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Putting families at the heart of their baby's care

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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

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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.

“No food or drinks were provided and we were unable to eat on the ward at all, so although I took a packed lunch every day, I had to pay for drinks in order to be able to sit in the coffee shop and sneakily eat my own lunch” Mother of twins born at 30 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.

Having a baby in neonatal care will always be an incredibly stressful and difficult time for families, but having the right facilities and support in place to help with the financial costs parents face can help to relieve some of these pressures and enable parents to focus on their baby, and their hands-on role in his or her care. It is also particularly important that there is equitable provision of support for parents across units, to facilitate ongoing parental involvement and family-centred care when a baby is transferred between units.

For families, a transfer from a neonatal unit which offers a lot of support to one which offers very little can be disconcerting, frustrating and stressful, and can undo patterns of parental care such as breastfeeding and skin-to-skin contact which had been established in the previous unit. Conversely, moving from a unit which offers little support to one where there is far more available can cause great distress to parents as they become aware of how much they have missed out on in their baby's first days and weeks of life.

4. The need for high quality developmental care training at the heart of family-centred care

Bliss advocates that neonatal staff should be provided with the funding and opportunities they need to develop and maintain their skills. Indeed, the availability of and access to staff training and education - and particularly training in developmental care - is a core element of units being able to deliver excellent family-centred care.

Since 2014 Bliss has partnered with the Family and Infant Neurodevelopmental Education (FINE) programme to develop a training toolkit for neonatal health professionals in the UK. FINE is a training model for health professionals that promote developmental care through sensitive interactions with the baby, engaging parents as partners in care, and individualising care according to infant behaviour, medical and developmental status (Warren, 2017).

The FINE programme is based on three basic principles:

- **Sensitive care is good for the brain** - this is neuroprotective because it helps to minimise stress and pain and to provide a nurturing environment.
- **The importance of relationships between infants and caregivers, and between families and health professionals** - the parent-infant relationship is key to a baby's future development and health, and it thrives when parents have opportunities to be close to and involved in their baby's care and comfort.
- **Care for infants should be individualised** - Every infant is unique, and their needs will change according to circumstances, maturation and medical status. Some interventions may be good for all; others need to be carefully adjusted to maximise the infant's, and the family's, strengths and to protect their vulnerability.

Within the framework of these three principles there are six core themes within FINE that cover both theory and practice in developmental care: infant development; observation of the baby; family participation; reflective practice; understanding how systems work; and supporting evidence. Through the FINE programme - which currently has 2 levels: the Foundation Toolkit; Practical

Skills - neonatal professionals can develop the skills they need to work collaboratively with parents to give high quality family-centred care that follows the principles of sensitive, relationship-based and individualised care.

5. The family integrated care model

In recent years, the work of the Mount Sinai Hospital in Toronto in developing a new model for delivery of family-centred care, Family Integrated Care - has attracted a lot of interest and attention in the UK, and indeed other parts of the world. This model, originally based on neonatal practice in Estonia, establishes a structure to support parents as partners in the neonatal care team for their baby, and places significant emphasis on empowering health professionals to be coaches, mentors and counsellors for parents. Parent education, mainly delivered by nursing staff together with 'veteran parents', teaches parents what they need to know to become fully active team members caring for their baby on the neonatal unit. Parents are taught and supported to be involved in all possible aspects of their baby's daily care - including feeding, changing nappies, and administering oral medication - as well as to play an active role in daily ward round discussions. Staff training is vital to ensure this education for parents enables them to deliver hands-on care in a way that best supports their baby's development.

5.1. The UK family integrated care working group

In light of the strong interest across a number of units in developing Family Integrated Care in the UK, Bliss has convened a working group bringing together a range of experts to consider how it can help to build on and enhance existing programmes to improve both family-centred care and developmental care, all designed to improve the quality of neonatal care provided for babies and families. The working group is multidisciplinary, and is made up of health professionals and parents from five hospitals across England, Scotland and Wales which have started to take forward their own approach to implementing the Family Integrated Care model. The group was established in 2016, and its aims have been agreed as:

- To share knowledge and best practice of Family Integrated Care in the UK
- To build on the current body of evidence surrounding Family Integrated Care
- To hold a national conference on Family Integrated Care for health professionals
- To link with international partners to promote the work going on in the UK
- To develop a framework for Family Integrated Care in the UK that can be adopted/adapted by individual units
- To seek ways to incorporate Family Integrated Care into the Bliss Baby Charter

By September 2017 Bliss, supported by the working group, had delivered three Family Integrated Care conferences to over 250 health professionals. These conferences provided an introduction to the Family Integrated Care model, and its relationship to complementary models of care, and also provided delegates with practical tips on how to implement Family Integrated Care on their unit. There were also a number of opportunities to hear from parents who have been on a unit delivering Family Integrated Care and their experiences of this.

“Fantastic overview of FICare and excellent reflections of the units and personal experiences” Delegate from Bliss Study Day, 2017.

In the coming year Bliss will be doing further work to explore how best practice from the Family Integrated Care model can be incorporated into an updated version of the Bliss Baby Charter, providing units with further opportunities to build on the level and quality of family-centred care that they deliver. In doing so, we will continue to focus on how to support the delivery of consistent support for parents and families across neonatal units throughout the UK.

“I am confident there will be a ‘FICare movement’ and the future for neonates and families is bright.” Delegate from Bliss Study Day, 2017.

6. Conclusions

Bliss is committed to working with parents and professionals in neonatal units across the UK to support the delivery of a truly family-centred approach to care for all babies born premature or sick and their families. We know that meaningful parental involvement in their baby’s neonatal care, delivered in a developmentally supportive environment, has proven health and developmental benefits for babies and also improves bonding and emotional wellbeing for the whole family.

In order to achieve this, neonatal units and professionals must embark on a programme of quality improvement, encompassing the culture on a unit, the provision of staff training and support, and the availability of practical, financial and emotional support for parents. The Bliss Baby Charter provides a comprehensive framework for units to start on this journey, supported by FINE developmental care training, and Family Integrated Care provides a

further framework for those units keen to adopt this structured approach.

Bliss will continue to strive towards increasing and improving parental involvement in their baby’s care, through our own work on the Bliss Baby Charter and supporting the Family Integrated Care working group, as well as through our work to influence other national bodies, to ensure that parents are always put at the heart of their baby’s care.

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