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Interdisciplinary Recommendations for Psychosocial Support of NICU Parents

Developed by

The Workgroup for Psychosocial Support of NICU Parents

(Convened by the National Perinatal Association)

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Recommendations for Palliative and Bereavement Care in the NICU

A. General recommendations:

1. Parents who lose a baby before, during, or shortly after birth, or later in the NICU should be offered:
 - a. Anticipatory guidance regarding the grieving process, including how mothers and fathers, and other family members, may grieve differently. This anticipatory guidance should begin antenatally if a life-limiting diagnosis has been determined.
 - b. Participation in bereavement rituals, including those that meet their spiritual, religious and cultural preferences. These rituals that may include a variety of practices and items that will help them remember their baby, such as provision of hand prints and foot prints, photographs, etc. Smooth communication should be facilitated between parents and the staff of the NICU and obstetric units throughout the dying process; a Master's level perinatal social worker or other designated person can assist with this.
 - c. Psychosocial support for all members of the family, including but not limited to grandparents and the baby's siblings.
 - d. Peer-to-peer support and/or referral to community or internet support organizations (see "Recommendations for peer-to-peer support for NICU parents," in the comprehensive document*).
 - e. Counseling and/or counseling resources regarding both the physical and psychological considerations of attempting another pregnancy.

- f. Post-hospital follow-up in a variety of forms, including individual contact by a staff member at various time periods as well as a conference four to six weeks after the baby's death to review autopsy and other results that will help parents understand what happened to their baby.
2. When intensive care will not be provided, a collaborative, interdisciplinary approach should be used to provide palliative care including bereavement care to any family whose fetus or neonate is facing a life-limiting condition or imminent death.
3. Physicians and nurse practitioners should follow the guidelines outlined by the American Academy of Pediatrics when engaging in discussions with parents about whether to initiate or continue intensive care for a baby who may not survive; neonatal nurses and perinatal social workers should be included in the decision-making process as well. Intensive care should be provided only if it is believed that the baby will benefit from it. The best interests of the baby should be the guiding standard.
4. In cases where there are disagreements between parents and the healthcare team when making end-of-life decisions, particularly around the futility of further care for a baby, a Bioethics consult should be obtained and/or the case presented to the hospital Bioethics Committee.
5. Parents whose babies with life-limiting conditions survive to hospital discharge should be offered both practical and psychosocial support to help them prepare for discharge, learn how to care for their baby, and cope with their baby at home, and/or they should be referred to a hospice with experience caring for infants. Their baby's PCP, neonatal specialist, or medical home, and any subspecialists involved in their baby's care, should be fully involved in making and carrying out home care plans and providing follow-up support.

B. Parents anticipating a perinatal loss should be offered:

1. An antenatal interdisciplinary conference to develop the following plans, which should be individualized according to parents' desires and cultural, spiritual and religious beliefs:
 - a. A birth plan, which should include parents' preferences regarding the conduct of labor, the circumstances surrounding delivery, and the care for baby and parents after the baby's birth;
 - b. A plan for the extent of resuscitation to be performed and whether to allow a natural death; and
 - c. A palliative care plan as indicated and desired when babies are not expected to survive. This should include parents' preferences on where the baby's care will be delivered, how nutrition will be provided, and how baby's pain and discomfort will be managed.
2. Encouragement to bond with their baby and to create memories throughout the pregnancy, whenever feasible, recognizing the barriers they may face in bonding.
3. Psychosocial support for all members of a family, including grandparents and the infant's siblings.
4. Both practical and psychosocial support to help them cope with their baby at home when infants with life-limiting conditions survive to hospital discharge.

C. Health system recommendations:

1. All health professionals that work with pregnant women, neonates and their families should receive education and demonstrate competence in palliative and bereavement care that is appropriate within their scope of practice, and training in how to communicate effectively and empathetically with families.
2. Policies for palliative care and bereavement practices in any part of a healthcare system should be in place and easily accessible to all staff, to ensure a standard of care for all families.
3. Palliative and bereavement care resources in the community or in other areas should be available to anyone who is providing care to a neonate and family facing a life-threatening condition or imminent death or has experienced a loss whether or not there is a palliative care team or program at a specific institution.
4. Hospitals should work in partnership with their local organ donation organizations to determine whether specific babies are eligible to become organ donors and to assess, in collaboration with the family, whether organ donation is the right choice for them.
5. Healthcare staff that provide palliative and/or bereavement care should receive psychosocial support and engage in self-care, to enable them to provide optimal care to the families they serve, as well as to prevent burnout, compassion fatigue or secondary traumatic stress. The perinatal social worker, NICU psychologist, or pastoral care staff can be instrumental in providing this support.

*The comprehensive document is “Interdisciplinary Recommendations for Psychosocial Support of NICU Parents,” available elsewhere on this website (www.support4NICUparents.org).

For any questions or comments about the Recommendations, please email info@support4nicuparents.org.