

Supporting parents of premature babies and babies who have spent time in special care: an outreach project

Postnatal leader Catherine Neil describes the multi-agency project she set up to offer much-needed support to parents of premature babies.

One in nine babies (80,000 in total) born to parents in the UK spends at least a few days in a neonatal unit.¹ For affected parents, the first days and weeks of parenthood are very different from those whose babies were born healthy and full-term.

Warren describes such parents as being 'hurled' into parenthood without the essential time of preparation that a full-term pregnancy usually provides.² They feel a sense of deep shock and crisis during this time: machines become life-givers (where previously the mother's body was what sustained the baby), and staff are the primary care-givers. Parents often feel as if they have failed and that they don't have a purpose. Understanding the impact this has on the family and their interaction with their baby is essential when considering how best to work with these parents.

As a mother who had a preterm baby at 34 weeks myself, I reflected upon the shock, distress, trauma, anxiety and separation I experienced in my baby's first days spent on the neonatal unit. This, combined with contact on NCT Early Days courses with mothers whose babies had been very ill when they were born, led me to consider how I could support these parents in my professional capacity.

The POPPY Project

Researching the effect of premature birth on the family, I found the Poppy (Parents of Premature Babies Project) report especially significant.³ Recognising the far-reaching impact of having a baby requiring intensive or special care, it speaks of the need for units to create a model of family-centred care. This includes recognising that parents need a great deal of emotional support, fathers need opportunities to express their feelings, and families need to feel valued in their roles with their babies.

The editor of our local NCT newsletter had had a baby, born at 26 weeks, who spent five months on the unit. Through her, I received an introduction to staff on Buscot, the local neonatal unit based in the Royal Berkshire Hospital in Reading, and the charity Babies in Buscot Support (BIBS), which provides essential support to parents who have a baby on the unit. The BIBS committee and hospital staff were delighted to form a relationship with NCT that could contribute to their efforts to create a family-centred unit. After I had made a presentation to the BIBS committee, they agreed to the principle of a weekly drop-in.

Adapting to parents' needs

This was followed by months of meetings with BIBS, Buscot staff members and the premature babies charity BLISS, who adopted the project as an Affiliate Group. In September 2011, with the help of a very generous grant from BIBS and Awards4All (the Big Lottery Fund), we finally launched the NCT Buscot Parents' Drop-in: a free, two-hour, weekly drop-in session in the neonatal unit's family room.

Parents come to seek our support and share their experiences with others in the same position. A formal, topic-based, Early Days format does not work with this group of parents, as parents need to be able to come and go during ward rounds. We encourage conversations in small groups (sometimes only two or three parents or grandparents), to explore the current situation with their baby and to talk about the challenges of bonding, expressing breastmilk, maintaining hope and preparing for discharge home. Parents from different backgrounds, nationalities, ages and ethnicities come to the sessions, all linked by the experience of having a poorly or preterm baby.

The project has now been running for 18 months. After the first year the Awards4All grant ended, and BIBS agreed to fully fund my weekly drop-in with a further grant. This enabled us to increase from the number of sessions where the NCT breastfeeding

counsellor was present. Gina Outram, lead sister on the unit, says, 'The NCT-led group creates a platform for feedback from parents to the neonatal nursing team. Catherine shares comments and suggestions with staff, helping us to develop a high-quality neonatal service by working in partnership with parents.'

As a result of my work on Buscot, I was invited to co-write the Level 5 Module, Understanding the Neonatal Unit Experience, for the University of Worcester, with breastfeeding tutor Lesley Taylor, who has supported parents for many years as a breastfeeding counsellor on a neonatal unit. I also represent Buscot parents' interests on the Maternity Services Liaison Committee (MSLC) at the Royal Berkshire Hospital, as well as volunteering on the BIBS committee itself.

The work has given me an opportunity to reach a group of parents who, due to the difficult circumstances of their baby's birth, often miss out on the mainstream support that NCT is able to offer.

What parents say

'Catherine provided the service that I really needed...she was easy to talk to and gave me the reassurance and encouragement that I needed. The breastfeeding counsellor encouraged me and made it possible to form a bond with my son. I cannot imagine how I would have coped without the support of the NCT service that I so looked forward to every week.' Irene, mother of Ed, born at 25 weeks (16 weeks on Buscot)

'Having the postnatal practitioner there definitely helped put things into perspective...I felt I was not the only one going through this experience. I don't know how I would have got through my testing times in Buscot without her.' Asma, mother of Mohammed, born at 28 weeks. (Nine weeks on Buscot)

References

1. Shannon, C. Bliss family handbook: information and support for families of preterm and sick babies. London: Bliss; 2011.
2. Warren B. The premature infant in the mind of the mother. In: Tracey N, editor. *Parents of premature infants: their emotional world*. London: Whurr Publishers; 1999.
3. POPPY Steering Group. Family-centred care in neonatal units: a summary of research results and recommendations from the POPPY Project. London: NCT; 2009. Available from: <http://www.poppo-project.org.uk/research.html>