be cared for by their parents with the support of staff in these rooms."*

"We were unable to knock down the entire hospital and start from scratch; we had no option but to work within the confines of the four walls we already had. Some of the rooms may be small but there is enough room in all of them for two parents to stay with and care for their baby."

Every baby is monitored regularly by the nursing team and is seen by a doctor every day. Parents are fully supported to be their baby's main carer.

"Some parents spend almost their entire time on the unit in an ICR which can mean being with their baby for many weeks or months. If they need time out or to care for older siblings, they can nominate alternative carers to come and look after the baby for a while – lots of grandmas really love this opportunity!"

Staff have seen a tangible difference to the care and outcomes of babies and families who stay in the ICR.

"The benefits for families have been numerous – we've noticed a trend towards earlier discharge, earlier establishment of breastfeeding, and a general increase in parental confidence in caring for their baby at discharge."

"Staff have also felt the benefit. They build closer relationships with families and teach parents to fulfil their baby's care needs well before their baby is discharged which was not possible when we only had rooming-in facilities."

"Parents regularly tell us what a positive impact having the chance to stay in an ICR has had on their family – one mum commented to me that 'the first night I spent in ICR was the first night that I felt like a parent.' Hearing this from parents just reinforces how important it was for us to work with what we had to produce the best kind of family-centred environment we could."



Please do not pull the
cable out of the
socket.
Thank you.

Hand hygiene
instructions

WC
Toilet

Eating and drinking at the hospital

For parents to engage fully in the care of their baby, and stay with them for as long as they wish, it is vital that their visits are not frequently interrupted by their need to eat. Parents can be supported to stay and care for their baby for longer by the unit having an adequately equipped kitchen space and by having a scheme in place for families to access free or discounted food from the hospital. Despite welcome improvements in the number of hospitals able to support families with food and drink costs, and with facilities for preparation, there is still a huge variation. Some units which could previously offer support in 2013 now cannot, and schemes to help with costs vary widely in accessibility and affordability.

Kitchens

National standards

The *Toolkit for High-Quality Neonatal Services* states that units should have a kitchen area which includes a kettle and microwave so parents are able to make hot drinks and snacks; these should be free of charge.

Despite the importance of good meal-making facilities for family-centred care, 11 out of 83 units have no kitchen facilities at all. Every snack, hot drink and meal needs to be bought from expensive canteens or franchises at the hospital. For those unable to afford this and who are not eligible for reduced or free meals at the hospital, they will have no choice but to go home to eat. Six of these units are LNUs and three are NICUs, meaning that parents of the sickest and most vulnerable babies are often forced to leave the unit to eat.

A further quarter of units (19 out of 72) only have limited facilities meaning parents often need to leave the unit – either to go home or to buy food elsewhere – to eat a hot meal, or sometimes even a hot drink.

Neonatal units, particularly those with intensive care cots, are relatively few in number and are spread across England. For most babies who need this care, it is not available on their doorstep. While research is still being carried out to assess how far families in England have to travel, findings from two networks indicate families with a sick baby will need to travel over 30 miles, on average, to be with them.²¹ For some, leaving to have an evening meal will be the end of their visit – a visit which could have lasted hours longer had a microwave and fridge been accessible.

Eating well and eating regularly is also important for mothers to establish breastfeeding or expressing and to maintain their breastmilk supply. For vulnerable babies, particularly those born very premature, the antibodies and nutrients in their mother's breastmilk are especially important for their development, warding off infection and helping them grow.²¹

As with accommodation, poor food and drink making facilities can be the result of a lack of space and poor planning. However, NHS Trusts have an obligation to have these facilities in place for parents as they are crucial for enabling them to stay long periods with their baby. They must ensure these facilities are included in plans and budgets for any redevelopment or expansion, and in the meantime source local solutions to make sure parents do not have to leave the unit repeatedly to eat and drink.

Best Practice Case Study

Conquest Hospital neonatal unit, Hastings

“As a recipient of the Bliss Baby Charter grant fund, we were able to fully refurbish our parent kitchen facilities which were no longer fit for purpose. There was an extreme lack of cupboard space so food was being left out on any available surface, and there was no dedicated workspace where drinks and meals could be prepared. Due to the kitchen being 18 years old, the cupboards were also tatty and discoloured. This was not the relaxing, functional space we wanted for families.

“Since the refurbishment, families now have the space to prepare drinks and meals, and to eat them in comfort. This has enabled families to spend longer on the unit with their baby as they no longer have to leave to eat, and has reduced the costs of having to buy meals at the hospital. Because of the addition of a breakfast bar, parents now also have the space to sit, chat and socialise for a little while.”

Best Practice Case Study

Warwick Hospital

“While we were lucky to have a dining room space, it wasn’t fully-functional before we received our funding from the Bliss grant fund. We have been able to buy comfy furniture, a fridge and freezer and other equipment like cutlery to furnish the area and bring it up to standard.

“This has helped support babies on the unit because their mothers are able to bring in healthier meals from home which helps support their breastfeeding and expressing.

“The space is generally more parent friendly. The dining area is now less crowded and parents can sit and enjoy meals together without having to leave the unit.”

Supporting parents with food costs

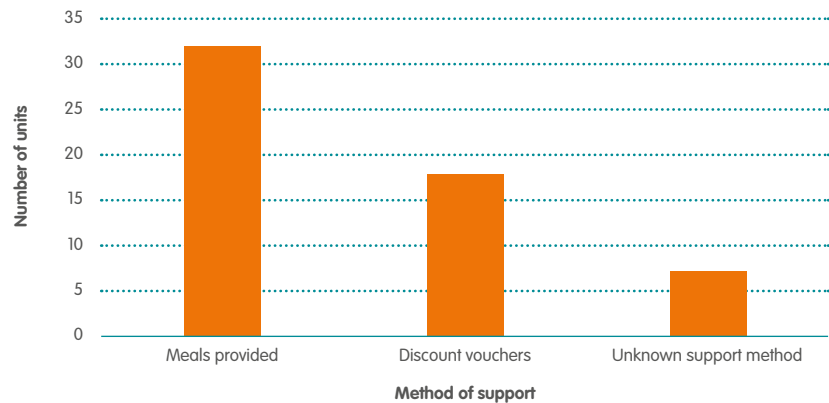
With so many units only able to provide limited meal making facilities, or none at all, the cost of buying food and drink from hospital canteens and expensive franchises quickly adds up. This financial burden is a real barrier to parents being able to visit and stay with their baby, so access to support with meal costs is a very important and practical solution for NHS Trusts to keep parents with their baby for as long as they want to be.

Parents at a third of units (29/86) had no access to financial support for food and drink costs.

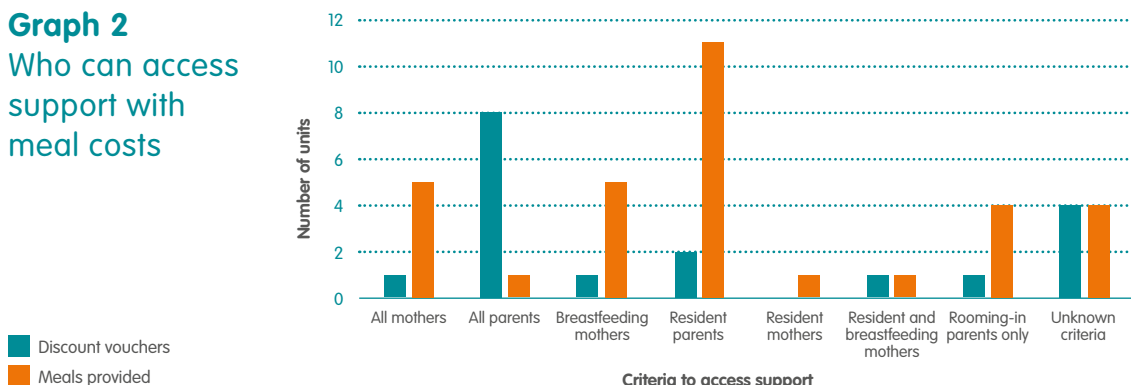
Worryingly, four out of the 11 hospitals with no food and drink making facilities at all also could not provide financial assistance with daily meal costs.²²

The overall number of units able to provide help with food and drink costs has increased from 47 units in 2013 to 57 units in 2015. While this overall increase is very welcome, an examination of the responses from the 75 units that provided data on this issue in both 2013 and 2015 reveals a level of vulnerability of such support packages in the current climate of NHS funding pressures. Of those units who provided data for both years, 12 units are now able to offer support to parents with food and drink costs when they could not in 2013. However 10 units which previously provided this support are no longer able to do so. Units that can provide help with meal costs offer assistance to parents in two ways: either through discount vouchers or by providing a full hospital meal; a small number did not provide enough information to determine exactly how they supported parents (please see **Graph 1**). Of the 50 units who told us they were currently able to offer some support with meal costs through discount vouchers or by providing meals, the majority of these impose strict criteria to access these schemes, meaning that many parents at these units are not entitled to assistance at all (please see **Graph 2**).

Graph 1
How units support families with meal costs



Graph 2
Who can access support with meal costs



Access to full meals is often reserved for those parents who are resident on the unit, breastfeeding mothers or mothers only. As units are lacking substantially in accommodation, it is likely that a very small proportion of parents will meet the criteria of being resident on the unit, and those that do will only meet the criteria for a short amount of time. Limiting access to just breastfeeding mothers may cause feelings of guilt among those who are unable or do not want to breastfeed, and also means fathers are excluded from support.

While the majority of units which offer discount vouchers are able to do so for all parents, only a relatively small number of units have this kind of scheme. Further, the amount that the discount covers varies from unit to unit, meaning even parents who receive these discounts may incur costs that are significant to them depending on their own personal finances.

Some staff have told us they try to be as flexible as they can be when interpreting the concession criteria to ensure as many parents can access the available support as possible, however the criteria is not set by them. These decisions ultimately rest with the NHS Trust. Unfortunately, in units where the criteria is strict, there is little the staff can do to make sure every parent who could benefit from this support does.

Schemes to support parents with meal costs are essential to ensure they do not have to leave their baby for long periods, just to eat. It is vital that NHS Trusts consider the impact of strict criteria which prevent the majority of parents accessing this support, inhibiting effective family-centred care being practised in neonatal units across the country.

“ I had to use my credit card to pay for the extra food costs while our baby was in hospital. We hadn't budgeted for this extra expense while I was on maternity, and had no other way to pay. ”

Mother of a baby born at 33 weeks

“ Family and friends had given us money to spend on the babies as a gift for their birth, but I had no choice but to spend it on food and travel costs instead. ”

Mother of twins born at 32 weeks



Car parking

In 2013 we discovered the cost of car parking could be a huge financial burden to families who had to drive to the hospital daily to visit their baby. While most hospitals do offer discount schemes to families, relatively few can provide parking fully free of charge. Sadly, the cost of parking has increased over the last few years and some hospitals which previously had free parking schemes for parents now have costly concession schemes in place instead.

Support parents should expect with parking at hospital

In 2014, the government issued guidance to NHS organisations which stated that they should offer free or reduced parking to certain visitors, including those visiting someone gravely ill or a long-term patient.²³

The *Toolkit for High-Quality Neonatal Services* expects units to provide easily accessible written information, available in a variety of languages and formats, which includes details on travel to and parking at the hospital.

Charges

Our analysis of 2013 and 2016 parking data shows **nearly half (62/126) of Trusts increased either their hourly or all-day parking rate over this period** (see methodology). In the majority of instances, the increases are minimal, coming in at under £1. However, several units have seen dramatic price hikes, including one hospital which now charges £22.80 more for all-day parking than it did in 2013, resulting in parents having to pay up to an extortionate £72 a day at this particular hospital if they have no other means of getting there other than by car.

No parent should have to interrupt their visit repeatedly to top-up the parking meter, or go home before they want to because they cannot afford to park for a few more hours. For parents whose baby is critically ill or dying, parking charges can add a cruel layer of additional stress at this time. There have been instances of visitors being fined because a close family member was dying and they did not want to leave their side.²⁴ No parent should be put in a position where they have to contemplate receiving a hefty fine because they needed to be with their baby.

While increasing parking tariffs may seem a simple answer to the problem of spiralling costs at many hospitals,²⁵ Trusts have a duty to ensure parents of sick babies are able to be with them. Car parking costs can stand in the way of family-centred care, especially when the baby is extremely premature or sick and will spend a long time in hospital. It is essential that the cost of parking does not limit the number or duration of visits.

Concessions

Despite most hospitals (123 out of 139) offering reduced parking to parents in 2016, there has been a significant decrease in the number offering free car parking, which is shown in Graph 3. **Of the 48 units that gave parents free parking in 2013, a third (16/48) now either charge families concessionary rates, or make them pay the full parking rate.**

Graph 3
Parking
concessions in
2013 and 2016



“Only one out of the three hospitals my son was in during his three months in neonatal care offered reduced parking costs. I was shocked to have to spend hundreds in parking to care for him.”

Mother of a premature baby

“Nobody told me about the parking help until two weeks in. They need to make sure they let people know these things at the hospital.”

Mother of a premature baby



**One third of hospitals
now charge parents
for parking, when
they could previously
park for free**

Our analysis of hospitals that have parking charges with reduced rates available shows **27 per cent (16 out of 60) of hospitals have made their concession schemes more expensive over the three year period** – equating to an average increase of £5.50 per week. Only a single Trust in this category has reduced the cost of parking in this time.

At those hospitals which still charge parents the full rate, costs at seven units are over £10 a day. The most expensive daily charge is £72. For families at these units, this will add significantly to the costs they already face and may prevent them from being able to visit their baby.

This shift towards charging rather than offering free parking indicates that NHS organisations are adopting new ways to follow the letter of the 2014 parking guidance while failing to reduce the burden of costs on parents.

Many Trusts require parents to fill in applications, approach several staff to grant them a concession, or enter into a complex process of paying a certain rate for a number of days or weeks before qualifying for a different tariff. The mind-boggling array of procedures, forms and steps would be confusing and inconvenient for anyone, but it is especially difficult for parents dealing with the extremely stressful and traumatic situation of having a baby admitted to neonatal care. The complexity of many of the schemes can be enough to deter parents from accessing them at all.

Some Trusts have different sets of concessions for different patient and visitor groups. As a result, some hospitals are able to provide free parking to those having cancer treatment or dialysis, for example, but require parents of babies in neonatal care to pay costly parking charges. Constant parental involvement is essential for babies to get the best possible care; parents therefore need to be able to access schemes which will allow them to be with their baby and help give them the best possible chance.

Best Practice Case Study

Norfolk and Norwich University Hospital

The unit at Norfolk and Norwich Hospital has in recent years successfully worked with their Trust to introduce a new scheme to support more parents to spend longer with their baby.

Since Bliss' *It's not a game: the very real costs of having a premature or sick baby* report, parking has been reduced to £2 a day for two weeks and is then free thereafter. Parents are now also given half price vouchers for the hospital canteen.



Hardship funds and other support

National standards on signposting to other organisations

The *Toolkit for High-Quality Neonatal Services* states that families need to be able to easily access written information, which is available in languages and formats appropriate to the local community, covering relevant services including social services, benefits advice and local and national support groups.

Trusts must have policies to provide financial support for families when there is a long-term admission and/or a long-distance transfer away from their local unit. Information about this financial support must be made available to families.

Not every family will need referral to emergency funds or other sources of support. But for those who find themselves in financial crisis while their baby is in hospital, not being able to access external support can mean the difference between being with their baby, or not.

While there have been some positive improvements since 2013 with 40 per cent more units (24 out of 65) now able to refer to a service or fund than could previously, still less than half of all units (34 out of 72) said they were able to signpost parents to a source of support in 2015. This leaves the majority of parents with nowhere to turn if they find themselves unable to cope with the costs and pressures which come with having to go to hospital every day.



Who are units signposting parents to?

For those families that are finding their increased living costs a substantial barrier to being with their baby, units may be able to refer to other sources that can provide additional support. In some instances, this support is a fund or grant providing monetary assistance for general living costs, or specific areas of expenditure such as travel costs. In other instances, the support is more practical, such as a donation of baby clothes, nappies or food.

Nurses and other neonatal staff try their hardest to ensure parents are not prevented from being with their baby due to costs. However, neonatal staff are unlikely to receive any external guidance on where to signpost parents in need of financial help. It is therefore essential that staff are supported to refer to organisations which are appropriate to the needs of parents whose baby is receiving neonatal care, to maximise their chances of successfully accessing help.

Units told us they signpost families to a variety of different organisations and bodies who can help support parents to be with their baby. Some signpost to large, national organisations; and in some cases the hospital will have its own established emergency fund for patients or visitors who need it. Other units have a charity attached who can provide practical and sometimes monetary support, or a unit social worker who can provide practical help and support with finding additional funds locally.

A smaller number of units said they have a dedicated family-centred care lead nurse who will advise families on financial and practical support available and help them access and complete all necessary forms. A couple of units also suggested that their only additional source to refer to was the hospital chaplain who could provide emotional support and sometimes practical donations of food or baby clothes.

The most popular referral cited by units was the Family Fund. This is a national organisation which does essential work providing families with hardship grants or other practical support to help them cope with the additional pressures of caring for a disabled or sick child. However, several units also noted that applications to this fund are largely unsuccessful; and this is perhaps to be expected in light of the Family Fund criteria for grants which may automatically disqualify many applicants.

For example, a key Family Fund criterion is that the child must be seriously ill with a condition that is expected to last 12 months or more and seriously impact on family life. For most babies receiving neonatal care, it is simply too early to know what the long-term effects of their early birth will be so only a small proportion of families will qualify against this criterion while their baby is on a neonatal unit. As such, the Family Fund may not be an appropriate source to signpost the majority of parents to in the first place.²⁶

The support each organisation or individual provides varies greatly, and criteria to access monetary funds can be particularly restrictive. Some units have changed where they refer parents to for additional support, and three units have lost a source to refer parents to altogether, including one unit which was able to refer to a local charity in 2013, but that charity is now unable to offer help to parents.

Despite being a valuable safety net for families who are struggling with their finances at this difficult time in their lives, the changing nature of support shows that these packages of assistance are fragile themselves. It is not guaranteed that parents will always be able to access them and the level and type of support on offer can fluctuate.

At Bliss, we would like to play a greater role in mapping what these appropriate sources are at both a local and national level, and to communicate this to parents and health professionals, and we will be taking this work forward throughout 2016 and 2017.



Communication

Despite some worrying trends highlighted in this report, most units are able to offer at least some facilities and practical support to help make parents' time with their baby on the unit as stress-free as possible. However, having facilities available only improves parents' experiences if they know they exist.

Parents' experiences of neonatal care: Findings from Neonatal Survey 2014 from the Picker Institute revealed only 41 per cent of families said they received enough information about financial support available to them which could help them cope with their baby's stay – the lowest scoring question in the whole survey.²⁷

While staff take great efforts to ensure parents are fully informed of the support available to them, most neonatal units will be under significant pressure due to staffing and over-occupancy issues which are affecting units across the country.²⁸ The under-resourcing of units contributes to staff not always being able to prioritise informing parents about what support is on offer to them.

Many units told us that financial information and help with accessing support is largely given to parents in leaflets, displayed on posters or is included in welcome packs; only a handful of units stated they had a dedicated member of staff who was responsible for telling parents about support and offering them help in accessing it. This suggests that the onus is usually on parents to ask for help.

However, it is not unusual for parents to feel embarrassed, guilty or ungrateful about admitting they are struggling with costs and need help, as they do not want to put additional pressures on busy nursing teams. Younger parents can find it particularly difficult to discuss their worries or concerns with staff.²⁹ This is a significant barrier to parents accessing the support they need and which is sometimes freely available to them. To normalise this support and to remove the taboo surrounding finances, neonatal services need to ensure staff do have the time to proactively inform parents about what is available and how to access it as soon as their baby is admitted to the unit.

Having a dedicated family support lead can help prevent parents from falling through the gaps. Identifying named staff to have this responsibility built into their role may also relieve pressure on staff within the unit as a whole because the responsibility of informing parents is delegated to one person. Other staff members will know to refer parents to the family support lead if they have questions that they do not have sufficient time to answer.

“You had to ask for help as the information was not given freely. It was only when we asked for help that we got told about everything that was available.”

Mother of twins born at 25 weeks

Best Practice Case Study

Queen Alexandra Hospital neonatal unit

“At our unit there is a designated member of staff that meets with families one to one to make sure all information is understood about how the unit is run, and what facilities are available. Written information is also provided in an admission bag and we offer parents a DVD to watch prior to admission if it is likely they are going to give birth to a baby who will need NICU support.”

Conclusions and recommendations

Every year the parents of over 84,000 babies in England find themselves trying to navigate the world of neonatal care. For most, the experience will be unexpected, overwhelming and frightening. These parents need all the support they can get so they can focus on the one thing that matters most: their baby.

Improving the facilities and financial support schemes to make this happen should not be an optional extra for services to consider as an after-thought, after medical equipment and clinical care. They are an essential component of a modern neonatal service to enable parents to actively engage in hands-on care for their baby.

Supporting parents to care for their baby

For babies to have the best possible outcomes it is essential that their parents are able to care for them every day on the neonatal unit, and that their visits last as long as they would like without frequent and lengthy interruptions from having to go home to sleep, eat or due to running out of money for parking. However, many units in England are simply lacking the facilities and support mechanisms to create an environment that is fully conducive to effective family-centred care.

Recommendation

1 Units should adopt the Bliss Baby Charter and use the audit toolkit to identify where improvements could be made to family-centred care. Through this audit and action planning process, units will be supported by Bliss to make changes, including the development of action plans and support with accessing funds to make improvements to family facilities available on the unit.

Accommodation and kitchen space

The *Toolkit* is clear that adequate accommodation and kitchen space is a necessity to keep families together and allow parents the opportunity to participate fully in family-centred care – yet only a handful of units meet these standards in full. This is in stark contrast to paediatric services which are all able to provide accommodation for families, demonstrating that if it is prioritised and resourced sufficiently, these issues can be resolved.

Recommendations

2 NHS Trusts and commissioners must ensure plans are drawn up for future expansion or redevelopment of hospital sites over the longer-term which include facilities for parents in line with the *Toolkit* standards. Families and members of the public should be given the opportunity to comment on redevelopment plans that will affect the experiences of parents with a baby in neonatal care.

3 Where it is not immediately possible to build more accommodation for parents on site, Trusts must find alternative ways to combat the shortage. For example, this could include making arrangements with local hotel chains or bed and breakfasts to provide free accommodation to parents, or building relationships with charitable organisations which may be able to provide accommodation to parents.

- 4 Where it is not immediately possible to provide kitchen space with the necessary appliances, Trusts must find other solutions, for example by implementing an easily accessible discount meal scheme.

Meals

While many units do provide support with meal costs, strict criteria prevents them from reaching every parent who needs support. This forces parents to regularly leave the neonatal unit to buy or make meals.

Recommendations

- 5 Trusts with an existing scheme in place to support parents with meal costs should review their access criteria to assess their impact on parents' ability to spend as much time with their baby in hospital as they would like.
- 6 Trusts with units which are unable to offer support should review whether there is a need to help parents with meal costs, and take steps to implement a scheme which will be accessible to all families who need it.

Car parking

There has been a sharp increase in the numbers of Trusts charging parents for parking. Even where parking concessions are available, many are still costly, and are complicated to access. Car parking costs remain a substantial barrier to parents being with their baby as often, and for as long as, they would like.

Recommendations

- 7 The government should review the 2014 parking guidance to include 'family members responsible for providing direct care to patients' as a separate category to 'visitors' and recommend this group have access to free parking. The government should take further steps to ensure Trusts are complying with the recommendations.
- 8 Trusts should review current parking policies and concession schemes, including any application processes, to ensure they are not creating barriers for parents visiting their baby. Parents should be consulted during these reviews.
- 9 Where concessions are offered, Trusts must ensure that these are clearly displayed on their website on both the car parking information pages and the neonatal unit pages.
- 10 Units must ensure that every parent is informed of the hospital's unique parking scheme upon their baby's admission, and offer support with completing forms and applications, if necessary.

Hardship funds and other sources of support

The number of units being able to refer to external sources of support has increased over the last three years. However, these sources can be fragile and limited in their scope.

Recommendations

11 Neonatal units should review the suitability of the organisations that they currently refer parents to, particularly if the Family Fund is the only option currently. Units without any services to refer families to must review the needs of their local population and source appropriate organisations to sign-post to, with the support of Bliss.

12 At Bliss we commit to completing an exercise which maps sources of support, including financial support, for parents by summer 2017. Bliss will communicate the findings to neonatal units to help them determine appropriate sources of support for families at both a local and national level.

Communication

The lowest scoring answer on the Picker Institute's 2014 survey of parents with babies in neonatal care was about receiving sufficient information about financial support on offer at the unit. Poor communication means parents who could benefit greatly from readily available assistance are falling through the gaps, and the time they can spend with their baby is affected as a result.

Recommendations

13 Units must ensure there is a designated family support lead who is responsible for ensuring parents understand the support which is available to them, and how to access it.

14 Units should ensure that details regarding sources of support such as car parking reductions, meal discounts and external organisations' support are included in parents' welcome pack when their baby is admitted to the neonatal unit.

Bliss Baby Charter

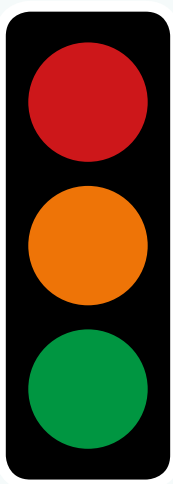
Bliss knows the positive long-term impact family-centred care can have babies born premature or sick and their families. We also know how difficult it can be to implement the often significant changes required to ensure family-centred care is embedded as well as it can be on a neonatal unit.

To help health professionals assess how their unit is doing, we developed the *Bliss Baby Charter*. It is divided into seven principles, which summarise the care and support that babies, parents and families should receive.

The *Bliss Baby Charter Audit Tool* was developed to help unit staff assess how well they are delivering against the standards outlined in the Charter's seven principles of care. Neonatal units self-assess how well they are managing to meet these standards using a red-amber-green scale and complete action plans to improve red and amber areas into green. Bliss supports units to keep reassessing to ensure practical changes and improvements to how family-centred care is facilitated are implemented. Once units have demonstrated their commitment and shown these improvements they can be awarded Bliss Baby Charter Accreditation. Our aim is for this to become a quality standard that services can use as a meaningful and effective benchmark for assessing performance, rewarding achievement and driving improvement.

The *Bliss Baby Charter* is based on national guidelines and supports the Department of Health's *Toolkit for High-Quality Neonatal Services* (2009), the *All Wales Neonatal Standards*, 2nd Edition (2013), and *Neonatal Care in Scotland: A Quality Framework* (2013).

If you would like to find out more about how the Bliss Baby Charter could benefit your unit please visit bliss.org.uk/baby-charter-audit-tool





Methodology

In June 2015, Bliss sent a survey to the 161 neonatal units in England that were operational during 2014/2015. 101 (63 per cent) units responded. Some of the information from these surveys was first published in the England *Bliss baby report 2015: hanging in the balance*.

In July 2015, Bliss asked parents to tell us about their experiences of neonatal care in an online survey. 224 parents in England responded, telling us about their experiences of neonatal care across the country. Some of the parent quotes in this report come from this survey. Other quotes are from our 2013 parent survey which assessed financial hardship among families with a neonatal experience, and feedback from parents on Bliss social media sites.

Bliss asked neonatal units how they supported parents with the additional costs they face when their baby is admitted to neonatal care in our 2013 unit survey, for which 154 responses were gathered from units in England. This survey formed the basis of our 2014 report, *It's not a game: the very real cost of having a premature or sick baby*. Some of the 2013 data was used to compare with what neonatal units told us in 2015, to highlight where there have been improvements and where persistent challenges remain.

In our 2013 survey, we received comprehensive details about car parking charges and existing concessions from most neonatal units (151 out of 154). This information is largely available online on hospital or NHS Trust websites. Bliss and a group of volunteer campaigners gathered cost and concession data on most hospitals with a neonatal unit in the UK (150 out of 160). Using this information, it has been possible to directly compare how costs and concession policies have changed over the last three years in England.

References

- ¹ 84,573 babies were discharged from neonatal care in England in 2014. This figure is the England portion of the 90,253 babies who were discharged from neonatal care in England, Scotland and Wales in 2014: Neonatal Data Analysis Unit (2014), NDAU 2014 report, *Imperial College, London*. Researchers at NDAU kindly provided the nation breakdown for Bliss, and is unpublished in their report.
- ² O'Brien K, Bracht M, Macdonell K, McBride T, Robson K, O'Leary L, Christie K, Galarza M, Dicky T, Levin A, Lee S (2013) 'A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit,' *BMC Pregnancy and Childbirth*. 13(Suppl 1):S12,
- ³ Flacking R, Lehtonen L, Thomson G, Axelin A, Ahlqvist S, Hall Moran V, Ewald U, Dykes F. (2012) 'Closeness and separation in neonatal intensive care,' *Acta Pædiatrica* 101:1032–1037
- ⁴ POPPY Steering Group, Family-Centred Care in neonatal units, <http://www.poppy-project.org.uk/resources/Poppy+report+for+PRINT.pdf> p.6
- ⁵ Vigod, S.N., Villegas, L., Dennis, C.L., Ross, L.E. (2010) Prevalence and risk factors for postpartum depression among women with preterm and low-birth weight infants: a systematic review, *BJOG*, 117(5), pp.540-50
- ⁶ Hynan, M.T., Steinberg, Z., Baker, L., Cicco, R., Geller, P.A., Lassen, S., Milford, C., Mounts, K.O., Patterson, C., Saxton, S., Serge, L., Stuebe, A.,(2015) 'Recommendations for mental health professionals in the NICU,' *Journal of Perinatology*, 35 S14-S18
- ⁷ Kaffashi F, Scher M, Ludington-Hoe S, Loparo K (2013), 'An analysis of the kangaroo care intervention using neonatal EEG complexity: a preliminary study,' *Clinical Neuro physiology*. 124(2):238-46
- ⁸ NHS and Department of Health (2009), Toolkit for High-Quality Neonatal Services, accessed [online] at: https://www.nepho.org.uk/uploads/doc/vid_8769_Toolkit%20for%20high-quality%20Neonatal%20services.pdf Principle 3: Care of the baby and family experience pp.46-50
- ⁹ POPPY Steering Group, (2009), Family-Centred care in neonatal units. A summary of research results and recommendations from the POPPY project, London: NCT, accessed [online] at: <http://www.poppy-project.org.uk/resources/Poppy+report+for+PRINT.pdf> p.5
- ¹⁰ National Maternity Review, (2016), Better births: improving outcomes of maternity services in England: A Five Year Forward View of Maternity care, accessed [online] at:<https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf> p.65, section 4.57
- ¹¹ O'Brien, K., Bracht, M., Macdonell, K., McBride, T., Robson, K., O'Leary, L., Christie, K., Dicky, T., Levin, A., Lee, S.K., A pilot cohort analytic study of Family Integrated Care in a Canadian neonatal intensive care unit. *BMC Pregnancy and Childbirth*, 13(Suppl 1):S12
- ¹² Gooding, J.S., Cooper, L.G., Blaine A.I., Franck, L.S. Howse, J.L., Berns S.D., (2011) Family support and family-centred care in the neonatal intensive care unit: origins, advances, impact. *Seminars in Perinatology*, Vol. 35, Issue 1, pp.20-28
- ¹³ NHS and Department of Health (2009), Toolkit for High-Quality Neonatal Services, accessed [online] at: https://www.nepho.org.uk/uploads/doc/vid_8769_Toolkit%20for%20high-quality%20Neonatal%20services.pdf pp.46-50

- ¹⁴ Bliss (2016), Bliss baby report 2016: transfers of premature and sick babies
- ¹⁵ Bliss (2014), It's not a game: the very real costs of having a premature or sick baby in Britain
- ¹⁶ The statistics on units with accommodation for parents of critically ill babies are slightly different to those used in the Bliss baby report 2015 as they include further survey responses received since the deadline for our 2015 report.
- ¹⁷ National Maternity Review, (2016), Better births: improving outcomes of maternity services in England, p.65, section 4.57.
- ¹⁸ Bliss (2016), Transfers of premature and sick babies
- ¹⁹ Bliss, (2015), Bliss baby report 2015: Hanging in the balance (England), p.23
- ²⁰ Allen M, Spencer A, Gibson A, Matthews J, Allwood A, Prosser S, et al. (2015), Right cot, right place, right time: improving the design and organisation of neonatal care networks – a computer simulation study. *Health Serv Deliv Res* 3(20).
- ²¹ Bliss, (2013), The best start: A guide to expressing and breastfeeding your premature baby, 10th Edition, pp.6-9
- ²² The statistics on units able to offer meal concessions to parents are slightly different to those used in the Bliss baby report 2015 as they include further survey responses received since the deadline for our 2015 report.
- ²³ Department of Health (2014), Guidance: NHS patient, visitor and staff car parking principles, accessed [online] at: <https://www.gov.uk/government/publications/nhs-patient-visitor-and-staff-car-parking-principles/nhs-patient-visitor-and-staff-car-parking-principles>
- ²⁴ BBC News (2014). Hospital car parking guidance to reduce some charges. [ONLINE] Available at: <http://www.bbc.co.uk/news/uk-28905695>. [Accessed 14 March 16]
- ²⁵ NHS Trust Development Authority and Monitor, (2016), Quarterly report on the performance of the NHS provider sector: 9 months ended 31 December 2015, accessed [online] at: https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/501919/Q3_report.pdf
- ²⁶ See more on the Family Fund's criteria: <https://www.familyfund.org.uk/FAQs/our-disability-criteria>
- ²⁷ Picker Institute Europe, (2015), Parents' experiences of neonatal care: Findings from Neonatal Survey 2014, p.22
- ²⁸ Bliss, (2015), Bliss baby report: Hanging in the balance (England)
- ²⁹ Picker Institute Europe, (2011), Parent's experiences of neonatal: A report on the findings from a national survey, p.16

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† 020 7378 1122

e ask@bliss.org.uk

w bliss.org.uk

**a Bliss, 2nd floor Chapter House,
18-20 Crucifix Lane,
London SE1 3JW**

Registered charity no. 1002973 Scottish registered charity SC040878

bliss.org.uk