



**National  
Association of  
Neonatal  
Nurses**

# **Palliative and End-of-Life Care for Newborns and Infants Position Statement #3063**

NANN Board of Directors  
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Infants born with life-limiting conditions or who develop life-limiting conditions during their neonatal hospitalization may receive palliative care. *Palliative care* focuses on improving a patient's quality of life and may be offered concurrently with curative care to treat symptoms, minimize suffering, and offer improved quality of life. Through the ongoing assessment of care goals, parents, nurses, and other providers determine the appropriateness of continuing intensive therapies and weigh the benefits of shifting the goals of care toward the provision of comfort for the infant and family.

End-of-life care, one aspect of palliative care, supports a peaceful, dignified death for the infant and the provision of support to the family and healthcare providers. Neonatal nurses are essential to the provision of palliative and end-of-life care.

As the professional voice of neonatal nurses, the National Association of Neonatal Nurses (NANN) recommends that neonatal nurses be trained and participate in offering services related to providing palliative and end-of-life care.



## **Association Position**

Palliative and end-of-life care for infants and their families are an integral component of neonatal care, and neonatal nurses should be trained and participate in setting care goals and providing services involved in this essential care. Nurses and nurse practitioners work with physicians and others to provide symptom management, relief of suffering, and dignity for infants and families.

## **Background and Significance**

The World Health Organization (WHO) (2014) estimates 1.2 million children worldwide are in need of palliative care at the end of life. The most frequent causes of death by disease groups are congenital anomalies (25.06%) followed by neonatal conditions (WHO, 2014; 64%).

More than 29,000 infants under 1 year of age die each year in the United States, and 66% of these deaths (Xu, Kochanek, & Tejada-Vera, 2009) occur during the neonatal period, many in the neonatal intensive care unit (NICU) (Brandon, Docherty, & Thorpe, 2007). Every year, more than 500,000 children live with a life-limiting illness (Himmelstein, Hilden, Boldt, & Weissman, 2004). Palliative care is appropriate for neonates with a wide range of life-limiting conditions, including severe prematurity and its accompanying complications, birth-related trauma, genetic abnormalities, or complex congenital anomalies, whether the condition will result in death during the infant's first few hours of life or after several years (Aladangady & de Rooy, 2012; Goodger, 2009; Mancini, Uthaya, Beardsley, Wood, & Modi, 2014).

The model of palliative care is focused on quality of life; within that model curative and comfort interventions may coexist. WHO (2014) states that, in the case of life-limiting conditions, palliative care should begin at the same time that curative care begins. The International Council of Nurses (2012) views the nurse's role as fundamental to a palliative approach that aims to reduce suffering and improve the quality of life for dying patients and their families through early assessment, identification, and management of physical, social, psychological, spiritual, and cultural needs.

NICUs should have ready access to all components of palliative and end-of-life care either through their own programs or community organizations.

## **Recommendations**

1. Palliative care should be offered at any period in which the infant's life may be limited—prenatally, at the time of birth, and after the birth—and in any location, including in the labor and delivery suite, in the NICU, and at home following discharge.
2. When a prenatal diagnosis is made, palliative care should be offered prior to delivery. Families should be supported in decision making for a pregnancy termination, an early induction of labor, or continuing the

- pregnancy with a live birth, and supportive palliative care should be provided for any live births (Wool, 2013).
3. When continuation of the pregnancy is chosen, planning and decision making for the birth includes choosing who will deliver the baby, where the delivery will take place, and who will be present; delineating the resuscitation plan for the infant; and planning for comfort measures immediately at birth (English & Hessler, 2013). Spiritual or traditional support at the time of birth, if desired, should also be planned.
  4. All care goals should be developed as a team and include the parents. Goals of care should be easily accessible to the entire interdisciplinary team to avoid fragmentation in care. The provision of palliative care services and the infant and parents' response to the intervention/service should be documented. Care goals should be reassessed regularly and revised as needed. Care goals should be established and revised through team consensus. As part of the caregiving team, parents should participate in all aspects of the decision-making process.
  5. Family conferences are essential to the providers' understanding of families' needs and their hopes and goals for their infant. Use of a parent diary or family medical record (e.g., the Penticuff Family Medical Record [Penticuff & Arheart, 2005]) allows families to track their infant's progress and better understand when the infant is not getting better.
  6. An advocate or palliative care provider should be identified prenatally or at delivery/diagnosis for each infant and family in need of palliative services. The advocate should be able to guide and comfort parents across the illness trajectory including prenatal, labor and delivery, and NICU care.
  7. When an infant with a potentially life-limiting condition is being transported to a tertiary care center, providers should ensure that parents are also informed that the result of transport may include end-of-life or palliative care.
  8. Brochures that define palliative care, identify team members, and explain the services offered should be available to families both prenatally and following birth regardless of the care setting.
  9. Palliative care family support services should include perinatal/neonatal social workers, hospital chaplains, and clergy, and palliative care team members to provide emotional and spiritual support, a child-life specialist or family support specialist to support the infant's siblings, a parent who has had a child in the NICU to assist with navigating the NICU experience, and a lactation consultant to assist mothers who want to breastfeed their infant or donate breast milk at the end of life and to help

mothers manage cessation of lactation (Moore & Catlin, 2003).

10. Palliative care should include
  - a. review of curative focused orders
  - b. written palliative care orders to manage discomfort, pain, and other distressing symptoms, such as gasping or seizures using the least invasive effective route of delivery available (i.e., buccal, dermal, or rectal if intravenous access is no longer desired or available)
  - c. comfort measures such as holding and kangaroo care
  - d. ongoing assessment of pain and sedation with a validated instrument to measure. Available assessment scales include:
    - Premature Infant Pain Profile (PIP) scale (Stevens, Johnston, Petryshen, & Taddio, 1996)
    - Neonatal Pain Agitation and Sedation Scale (Hummel, Puchalski, Creech, & Weiss, 2008)
    - Neonatal Infant Pain Scale (NIPS) (Lawrence et al., 1993)
    - Pain Assessment in Neonates (PAIN) (Hudson-Barr et al., 2002)
    - Modified Infant Pain Scale (Buchholz, Karl, Pomietto, & Lynn, 1998)
    - Children's and Infants' Postoperative Pain Scale (Buttner & Finke, 2000).
    - EDIN scale (Échelle Dolour Inconfort Nouveau-né / Neonatal pain and discomfort scale) (Debillon, Zupan, Ravault, Magny, Dehan, 2001)
  
11. End-of-life care should be provided in a private home-like environment in a location in or near the NICU to allow family members to be together. Alarms and pagers of those in attendance should be turned off. Light levels should be adjusted for family comfort.
  - a. End-of-life order sets should include
    - discontinuation of routine vital signs and labs
    - frequent assessments to identify infant pain and distress, managed with normal medication doses based upon milligram per kilogram
    - documentation of infant response to pain and sedation medications
    - discontinuation of painful assessments (eg, heel sticks, measurement of blood gases)
    - offering small amounts of oral fluids such as drops of breast milk and lip lubrication as a comfort measure.
  - b. Assess parental preferences regarding the following support and memory-making activities:
    - whom the parents want present
    - bathing, dressing, and holding the infant

- taking the infant outside
  - spiritual support
  - taking family photographs (by lay or professional photographers)
  - making handprints and footprints
  - cutting locks of hair
  - holding special spiritual or religious ceremonies.
- c. If the family is not available, nurses or other care providers should hold and comfort the infant.
  - d. Family should be accompanied by staff when leaving the NICU.
12. When palliative care includes the removal of life-sustaining treatments in the NICU or at home, supports from the palliative care providers or hospice should be available. Before removal of life-sustaining treatments, a plan should be in place to manage the infant's symptoms.

Prepare the family for what they will observe (infant may continue to breathe and have a heart rate for minutes or hours; gasping and other noises may occur). Assess parental preferences, including whom they want present, whether they want to hold the infant, and whether they wish to participate in any rituals or memory-making activities before or during the removal of therapies.

Prior to the removal of life-sustaining treatments any neuromuscular blocking agents should be weaned. Depending upon the infant's physiologic state this could take several hours. Pain and sedation medications should be given in normal doses.

Discontinuation of life-sustaining treatments should include

- a. discontinuation of vasopressors
  - b. gentle suctioning and removal of endotracheal tubes or other respirator support.
13. NICUs should have a relationship with a local hospice or palliative care organization to ensure seamless continuity of care. Where local hospices do not provide pediatric care, pediatric home health agencies and a primary care pediatrician may oversee the infant's palliative care needs. Infants who are discharged with life-limiting illnesses should have a plan of care, including necessary resources and a portable non-resuscitation plan to avoid unnecessary resuscitation.
14. Whether the infant who continues to live will receive artificial nutrition and hydration (ANH) should be discussed. ANH is viewed as a life-extending technology and may or may not be appropriate in palliative care (Diekema & Botkin, 2014). The family and staff members must be aware that the infant who receives only oral measures as comfort may not expire for 1 to 3 weeks (Hellmann, Williams, Ives-Baine & Shah, 2013). Families may appreciate this time without artificial feeding as time to get to know their infant and enjoy care without tubes and lines (Hellmann et al., 2013;

Vesely & Beach, 2013). Local pediatric inpatient hospices, if they exist, can support parents and the baby during this difficult period (Vesely & Beach, 2013). Insertion of a feeding tube has the potential to extend life and prevent the natural dying process. Researchers who study adult patients at the end of life report that adults are more comfortable when they are not fed. When adults are being fed at the same time that organs are shutting down, they often develop complications such as pulmonary edema, cardiac failure, painful abdominal distention, diarrhea, and aspiration pneumonia (Winter, 2000). When not receiving nutrients, the body releases endorphins that provide analgesia (Carter & Leuthner, 2003).

15. Palliative care should be continued after an infant's death in the form of bereavement care. NICU staff may do their own bereavement follow-up of families, or they may connect families with identified community services. Bereavement care may include
  - a. giving parents a gift such as a stuffed teddy bear to take home (which allows them to leave the hospital without empty arms)
  - b. calling the family to offer support in the days and weeks following the infant's death
  - c. sending the family a card, e-mail, or letter from the staff. If possible, personalize the message and send it signed by the team.
  - d. contacting the family on anniversaries of the infant's birth or death, as the family wishes (by telephone, card, text or e-mail)
  - e. introducing the family to a member of a local support group or a support organization such as Share: Pregnancy and Infant Loss Support ([www.nationalshare.org](http://www.nationalshare.org)), Pregnancy Loss and Infant Death Alliance ([www.plida.org](http://www.plida.org)), and the National Infertility Association's RESOLVE ([www.resolve.org](http://www.resolve.org))
  - f. offering a bereavement brochure that provides support contacts
  - g. providing sibling support
  - h. storing a photograph parents declined to keep for at least 6 months to ensure they do not change their mind about wanting to have photos
  - i. meeting with the family as a team to talk about autopsy, express emotions about end-of-life care, and discuss care decisions that were made
  - j. performing a memorial day event for the families in the loving memory of their babies.
  
16. Support services should be offered to all members of the healthcare team and include facilitated debriefing after difficult deaths.

## **Conclusions**

Palliative nursing care requires a mindset of providing support for family members during the illness and loss of both the infant and the family's dreams for the child they would not have. Care of the family is a central focus, and the nurse

is the consistent caregiver. Palliative care is an interdisciplinary endeavor. When the transition is made from curative to purely palliative efforts, the best results occur when the team is in consensus and all disciplines support the transition. Consensus includes decisions about appropriate treatment options for individual infants (Mendes & Justo da Silva, 2013). Case conferences, palliative care conferences, and consultation with the ethics committee can help the interdisciplinary team resolve conflict and reach consensus (Brandon et al., 2014). Communication among team members and with the infant's family is essential to the ongoing assessment and provision of care to maximize the infant's quality of life.

NICU nurses wishing to specialize in this form of care may be trained through ELNEC (End of Life Nursing Education Consortium) or Resolve through Sharing Bereavement Training out of Gundersen Lutheran Hospital. Certification in Perinatal Hospice and Palliative Care is now offered by the American Nursing Certification Center.

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