Parents as partners in neonatal care: The Integrated Family Delivered Care (IFDC) Project

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'It’s all the beeping and strange equipment ... it’s all so overwhelming. And it’s not what you expected or dreamed of. I mean nobody wants that you know.’

Parent of baby in neonatal unit

One in eight babies born in the UK will be admitted to a neonatal unit for specialist care for babies who are born prematurely, have a low birth weight, or have a medical condition requiring specialist treatment.

Over 95,000 families a year in England will be affected; some with multiple births — twins and triplets. No parent when imagining their pregnancy and delivery of their newborn baby wishes to be separated immediately after birth, but this is what happens to many new parents of sick and premature babies.1

The neonatal environment can be a shocking and frightening experience for parents. For most this was not what they imagined early parenthood would look like. One parent said, ‘I’ve lost the chance to look after my baby, to do the things that it’s usually the norm with most mothers; bring a baby home from the hospital right away and show them off to the world, I’ve lost that chance’.
Their babies are often very sick or fragile, requiring medical support and interventions. They may be separated in an incubator or connected to breathing equipment and monitors, making it difficult to pick up and cuddle them. They may need tube feeding and are not able to feed from the breast or bottle yet. This environment can leave parents feeling helpless and scared.

“...I wasn’t there so much. I lay in the maternity unit in my bed. I wanted to see him but at the same time I didn’t because I didn’t want to get attached. I thought he would die and I had to be prepared for that.’

For parents, neonatal care can arouse deep emotions and anxiety. Stress can be detrimental both to baby and parents and their developing relationship. They may feel like they have failed as parents which can lead to high levels of postnatal depression and post-traumatic stress for mothers and fathers.2,3 Siblings and grandparents are often limited in the time they can spend with the new baby, and it can be an anxious and difficult time for the whole family.

Nurturing parents

Supporting and nurturing the parents in this situation is vital to enable bonding and prevent longer-term problems of anxiety and trauma. Even in these early days babies know their parents voice, smell and touch and are soothed by their loving presence. It is essential to the baby’s care and outcome that their parents are with them as much as possible, getting to know and care for them. It can enable parents to reclaim an alternative parenting role:

‘I felt like a true mother. Before he was so small and I couldn’t handle him. I knew I was his mother but now I was doing everything a mother is supposed to do and once I started doing all that it was more real.

The traditional model of neonatal care is much the same as maternity care was in the 1950s; doctors and nurses know best. Newborn babies were taken to vast nurseries to be cared for and only returned to their parents when doctors deemed it appropriate. This early separation had consequences on bonding, breastfeeding and parenting confidence. While much of maternity care has progressed it has been more of a challenge to nurture parenthood in the neonatal environment. Further work is still needed to fully recognise the rights of the child — to be treated as human beings with a distinct set of rights instead of as passive objects of care, according to the UN Convention on the Rights of the Child. Neonatal care strives to save lives and improve outcomes and is a high tech, specialist, intensive environment. It has gradually adapted to consider the baby’s developmental needs and impacts on the family. But care needs to support building a family, not just nursing a baby.

Child psychoanalyst Donald Winnicott once wrote, ‘there is no such thing as a baby… there is only a baby and someone’. He was referring to the complete dependence an infant has on his or her caregivers, and how crucial the first relationships are for later outcomes. Babies who have strong bonds with their parents have better neurodevelopmental outcomes.4
Promoting family-centred care

Family-centred care, involving families in the care of their own children, has been identified as key to future neonatal service delivery by NHS England (in 2013) and the British Association of Perinatal Medicine (in 2014). The recent report from the National Maternity Review (2016) 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. The past 20 years have seen a shift in considering the environment for the baby and how we make it most conducive for optimal development. A bright and noisy neonatal nursery can impact on fragile developing brains, eyes and nervous systems. An incubator although warm is a very different environment to the womb, and care and interventions need to be done with support to avoid unnecessary stress and stimulation. Babies can be supported with appropriate bedding and positioning, and by considering how they can support themselves through pain or stress. This shift in neonatal care is known as ‘developmentally supportive care’.

However, even if our care is developmentally supportive and family-centred, parents can still be left feeling unconfident and excluded from their true role as parents: being the people who know their baby best and ultimately are responsible for them. Relationships between parents and staff require respect and support and for parents to be true partners in their neonatal care.

The concept of family-centred care began during the 1970s in Estonia and other low resource settings, where limited availability of neonatal nurses and high-tech care led doctors to allow parents to care for their sick and preterm babies. In this ‘humane neonatal care’, parents caring for their babies were seen to be careful and loving and doing the best they could, making sure their hands were clean to reduce infection and watching their babies closely, helping to prevent complications. The outcomes of these babies were better than with traditional care, with improvement in weight gain, reduction in infection, length of stay and improved satisfaction among parents and staff.

Loving care helps babies grow

These ideas have been expanded, structured and evaluated, with similarly positive findings. Preliminary results from an international clustered randomised controlled trial of family-integrated care, the largest of its kind showed decreased parental anxiety and depression, increased bonding, improved infant health, a reduction in infection rates and a decreased length of stay. As well as medical benefits, the trial showed that babies receiving more care from their parents gained weight better. Loving care helps babies grow. Encouraging parents to spend as much time as possible in giving skin-to-skin/kangaroo care led to better bonding and increased rates of breastfeeding.

Preventing the separation of mothers and their babies, and keeping them in skin-to-skin contact to provide comfort, soothing and interaction with their babies, appears to buffer the potentially toxic effects of stress. Overall this improves outcomes and helps the development of coping strategies, reducing depression, anxiety and post-traumatic stress. This model of care is not new, it is intuitive and is what parents instinctively want to do when supported and given the chance.
Can we deliver family-centred care in the UK?

The neonatal service at Imperial College Healthcare NHS Trust supports the principles of family-integrated care. We have an established multidisciplinary approach with 24/7 access for parents facilitated by headphones. Parents are encouraged to attend ward rounds, present their babies and participate in the decision making process, and have skin-to-skin cuddles. We have a donor milk bank and our breastfeeding rates at discharge are above the national average.

Our project aims to support parents to become equal members of the neonatal team and participate in providing active care for their infant with the help of a comprehensive educational programme and competency based training.

'We understand and believe that even the best medical care cannot replace a parent’s presence and the love they can provide their baby.'

We have received a grant from Imperial Health Charity to implement and evaluate this model of care. With the help of veteran parent focus groups, the team has created education and training materials for parents. These are on our free-to-download Integrated Family Delivered Neonatal Care App for parents, which includes a diary to record skin-to-skin contact, expressing, feeding, growth and memories. This can be helpful to see a baby’s ups and downs and progress and can be a keepsake of a baby’s journey. Memories or news can be shared by parents by email which helps parents to update family and friends. A timeline maps development from 23 weeks gestation to term and provides parents with information about what they can do at each stage of their baby’s care. A glossary of medical terms helps navigate neonatal vocabulary.

Parents are informed of the project by one of our two funded project co-ordinators. They can access the App and parent teaching sessions and if they wish to participate will agree to work through the competencies and take over the majority of the care of their baby for about six to eight hours a day.
We are supporting nurses making the shift in their relationship with parents from co-dependence, in which parents watch nurses as experts in their baby’s care, to independence with mutual trust and respect. This enables parents to become equal partners in their baby’s care.

Nurturing families and supporting parenthood needs to start right at the beginning, especially for those with small, vulnerable and sick babies who have a frightening start. Bonding and ‘future proofing’ — building coping strategies and resilience — are even more important for families whose child who may go on to have longer-term healthcare needs. These families need to feel confident in their parenting abilities, and in how to interact and work with healthcare professionals. Parents are there for life, and as professionals we are there to support and equip them for that journey. Early results from a similar trial at the neonatal unit in St James Hospital in Leeds have shown that families who have had this model of care access healthcare services less post-discharge, hypothesised to be due to an increase in caregiver confidence and a reduction in anxiety.¹⁰

Hopefully this information will not just give insight into the experience of having a sick or preterm baby requiring neonatal care but also into this new care model to enable encouragement of parents to understand the importance of their involvement in their baby’s neonatal care.

We hope our resources and experience can be useful to others. Follow our Facebook page and download the IFDC mobile App.

References
Further resources

The Bliss report *Families kept apart: barriers to parents involvement in the baby’s hospital care* highlights the lack of support services and facilities available to parents on neonatal units and what you can do to support change.

**Best Beginnings** has a nice series of Small Wonders Films that give insight into life on the neonatal unit and what parents can do to support their journey.

**Unicef Baby Friendly Initiative** New neonatal standards emphasise the need to develop a close and loving relationship and enable parents as partners in care.

**Family Integrated Care** gives details about the Canadian experience.