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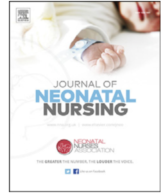
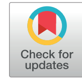


Putting families at the heart of their baby's care



Helen Kelly

Bliss, 2nd Floor, Chapter House, 18-20 Crucifix Lane, London SE1 3JW, UK

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ABSTRACT

Bliss is the UK's leading charity for babies born premature or sick, this paper explores the vital role of Bliss in supporting babies born premature or sick and in particular, the role Bliss plays in promoting family-centred care. The philosophy and benefits of family-centred care are well recognised yet there are still some barriers to implementing family-centred care in a neonatal setting. Bliss developed the Bliss Baby Charter in 2009 to standardise high quality family-centred care across the UK. This paper will discuss the principles of the Bliss Baby Charter and explore the emerging model of Family Integrated care and its relationship to family-centred care.

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1. Introduction

Bliss is the UK's leading charity for babies born premature or sick, and our vision is that every baby born premature or sick has the best chance of survival and quality of life. Ever since we were founded in 1979 Bliss has put babies and their parents at the heart of our work to improve neonatal care. Over many years we have developed our work with neonatal professionals, units and networks to ensure that parents are meaningfully involved in their babies' care throughout their stay on a neonatal unit. Evidence tells us the difference this makes to babies' outcomes (POPPY Steering Group, 2009), and many thousands of parents have told us the difference this makes to their confidence as a parent.

Our strategic plan 2016-19 sets out how we currently aim to achieve our vision through four key objectives: supporting parents to be as involved as possible in care and decision-making for their babies; supporting neonatal professionals to deliver high quality care and to involve parents actively in their babies' care; placing premature and sick babies' voices at the heart of decision-making to ensure that their best interests are always put first; and supporting research that can tangibly improve outcomes for babies born premature or sick (Bliss Strategy, 2016–19).

In the UK 95,000 babies are born premature or sick each year and admitted into neonatal care (National Neonatal, 2017). For these babies the care they receive in their first hours, days, weeks and months of life is vital for determining their future health and their long term outcomes. Evidence shows that if parents are supported and encouraged to take care of their baby whilst in hospital, this will result in better outcomes for both the baby and their family (Bliss Scotland baby report, 2017).

The most common term to describe parental involvement in babies' care on a neonatal unit is **family-centred care**. There are a number of different definitions of family-centred care and, although the wording of these can differ, its fundamental approach can be described as: ‘A philosophy of care that helps families whose baby is in hospital to cope with the stress, anxiety and altered parenting roles that accompany their baby's condition. It puts the physical, psychological and social needs of both baby and their family at the heart of all care given’ (Department of Health, 2009). Research has identified a number of positive outcomes of family-centred care: it can shorten a baby's length of stay in hospital and reduce re-admission rates, as well as improve bonding between parents and their baby and help parents to feel more confident and able to care for their baby both in the unit and at home (POPPY Steering Group, 2009; O'Brien et al., 2013).

Family-centred care is achieved by involving parents throughout the whole neonatal experience. This includes prior to admission (where possible), on admission, all the way through to discharge and the support provided at home. For some families the neonatal journey may be a short one of just a few hours or days. For other families whose babies spend a longer time on a neonatal unit this could last for weeks or even months. However, regardless of the length of stay all parents are a vital part of the care team and should be encouraged to be present on the neonatal unit to carry out daily cares for their baby, bond with them, and be part of the decision-making about their care. Feedback from parents has shown how important this kind of involvement is to help parents bond with their baby:

“Doing Emilia's care routine was such a rewarding and special thing to me. Other mums might see changing a nappy or feeding

E-mail address: helenkelly@bliss.org.uk.

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expressed milk through a syringe as a bit of a chore but to me these simple things meant everything. I couldn't pick her up or take her out in her pram so helping with her care routine was how I would bond with Emilia and I absolutely loved doing it." Mother of a baby born at 28 weeks.

"The nurse invited me to help her with Olivia's cares. After that I would count down the hours until I could go back and see her, I felt ready now. She was 11 days old when I changed her nappy and washed her with cotton buds, it was amazing." Mother of a baby born at 28 weeks.

There has been significant change and development over the years in the involvement of parents in their baby's neonatal care. In the earliest days of special care units parents were routinely separated from their babies throughout their entire hospital stay, allowed to see them only through the glass windows of 'viewing corridors' for fear of causing infection among these vulnerable babies7.

Times have moved on significantly since then and the importance of parents being involved in their baby's care is now widely accepted in the UK. However, in 2009 the POPPY (Parents of Premature Babies Project) report identified that there was insufficient attention being paid to how best to deliver genuinely family-centred care in neonatal units across the UK, and significant variation in practice between units as a result (POPPY Steering Group, 2009).

Bliss strongly supports a family-centred care approach to neonatal care, and we advocate this at the heart of all our work. In this paper we describe in more detail:

1. Our flagship Bliss Baby Charter programme, designed to support the standardisation of family-centred care across the UK
2. The importance of providing appropriate facilities and accommodation to enable parents to spend as much time as possible with their baby
3. The need for high quality developmental care training for neonatal staff to be at the heart of family-centred care, to ensure they deliver the optimum environment and care for babies and their parents
4. The emerging model of Family Integrated Care, and Bliss' role in supporting best practice across the UK.

2. The Bliss baby charter

The Bliss Baby Charter was first developed in 2009 as a set of seven core principles to standardise the foundations for high quality family-centred care across the UK. Since then, the Bliss Baby Charter has evolved into a comprehensive practical framework for neonatal units to self-assess their family-centred care and use as a tool to improve the quality of the care they deliver. The Charter enables units to audit their practices and develop action plans to achieve tangible changes that benefit babies and their families. Implementation of the Baby Charter ensures that parents are supported to look after their baby in a developmentally supportive environment.

Captured in seven core principles, the Charter ensures that families are at the centre of the care for their baby whilst on a neonatal unit. The seven Bliss Baby Charter principles cover:

- Social, developmental and emotional needs
- Decision making
- Specialist services and staff
- Benchmarking
- Unit information and support
- Feeding
- Discharge

Within each principle a series of detailed standards describe what facilities, guidelines, training, information and support should be in place to encourage parents to be with and care for their baby as much as possible. Units participating in the Charter are able to work towards Bliss Baby Charter accreditation - this can take place after a unit has gone through at least two audit and action planning cycles, and comprises an assessment conducted by health professional and parent assessors, who must agree that units are delivering at least 90 per cent of the standards for each of the principles within the Charter in order for accreditation to be awarded.

The Bliss Baby Charter gives units a clear focus that is based on, and supports, national standards including the Department of Health Toolkit for neonatal services (2009), the All Wales Neonatal Standards, 2nd Edition (2013) and Neonatal Care in Scotland: A Quality Framework (2013). The Charter has become a well-recognised standard for family-centred care and a framework for quality improvement within the neonatal community, and has recently been included as a Quality Indicator in NHS England's Quality Surveillance Team peer review process.

The Charter promotes a consistent level of family-centred care within different units and neonatal networks across the UK, which is not only important in its own right to ensure consistency of care, but is also particularly important given the number of babies who are transferred between units during their neonatal journey. As of October 2017 over 150 units across the UK are actively participating in the Bliss Baby Charter in England, Wales and Scotland, and three units have been accredited.

3. The importance of facilities in delivering family-centred care

For babies to have the best possible outcomes it is essential that their parents are able to care for them on the neonatal unit, and that their time on the unit lasts as long as they would like without frequent and lengthy interruptions from having to go home to sleep, eat, leave for ward rounds or due to running out of money for parking (Families kept, 2016). The provision of sufficient family facilities - including accommodation, travel costs, financial support, and kitchen facilities - is therefore essential to support parents in spending as much time as possible with their baby on a neonatal unit, and therefore to deliver high quality family-centred care.

Conversely, a lack of adequate facilities on or close to the neonatal unit presents a considerable barrier to parents spending time with and being involved in the care of their baby, which can have a significant impact on vital aspects of care such as breastfeeding and bonding (Neonatal Intensive Care N, 2010). While national standards across the UK are clear about what facilities units *should* be able to provide to parents, what units actually have available varies hugely.

This wide variation in the facilities and support available at different hospitals results in a postcode lottery for parents. In 2016 the Bliss report *Families kept apart: barriers to parents' involvement in their baby's hospital care* found that:

- More than one in three hospitals did 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
- Over 40 per cent of units had no, or very limited kitchen facilities for parents to prepare food or hot drinks
- A third of hospitals where parents could park for free in 2013 now charged parents for parking; and a further quarter of hospitals had increased the cost of their concessionary parking charges for parents since 2013.

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