

The neonatal experience – loss and grief without a bereavement

Loss and grief are feelings experienced when reality clashes with an expected future. For many parents of preterm and sick newborns, there is often a sense of loss and grief even if their baby does not die. To complement the existing skills of staff on a neonatal unit, a training day has been designed specifically to look at these issues; to enable staff to have a heightened level of awareness of how a parent may be feeling and to increase their confidence in supporting them.

Most parents find being in a neonatal unit frightening and threatening at a time when they are already extremely anxious and distressed. They may feel scared, disempowered, vulnerable and perhaps inadequate for not knowing how to help their baby. They may have little opportunity to feel that they are parents to their baby¹.

Providing support for parents is an important part of caring for critically ill babies. It is important to welcome and involve parents and try to help them feel at ease in an alien and very frightening environment. Staff should do whatever they can to help parents feel that they have some control over what happens to their baby. Parents should be listened to and professionals should try to understand their values, priorities and concerns^{2,3}. It is important to acknowledge the extreme stress and the sadness of the situation for the parents and also the difficulties caused by the nature of the pressures of the neonatal unit.

Communication is probably the single most important component of effective care. It underpins and colours everything that staff can offer. Excellent clinical care can be overshadowed by poor communication; failures of communication cause dissatisfaction and can lead to complaints about health care. Good communication builds trust and parents need to feel able to trust the staff who are caring for their baby⁴.

Parents are acutely aware and in tune with the different layers of communication, not just between parents and staff but also among staff. One parent highlighted the importance of this:

“...when there was a good flow of communication through the team, that’s when we were confident that our son was getting the best possible care”.

Parents have reported how they ‘hang on’ to every word a doctor or nurse says about their baby and therefore healthcare professionals should think about how they communicate in all of their interactions with vulnerable parents.

A sense of loss

For many parents of preterm and sick newborn infants, there is often a sense of loss and grief even if the baby does not die. The loss of the final trimester of pregnancy, the loss of the ‘normal’ birth experience, the joy of going home with a healthy newborn baby, the loss of privacy and a sense of not being in control. There is often a sense of a lost opportunity, particularly if the



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baby develops long-term health problems or a disability.

Some parents may experience many months on the neonatal unit living with the uncertainty of the future for their baby and their family. They may feel a sense of loss regarding their own identity and in their relationships, as the focus is now completely on their baby.

The parents' perspective – a workshop

It is essential for all healthcare professionals working within this environment to have an awareness and understanding of how parents of the babies they are caring for may be feeling^{2,5,6}. Family-centred care should be offered – a package of care which incorporates ‘looking after’ the family as a whole. With this in mind the authors, Paula and Alex, have collaborated with Child Bereavement UK (CBUK) to facilitate a one-day workshop that looks at the neonatal experience from the perspective of a parent. With particular emphasis on feelings of loss and grief, the workshop aims to enable healthcare professionals to have an

increased awareness and understanding of the parents' experience, to help increase their confidence in supporting parents through their neonatal journey.

The workshop is designed to be suitable for all neonatal nurses, doctors and other healthcare professionals working within neonatal units. It may also be appropriate for those working in antenatal departments, labour wards and postnatal wards. It explores key areas of neonatal care including:

- Loss and grief
- Communication
- Impact on the professional caregiver
- Moral and ethical issues around palliative and end-of-life care.

The workshop explores feelings and emotions where there has been a multiple pregnancy and one baby is critically unwell and the other baby/babies are well and at home⁷. There may also be the reality of one twin having died *in utero* or shortly after birth. Parents have reported that they often yearn for staff to acknowledge the baby who has died, rather than say nothing and assume that everyone has forgotten about that baby.

Complex needs and palliative care

Neonatal palliative care focuses on the best interests of the baby, while at the same time supporting the whole family, including siblings and grandparents holistically⁸⁻¹⁰.

A baby may require palliative care for any length of time: from a few minutes, to weeks or even months. Again, communication underpins every element of care and the success of palliative care in practice will primarily be determined by the ability to give and receive information and to respond appropriately¹¹.

Parallel planning for both life and death can be very confusing and difficult for parents to comprehend. Actively managing the possibility of improvement by providing interventions aimed at recovery, while recognising the possibility that the baby may not make any further progress, may deteriorate and die – parents must adjust to a future of uncertainty with a baby who may have many complex needs or may not survive¹¹.

Impact on the family

The family unit becomes fragmented; often parents are juggling with other children at home, visiting their baby on the NICU and having to deal with difficult circumstances at the same time. Existing children 'lose' their parents to the alien world of the NICU and a baby they may never have met.

This whole experience affects the way they parent their baby on the neonatal unit as well as other children at home. They cannot be in control of their baby's life and parents often feel disempowered and helpless. This workshop addresses how professionals can empower families and help them to be as involved as possible, ensuring that families are central to any decision making process^{12,13}.

Acknowledging that professionals may also experience difficult and sometimes painful feelings, the workshop provides opportunities for group discussions and exploration.

References

1. **Meyer E.C., Ritholz M.D., Burns J.P., Truog R.D.** Improving the quality of end of life care in the pediatric intensive care unit. *Pediatrics* 2006;117:649-55.
2. **Bliss.** *The Bliss Baby Charter Standards* [Online]. Available from: http://bliss.org.uk/wp-content/uploads/2012/02/Baby_Charter_2011.pdf [Accessed: 27 Dec 2012].
3. **POPPY Steering Group.** *Family-centred Care in Neonatal Units. A Summary of Research Results and Recommendations from the POPPY Project.* London: NCT; 2009.
4. **Coulter A., Entwistle V., Gilbert D.** Sharing decisions with patients: is the information good enough? *BMJ* 1999;318:318-22.
5. **Department of Health.** *Toolkit for High Quality Neonatal Services* [Online]. Available from: www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_107845 [Accessed: 27 Dec 2012].
6. **Nuffield Council on Bioethics.** *Critical Care Decisions in Fetal and Neonatal Medicine: Ethical Issues* [Online]. Available from: [www.nuffieldbioethics.org/sites/default/files/CCD%20web%20version%2022%20June%2007%20\(updated\).pdf](http://www.nuffieldbioethics.org/sites/default/files/CCD%20web%20version%2022%20June%2007%20(updated).pdf) [Accessed: 16 Apr 2013].
7. **TAMBA.** *Bereavement Support Group Booklet* [Online]. Available from: www.tamba.org.uk.
8. **BAPM.** *Palliative Care (Supportive and End of Life Care): A Framework for Clinical Practice in Perinatal Medicine.* [Online]; 2010. Available from: www.bapm.org/publications [Accessed 29 Apr 2013].
9. **Royal College of Paediatrics and Child Health.** *Withholding and Withdrawing Life Sustaining Treatment in Children: A Framework for Practice.* [Online]; 2004. Available from: www.rcpch.ac.uk/what-we-do/rcpch-publications/publications-list-title/publications-list-title [Accessed 29 Apr 2013].
10. **Association for Children's Palliative Care.** *A Neonatal Pathway for Babies with Palliative Care Needs.* Bristol: ACT; 2009.
11. **West Midlands Children and Young People's Palliative Care Toolkit Working Party.** *Children and Young People's Palliative Care Toolkit* [Online]. Available from: www.togetherforshortlives.org.uk/professionals/resources/2490_west_midlands_toolkit [Accessed: 16 Apr 2013].
12. **Branchett K., Stretton J.** Neonatal palliative and end of life care: What parents want from professionals. *JNN* 2012;18:40-44.
13. **Child Bereavement UK.** *Training for Professionals.* [Online]. Available from: www.childbereavement.org.uk/For/ForProfessionals [Accessed: 16 Apr 2013].



CBUK supports families and educates professionals when a child dies or when a child is bereaved. Currently it trains around 5,000 professionals each year across health care, social care, education, the emergency services and the voluntary sector.

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Future workshops include:

- Thursday 20 June 2013, Birmingham
 - Friday 6 December 2013, CBUK Head Office, Bucks
- For further details visit: www.childbereavement.org.uk/training/ourcourses