Developmental care – mapping the way forward in the UK: a BLISS initiative

BLISS believes it is essential to raise the profile of the importance of developmental care, and that there is sufficient evidence to support its introduction into units in the UK – from the perspective of both babies and their families. Uptake of developmental care in this country is increasing but BLISS would like to help speed up this process. The BLISS Developmental Care Special Interest and Support Group is helping to identify examples of good practice and innovative ways to make this happen.

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Key points

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1. BLISS supports the promotion of developmental care and believes that it has the potential to be of benefit to premature babies and their families.
2. It has set up a special interest and support group for any practitioners interested in working with this approach.
3. The group provides a supportive environment for sharing successes and challenges, and is working towards its vision of a UK model for developmental care.

We all know that babies of earlier gestations and lower birthweights than ever before are now surviving. More sophisticated technology and advances in medicine have increased the ability of neonatal practitioners to treat even the most premature infants. However, saving the lives of these babies is not enough; more and more attention is now, quite rightly, being given to the long-term outcomes and to the associated quality of life for these babies and their families.

Premature birth can bring with it a number of potentially negative effects, ranging from mild developmental delay to severe disability. Infants born very preterm at less than 32 weeks have poorer neurobehavioural outcomes than children born at term, including poorer school performance and higher rates of attention deficit disorder[1-3]. On top of that, the neonatal intensive care environment with its technology-heavy and task-oriented interventions can cause additional stress to the infant, compromising neurodevelopmental stability. There is growing evidence of how these critically important, yet stressful, medical interventions impact on the infant's neuromotor, behavioural and growth milestones, thus giving these babies even more obstacles to deal with. If there is a way to care for babies on neonatal units that specifically aims to enhance their capacity for development, shouldn't it be followed as much as possible? Furthermore, if such an approach also explicitly acknowledges parents' rights and needs to play as full a role as possible in the care of their baby, shouldn't this be the approach that all units adopt?

Developmental care is such an approach.

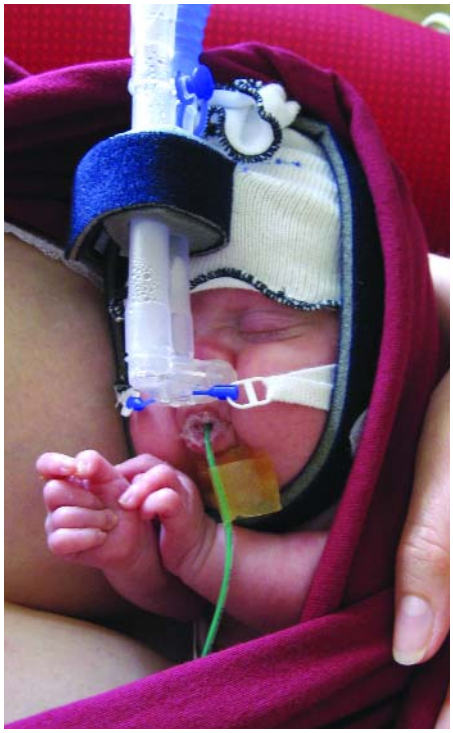

FIGURE 1 A positive experience with positive touch.

It relates to a broad category of interventions designed to minimise the stress of the neonatal unit environment. It includes control of external stimuli, integration of parents in care activities, and specific supportive behavioural techniques such as kangaroo care, positioning and non-nutritive sucking. A key element of developmental care is the recognition of the need for individualised care for each baby.

Why BLISS believes developmental care to be a good thing

For several years BLISS, the premature baby charity, has been promoting developmental care as a positive influence

on neonatal care. Our position has been shaped by the growing body of evidence which suggests that a developmental care approach can lead to a number of concrete benefits for the infant: fewer days on ventilation, shorter hospital stay, better growth and other effects[4-5].

What parents are telling us

Another significant influence on our views has been the experience of parents as told to us by the parents themselves. Through our various support services, BLISS comes into contact with thousands of parents across the UK. The stress of having a baby in neonatal care is well-documented[6-9] and BLISS is reminded of this daily via calls to our helpline, emails to our enquiry service and posts on our parent message board. While parents are generally highly satisfied with the care their baby received and are enormously grateful to the health professionals who have provided it, they are nevertheless often left shell-shocked by their experience of neonatal care. This is especially true of parents whose baby was born extremely premature and required weeks or sometimes even months of intensive care. There are a number of key factors leading to parental stress and anxiety, apart from the overriding concern of whether or not their child is going to survive and be healthy. These include the often unnerving impact of such a high-tech environment and their perceived inability to be a 'real' parent. The difference between the experience they imagined they were going to get (giving birth to a healthy term baby who they would care for themselves at home) and what they did get (a vulnerable baby, dependent on technology for its survival and separated from them by the walls of an incubator) can be extremely difficult to cope with. This can have long-term effects on the attachment between parent and baby and on family relationships[10].

The anecdotal evidence collected by BLISS shows that parents whose babies have been cared for on units where developmental care is widely practised have been hugely supportive of this approach. They have welcomed the opportunity to be more involved in their baby's care, have felt comforted in the knowledge that their role as a parent, ie as the key caregiver, has been recognised, and have felt that they were able to form a good attachment with their baby while still on the unit (**FIGURE 1**). Parents have shared with us their frustrations (and disappointment) when

FIGURE 2 A poster designed to improve the environment developed by Quality Improvement NICU Environment Team 2007 at North Bristol Trust.

their baby has been transferred from a unit where developmental care is practised to one where it is not. This is partly to do with parents feeling their role has been diminished ie they are not given the same opportunity and encouragement to be involved in the care of their baby and partly their perception that the care their baby is now receiving is not as good ie the individual needs of their baby are not so explicitly recognised and addressed.

Uptake in UK

Developmental care emerged in the 1980s and has since been adopted as routine practice in many Scandinavian countries. It is a growing practice in other parts of Europe, for example France. In the UK the uptake of this approach has been much slower. This may be due to the fact that there is limited evidence that outcomes for infants are improved if they receive NIDCAP-based care[11]. In 2005 BLISS commissioned a survey of neonatal unit practice across the UK, undertaken by Maggie Redshaw and Karen Hamilton of NPEU, which included some specific developmental care-related questions. The results from this survey showed that only 40% of units had a dedicated developmental care lead and only 24% had any staff that had been trained in a

FIGURE 3 We hold their lives in our hands – what we do today will affect the rest of their days.

developmental care approach. The majority of units stated that they modified noise and light but in many cases they did not appear to be using any other form of developmental care intervention.

While BLISS does not have updated data on these questions, from our perspective there appears to have been a shift over the past two years or so with many more units showing an interest in adopting a developmental care approach and an increase in expressed need for developmental care training for staff. We are aware of several units and neonatal networks that have created dedicated developmental care leads and also a number where substantial funding has been allocated to developmental care training for a significant number of staff.

BLISS developmental care group

Due to the unique position that BLISS holds within the neonatal community – neither wholly within nor wholly outside it – we are able to take an overview perhaps more easily than someone totally immersed one way or another. We could see that in some places real strides were being made in terms of introducing developmental care, with some creative uses of limited resources and innovative models being devised; in other places we were aware that there was a lone pro-developmental care voice trying to make itself heard (**FIGURE 2**).

In 2007 BLISS established the Developmental Care Special Interest and Support Group, with the aim of providing a common forum for anyone interested in promoting developmental care within their unit. The group has agreed terms of reference which set out its key objectives and the fundamental principles on which it has been formed.The group exists both virtually, through email contact and a specific forum for developmental care practitioners on the BLISS message board, and actually, through meetings. Membership is growing (about 45 registered people so far) with attendance at meetings increasing significantly with each event. Members represent all parts of the UK and are drawn from a range of disciplines – doctors, nurses, occupational therapists, speech and language therapists, neonatal network managers. The multidisciplinary and inclusive nature of the group is one of its strengths and allows a range of experiences and perspectives to be brought to the table.

Emerging issues

Sharing successes and challenges is a key function of the group, as is identifying points of good practice and strategies for managing change that can be adopted in units of any type and size.

There are a number of key issues that have emerged so far and which the group is addressing. It is vital that developmental care competencies are developed to ensure that this area of practice can establish and maintain a good professional reputation. These competencies must be evidence-based, and their development must be properly coordinated with appropriate training. Several members of the group are already working with colleagues in their units/networks to move forward on the creation of relevant and robust competencies; the group provides an excellent forum for sharing, discussing and improving on these works in progress.

Similarly, benchmarks related to developmental care are needed, and these also need to be evidence-based wherever this is possible. The group has been able to draw together the work done so far by a number of different networks, identifying their various strengths and weaknesses and suggesting ways to improve them. Members of the group are taking back ideas and information that they have gathered from the meetings to test in their own places of work.

While shortage of staff and money for training/development is a common problem, there is also a commitment within the group that these constraints need not prevent or even slow down the introduction of developmental care as an integrated part of neonatal care. While it is agreed that some form of dedicated developmental care lead is vital, the group is demonstrating that, with some creative thinking and innovative leadership, a lot can be achieved with limited resources. One Midlands network has created an effective model for promoting developmental care across all its units but which centres on one 21 hours a week post.

The group has not been set up to advocate one particular approach to developmental care over another. The members represent a wide range of experiences and ideas, with people who have been actively promoting and following a developmental care approach for years, through to individuals who are convinced of its benefits but who are just starting to think about what it might mean for their practice and how they might introduce it into their unit. The NIDCAP approach is represented on the group but also other, more organic approaches too. The group is aware that although there has been a significant increase in the interest being shown in developmental care, and that in some places this is translating into proactive introduction of appropriate practices, there is still a long way to go to make this a routine practice for the UK. It has been suggested that one reason for some lingering resistance on the part of some clinicians is the perception that developmental care isn't always appropriate

or applicable in a UK context, or at least this is the impression these 'resistors' have gained from some of the more formal developmental care training programmes. This may stem from the fact that developmental care emerged originally from the US and the NIDCAP approach was developed there. We need to convince everyone that developmental care is appropriate, and necessary, in all neonatal care settings.

Towards a UK model for developmental care

One possible way to address this is to create a UK model for the training in, and introduction of, developmental care. A model that explicitly takes account of the UK context: the demographics, the staffing ratios, the way the flow of babies is managed within neonatal networks. The group doesn't claim to know exactly what this would look like, but this is a vision that we are working towards and the group does believe that it can make a very real contribution to making this happen.

The role of BLISS

BLISS will continue to raise the profile of the importance of developmental care, believing as we do that it has the potential to make a positive difference for both babies and their families (**FIGURE 3**). We will continue to work with both clinicians and parents to find ways to improve the delivery of neonatal services, looking always for new approaches that will help raise the standards of care and facilities provided by all units.

We will continue to support the Developmental Care Special Interest and Support Group so that practitioners in the UK have the means to support each other and gain from each other's experience – and so that good ideas and best practice can be shared and widely adopted for the benefit of all. The group is already demonstrating that the commitment, energy and creativity necessary to bring about change and work towards our vision is there in abundance.

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