National
Association of
Neonatal
Nurses

Palliative Care for the Fetus, Newborn, and Infant

Position Statement
#3080

NANN Board of Directors
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As the professional voice of neonatal nurses, the National Association of Neonatal Nurses (NANN) recognizes palliative care as an integral part of perinatal and neonatal nursing, with a focus on relieving suffering, supporting families, and honoring dignity and values throughout serious illness and, potentially, end of life. NANN recommends that neonatal nurses be prepared to introduce palliative care early, provide comfort- and symptom-focused care, communicate compassionately, and collaborate to support families through decision-making and bereavement.

Association Position

Nurses and advanced practitioners play a vital role in collaborating with physicians and other healthcare providers to ensure symptom management, relief of suffering, and dignity for fetuses, newborns, and infants and their families. All nurses and advanced practitioners who provide care in perinatal or neonatal settings should be educated and trained in the provision of palliative care. Neonatal nurses should be competent in symptom management, advance care planning, ethical decision-making, memory-making, and compassionate communication. Further education, training, policy advocacy, and research related to palliative care are core nursing responsibilities across all practice settings, regardless of setting of care or level of specialization.

Definitions

Palliative care for newborns, infants, and their families is an integral component of neonatal care. It is appropriate at any stage of illness and may coexist with curative or disease-directed therapies.

- *Neonatal palliative care* is an interdisciplinary approach that prioritizes quality of life, symptom relief, and holistic support for infants with serious illnesses, beginning at diagnosis and provided alongside or independent of curative or life-prolonging treatment. Through holistic, early, and coordinated support, palliative care for the fetus, newborn, and infant aims to 1) improve quality of life, 2) manage suffering, and 3) align care with patient and family values (National Consensus Project for Quality Palliative Care, 2018). Palliative care can improve parents' quality of life, as well as enhance symptom management and pain relief in newborns (Mohammadi et al., 2025).

- *Perinatal palliative care* extends this approach into the prenatal period, integrating obstetric and neonatal care from the time of a potentially life-threatening or life-limiting fetal diagnosis through birth and the postnatal course.

- *End-of-life care* is a subset of palliative care focused on comfort, dignity, and family support when death is anticipated, and the goals of care are directed toward the dying process.

- *Hospice care* is a type of end-of-life care, defined by the National Hospice and Palliative Care Organization (NHPCO, 2023) as "the model for quality, compassionate care for people facing the last months of living with a serious illness."

Background and Significance

The provision of palliative care is a human right (Benini et al., 2022; World Health Organization, 2020) for all people with serious illness, regardless of their diagnosis, prognosis, age, or where they are accessing care (National Consensus Project for Quality Palliative Care, 2018). Yet there remains a great need for professional education, training, research, and program development to achieve universal coverage (Benini et al., 2022).

Globally, perinatal and neonatal palliative care are not yet widely available, and such care is inaccessible for many newborns and families who could benefit, particularly in low- and middle-income countries where neonatal mortality is highest. In the United States, perinatal and neonatal palliative care is increasingly recognized as a standard of quality care. However, access, consistency, and early integration vary widely across care settings. Continued investment in workforce education, equitable service delivery, standardized models of care, and research is essential to ensure that all newborns and families receive compassionate, high-quality palliative care regardless of location or prognosis (Dombrecht et al., 2023; Derrington et al., 2026).

Levels and Frameworks of Palliative Care

Palliative care teams are interdisciplinary, and an effective neonatal or perinatal palliative care team may include obstetricians, neonatologists, nurses, social workers, mental health professionals, chaplains, and healthcare providers who have expertise in pediatric palliative care or the illness of the fetus, newborn, or infant.

Palliative care services and models of care vary and are developed in accordance with context and population characteristics, the availability of resources, and the estimated number of eligible users for such care (Benini et al., 2022). The levels of provision of palliative care are (Benini et al., 2022; Martín-Ancel et al., 2022; Sieg et al., 2019):

1. **Primary palliative care:** Palliative care is delivered by healthcare professionals who do not specialize in perinatal and neonatal palliative care but incorporate its principles into routine clinical practice, such as obstetricians, neonatologists, midwives, and nurses (Seig et al., 2019). Regardless of the point of contact within the healthcare facility, appropriately trained healthcare professionals should be available to provide essential support focused on comfort, including basic pain and symptom management; clear and compassionate communication with families; and initial emotional support (Wool & Catlin, 2019).

2. **Intermediate or generalist palliative care:** Care becomes more structured and comprehensive because some healthcare professionals, in some contexts like NICU, have additional training or experience in perinatal/neonatal palliative care. General components include: formal prenatal consultation; development of a birth plan; access to other neonatal and pediatric specialties as needed; supportive care during prenatal, birth, and postnatal periods; and bereavement counseling (American College of Obstetricians and Gynecologists [ACOG], 2019).

3. **Specialized palliative care:** This level of palliative care is provided by full-time professionals in perinatal, neonatal, and pediatric palliative care teams who work collaboratively to manage highly complex clinical and psychosocial situations. Care extends beyond symptom control to include healthcare team consultation, ethical decision-making support, intensive family counseling, bereavement care, and, when appropriate, coordination of care across settings (hospital, home, or hospice).

At all levels, palliative care for the fetus, newborn, and infant should be delivered within an integrated framework. Globally, numerous palliative care frameworks exist at national, regional, and local levels, reflecting differences in health-system structures, resources, and cultural values. Nurses should be familiar with the frameworks that guide practice in their country, state, region, or institution, such as WHO's public-health model of palliative care, national clinical practice guidelines for quality palliative care, or national nursing competency frameworks (American Association of Colleges of Nursing, 2022; British Association of Perinatal Medicine, 2024; National Consensus Project for Quality Palliative Care, 2018; World Health Organization, 2020). Given the documented variation in nursing education, specialty recognition, and implementation of palliative frameworks across countries, current guidance emphasizes that local and regional frameworks should complement, rather than replace, global standards, while respecting local context and workforce capacity (Mendes & Justo de Silva, 2013).

Family-Centered Care

Palliative care for the fetus, newborn, and infant should be holistic and family-centered, addressing not only the patient's needs but also the emotional, psychological, social, cultural, and spiritual needs of the family, including siblings and grandparents.

Parents consistently report that high-quality palliative care is valued and beneficial, particularly when it supports their parenting role, reduces infant suffering, and centers on compassionate communication. At the same time, families also identify important gaps and shortcomings when palliative care is delayed, poorly explained, or framed narrowly as end-of-life care. Parents report greater satisfaction when palliative care is introduced early, integrated alongside life-prolonging treatment, and grounded in shared decision-making that respects family values and acknowledges uncertainty. When well delivered, palliative care improves parental coping, reduces decisional regret, and enhances the quality of care for both infants and families (Carter, 2018; Wojtkowiak & Mathijssen, 2022).

Cultural and Spiritual Support

Neonatal nurses should demonstrate cultural competence when providing perinatal and neonatal palliative care by recognizing, respecting, and integrating diverse cultural, spiritual, and family values into care to ensure equitable, individualized, and family-centered support. Resources are available to help healthcare providers provide culturally competent palliative care, including the American Psychological Association's Culturally Diverse Communities and Palliative and End-of-Life Care fact sheet and the Hospice and Palliative Nurses Foundation's Diversity in Health Care 6-video series.

Communication and Decision-Making

Parents must receive timely, honest, and comprehensive information to support informed decision-making when a life-threatening or life-limiting fetal or neonatal condition is suspected or confirmed. Nurses should take care that their communication is compassionate, clear, culturally appropriate, empathetic, and nondirective, acknowledging prognostic uncertainty and supporting family preferences and values and shared decision-making. When discussing diagnosis, prognosis, and quality of life, healthcare professionals must recognize and mitigate personal biases. Clearly and neutrally present all care options, including pregnancy termination, neonatal resuscitation and intensive care, and perinatal end-of-life care.

Use of a parent or family diary may help promote family-centered care, strengthen communication between NICU staff and parents, support parental coping, and foster a greater sense of closeness with the newborn (Sorrentino et al., 2025).

Neonatal nurses can support families by reinforcing information provided by the medical team, contributing to shared decision-making, and advocating for the best interest of the child while respecting parental values, preferences, and autonomy.

Scope of Clinical Palliative Nursing Care

Effective pain and symptom management is a core nursing responsibility. Nurses must ensure the use of appropriate assessment tools and interventions to minimize distress and promote comfort, recognizing the newborn’s vulnerability and inability to self-report suffering. The use of valid neonatal pain assessment tools is recommended. Pain and distressing symptoms, including gasping and seizures, should be managed according to current best practice (Association for Paediatric Palliative Medicine, 2024) in collaboration with a neonatal pharmacist. The least invasive route of medication administration should be prioritized (eg, buccal, transdermal, rectal, or subcutaneous) when intravenous access is not desired or no longer available; in cases of refractory symptoms, palliative sedation may be considered to ensure comfort.

Comfort measures should be prioritized and individualized to promote the infant’s well-being and family bonding. These include holding and skin-to-skin (kangaroo) care whenever possible, gentle positioning, swaddling, promote neuroprotective care interventions, maintaining a calm and quiet environment, and optimizing warmth and comfort. Encourage nonpharmacological strategies such as non-nutritive sucking, facilitated tucking, and the use of familiar sensory stimuli (eg, parental voice and scent). Oral care, including small amounts of human milk for comfort when appropriate, and basic hygiene measures should be provided, ensuring that all interventions remain focused on reducing distress and enhancing comfort.

Collaboration within the multidisciplinary team, inside and outside of the NICU, is essential to ensure coordinated and consistent care. Neonatal nurses should contribute actively to team communication and advocate for the integration of palliative care principles across all levels of care. Nurses also play a key role in ensuring continuity of palliative care beyond the NICU by facilitating referrals and coordination with hospice, palliative care services, or community providers and by supporting individualized discharge planning with clear goals of care and access to necessary resources.

Neonatal nurses provide education and emotional support to families, promoting safe, consistent, and family-centered care at home. They should actively provide clear, accessible, and culturally appropriate information about palliative care to families. Educational materials, such as brochures or digital resources, should be readily available and explain the principles of palliative care, the roles of the multidisciplinary team, and the services offered throughout the care continuum. Nurses should reinforce this information through ongoing, empathetic communication tailored to the family's level of understanding and emotional readiness, reducing traditional misconceptions and fostering trust in palliative care as an integral component of perinatal and neonatal care (Benini et al., 2022; Wool & Catlin, 2019). Neonatal nurses also should actively advocate for and amplify the voices of families, their experiences, and what matters most to them.

Care Across the Continuum

A *palliative care birth plan* is a personalized, flexible advance care plan used when the fetus is suspected or confirmed to have a potentially life-threatening or life-limiting illness or condition; the plan integrates anticipatory curative and palliative interventions while centering the infant's best interests and the family's emotional, ethical, and relational needs (Cortezzo et al., 2020). It outlines family preferences for care across pregnancy, birth, and the neonatal period, including mode of delivery, fetal monitoring, maternal analgesia, presence of family members, and specific cultural or personal requests, as well as the desired balance between medical interventions and comfort-focused care, feeding, medications, and diagnostic procedures (Cortezzo et al., 2020).

The main goals of the plan should be to minimize unnecessary neonatal interventions while prioritizing comfort and quality of life, ensure care remains consistent with family values and goals, support informed and shared decision-making, promote memory-making and bonding, reduce psychological distress, and improve communication among all professionals involved. Birth plans also address family experience and anticipated scenarios, such as opportunities for bonding and memory-making, involvement of relatives, spiritual or cultural practices, care pathways if the infant survives or dies shortly after birth, and practical aspects following death, including postmortem care, cooling crib, milk donation, autopsy decisions, funeral arrangements, and any additional family-specific wishes (Cortezzo et al., 2020). Within the NICU, neonatal nurses should support the implementation of these advance care plans by ensuring they are clearly documented, easily accessible, routinely revisited, and updated, with recommendations made through interdisciplinary consensus so that any desired changes prompt a team meeting to reassess and maintain consistency and alignment with family wishes.

Some infants receiving palliative care may live for months or years with complex medical needs that require ongoing reassessment and support, while others may require care transitions earlier in their illness trajectory.

Care Transitions

End-of-life care can be considered for "unborn children with major health problems who may not live through birth, infants who may survive for only a few hours/days, infants with birth anomalies that may threaten vital functions, and infants for whom intensive care has been appropriately applied but developed an incurable disease" (Benini et al., 2022). Fetal or neonatal life-limiting conditions that might make a patient eligible for end-of-life care can be organized into five categories (Akyempon & Aladangady, 2021):

1. Conditions considered to be not compatible with long-term survival (eg, bilateral renal agenesis, anencephaly).

2. Conditions with a prominent risk of notable morbidity or death (eg, severe bilateral hydronephrosis, severe spina bifida).

3. Neonatal borderline viability when intensive care is no longer beneficial (eg, newborns born at 22-23 weeks gestation, with severe two-sided brain hemorrhage infarct).

4. Postnatal conditions that put the neonate at risk of severe impairment and poor quality of life or that require life sustaining treatment (eg, severe hypoxic ischemic encephalopathy, complex congenital anomalies, genetic conditions [trisomy 18]).

5. Postnatal conditions associated with intolerable neonatal suffering (eg, severe necrotizing enterocolitis).

End-of-life care may involve withdrawal of life-sustaining treatment, such as compassionate extubation, in the NICU or at home. Neonatal nurses should advocate for care coordinated with hospice or specialized palliative services when available and guided by a clear, individualized plan that includes symptom management, family support, and preparation for the possibility that the infant may continue to breathe after withdrawal. Parents should determine who will be present, and clinicians should provide clear, compassionate explanations of the process while managing care by discontinuing non-essential life-sustaining medications, weaning neuromuscular-blocking agents, removing invasive devices when appropriate, and using gentle suctioning for comfort if needed. Comfort measures should prioritize having the infant held by parents or family whenever possible; providing weight-based medications such as morphine to relieve distress, repeating doses as needed; and using oxygen only if it contributes to comfort within a calm, private, home-like environment with continuous emotional support for the family. Nurses should incorporate nonpharmacological interventions to manage the neonate's pain and symptoms;

provide opportunities for bonding, memory-making, and meaningful interactions among family members; offer spiritual and cultural support according to family preferences; and minimize disturbances, such as by silencing alarms and pagers and adjusting lighting.

Neonatal nurses should give clear, honest, and compassionate information about the use of artificial nutrition and hydration, recognizing that emotionally difficult decisions often occur under clinical uncertainty (Kang et al., 2025). They should explain that life-prolonging interventions are not always appropriate and that medical nutrition therapy should be used only when it is in the infant's best interests, provides meaningful benefit, and does not impose disproportionate burden or risk (Cardenas et al., 2026; Diekema et al., 2009; Druml et al., 2016). Nurses should clarify potential benefits and burdens, including the risk of prolonging the dying process or causing complications (Druml et al., 2016; Winter, 2000), and prepare parents for the likely clinical course while offering ongoing emotional support and sensitive explanation (Hellman et al., 2013; Vesely & Beach, 2013).

Transition to Home or Hospice Facility

The withdrawal of life-sustaining interventions most often occurs in the hospital setting; however, some parents may request that their child come to their home or a hospice facility for end of life. When this option is pursued, an interdisciplinary approach is essential to coordinate the safe transition from hospital to home and to ensure clear, consistent communication among the family, the medical and palliative care teams, and community-based providers. Care planning should support parental autonomy, with early discussions to address logistical considerations, including transportation, team members accompanying the infant home, pharmacologic management during transport, and detailed do-not-resuscitate orders, including plans should unanticipated extubation occur en route. Coordination with hospice or home-based teams is critical to ensure continuity of comfort-focused care and support for the family at home. Planning should include anticipatory guidance, bereavement support, and connection to resources available to families before and after the infant's death (Loganathan et al., 2018; Postier et al., 2018; Raed et al., 2019). NANN's *Practice Standards in Neonatal Transport, Fourth Edition* discusses specifics of palliative transport of infants to home or hospice facilities.

Loss, Grief, Bereavement, and Ongoing Family Support

Neonatal nurses are responsible for providing ongoing parental emotional support and recognizing signs of parental grief, which may begin at diagnosis and continue beyond death. Bereavement support should be initiated early and maintained as part of ongoing care.

After an infant's death, neonatal nurses can play a vital role in connecting families with comprehensive bereavement care and continuity of support (Lichtenthal et al., 2024). This includes accompanying and supporting families when leaving the NICU to ensure a compassionate transition from the clinical environment, providing emotional reassurance, and facilitating continuity of care. Nurses should provide or facilitate bereavement follow-up, either directly or through referrals to community services and support organizations. Communication and follow-up are crucial; maintaining ongoing contact with families through phone calls shortly after death, condolence cards, emails, or letters from the NICU team and offering follow-up contact on significant dates such as anniversaries, according to family preferences, can be very meaningful. Before families leave the NICU, nurses can offer meaningful items that were in contact with the baby (such as a teddy bear, pacifier, or cloth) to reduce the experience of leaving with "empty arms," and they should preserve and offer memory items such as photographs and footprints, allowing families time to decide if and when they wish to receive them.

Family and sibling support remains important throughout the bereavement process (Baughcum et al., 2017). Neonatal nurses should provide age-appropriate support for siblings and recognize their bereavement needs, as well as offer written information, such as bereavement brochures, that include available resources and contacts. Introducing families to local or national bereavement support groups and organizations, such as Share Pregnancy & Infant Loss Support, the Pregnancy Loss and Infant Death Alliance and RESOLVE: The National Infertility and Family Building Association, can help connect them with ongoing support. Facilitating a postdeath meeting with the NICU team allows families to ask questions, discuss autopsy results if applicable, and reflect on end-of-life care and decision-making. Finally, nurses can support or organize memorial and remembrance activities or events to honor infants and support the family's grieving process (Baughcum et al., 2017).

Neonatal nurses can advocate for access to appropriate family support services, including making timely referrals to specialized professionals such as social workers, chaplains, or spiritual care providers, and members of the palliative care team. Additional support should be considered according to family needs, including referral to a child life specialist or family support specialist to support siblings, peer support from a parent with NICU experience to help families navigate the NICU environment, and connection to a lactation consultant to assist parents who wish to donate human milk at the end of life or manage the cessation of lactation (Fonville & Perrin, 2026; Moore & Catlin, 2003).

Recommendations for Practice

1. Neonatal nurses have a professional responsibility to **provide primary palliative care to all infants with life-limiting or life-threatening conditions and their families** across perinatal, neonatal, and postdischarge settings.

2. Palliative care should **be introduced as early as possible in the illness trajectory**: prenatally, at the time of birth, and throughout the neonatal

period regardless of prognosis or treatment intent and **delivered concurrently with curative or disease-directed therapies when appropriate**.

3. Neonatal nurses are responsible for **ongoing assessment and management of pain and distressing symptoms**, ensuring that care remains comfort-focused, developmentally appropriate, and responsive to changes in clinical condition.

4. Neonatal nurses should **deliver family-centered, culturally appropriate care** that honors family values, cultural and spiritual beliefs, and preferences, while supporting parenting, bonding, memory-making, and shared decision-making throughout care and bereavement.

5. Neonatal nurses **support compassionate communication and shared decision-making** by facilitating clear, honest, and empathetic communication, reinforcing information provided by the interdisciplinary team, and advocating for the infant's best interests while respecting family autonomy.

6. Neonatal nurses should **support the development, documentation, implementation, and ongoing review of advance care plans**, beginning prenatally when applicable and continuing through the NICU course and care transitions.

7. **Collaborate with interdisciplinary and community-based team members**, such as physicians, palliative care specialists, social workers, chaplains, hospice teams, and community providers, to ensure coordinated, consistent care.

8. Neonatal nurses should **advocate for access to bereavement support before and after a death**, including memory-making, emotional support, and referral to appropriate institutional and community resources according to family preferences.

9. Neonatal nurses **should engage in ongoing education and training in palliative care, promote health literacy among families, foster an integrative culture that aligns palliative principles with routine neonatal care, and contribute to research, evidence-based practice, and quality-improvement initiatives**. Education can be gained through organizations like The End-of-Life Nursing Education Consortium and the Hospice & Palliative Nurses Association.

10. **Neonatal nurses should have access to ethical consultation, team debriefings, and resources that promote emotional well-being and**

resilience when caring for infants and families facing serious illness and loss.

Conclusions

NANN emphasizes the essential role of nurses in delivering compassionate, family-centered palliative care to the fetus, newborn, and infant in their settings of care. By integrating palliative principles into routine care, nurses support early identification of needs, effective symptom management, clear communication, and continuous family support across the care trajectory, including at end-of-life and during bereavement.

As consistent caregivers, nurses are central to fostering trust, supporting families through loss, and ensuring that patients and families receive care aligned with their values. In settings with limited specialized services, the nurse's role is critical to ensuring equitable access to quality palliative care. Through interdisciplinary collaboration, advocacy, and ongoing education, neonatal nurses contribute to coordinated, ethical, and evidence-based palliative care, ultimately improving outcomes for infants with serious illness and their families.

References

Akyempon, A. N., & Aladangady, N. (2021). Neonatal and perinatal palliative care pathway: A tertiary neonatal unit approach. *BMJ Paediatrics Open, 5*(1), e000820. https://doi.org/10.1136/bmjpo-2020-000820

American Academy of Pediatrics Section on Hospice and Palliative Medicine & Committee on Hospital Care. (2013). Pediatric palliative care and hospice care commitments, guidelines, and recommendations. *Pediatrics*, *132*(5), 966–972. https://doi.org/10.1542/peds.2013-2731

American College of Obstetricians and Gynecologists. (2019). *Perinatal palliative care* (Committee Opinion No. 786; reaffirmed 2024) [Committee opinion]. *Obstetrics & Gynecology, 134*(3), e84–e89. https://doi.org/10.1097/AOG.0000000000003425

American Association of Colleges of Nursing. (2022). *Primary palliative care competencies for undergraduate and graduate nursing students* (CARES/G-CARES, 2nd ed). https://www.aacnnursing.org/Portals/42/ELNEC/PDF/ELNEC-Cares-and-G-CARES-2nd-Edition.pdf

Association for Paediatric Palliative Medicine. (2024). *Association for Paediatric Palliative Medicine formulary: 6th edition 2024*. https://www.neonatalnetwork.co.uk/nwnodn/wp-content/uploads/2025/04/APPM-formulary-6th-edition-2024-Final-2023-10-26.pdf

Baughcum, A. E., Fortney, C. A., Winning, A. M., Shultz, E. L., Keim, M. C., Humphrey, L. M., Schlegel, A. B., & Gerhardt, C. A. (2017). Perspectives from bereaved parents on improving end-of-life care in the NICU. *Clinical Practice in Pediatric Psychology, 5*(4), 392–403. https://doi.org/10.1037/cpp0000221

Benini, F., Papadatou, D., Bernadá, M., Craig, F., De Zen, L., Downing, J., Drake, R., Friedrichsdorf, S., Garros, D., Giacomelli, L., Lacerda, A., Lazzarin, P., Marceglia, S., Marston, J., Muckaden, M. A., Papa, S., Parravicini, E., Pellegatta, F., & Wolfe, J. (2022). International standards for pediatric palliative care: From IMPaCCT to GO-PPaCS. *Journal of Pain and Symptom Management, 63*(5), e529–e543. https://doi.org/10.1016/j.jpainsymman.2021.12.031

British Association of Perinatal Medicine. (2024, July 11). *Recognising uncertainty: An integrated framework for palliative care in perinatal medicine*. https://www.bapm.org/resources/palliative-care-in-perinatal-medicine-framework

Cardenas, D., Burgos, R., Rothenberg, E., Ballmer, P., Barrocas, A., Bischoff, S. C., Cuerda, C., Genton, L., Gura, K., Hiesmayr, M., Jain, A. K., Klek, S., Poullenot, F., Schneider, S., Schwartz, D. B., Singer, P., Uyar, M., van der Werf, M., Weimann, A., & Druml, C. (2026). ESPEN practical guideline on ethical aspects of medical nutrition therapy. *Clinical Nutrition, 60*, 106622. https://doi.org/10.1016/j.clnu.2026.106622

Carter, B. S. (2018). Pediatric palliative care in infants and neonates. *Children, 5*(2), 21. https://doi.org/10.3390/children5020021

Cortezzo, D. E., Ellis, K., & Schlegel, A. (2020). Perinatal palliative care birth planning as advance care planning. *Frontiers in Pediatrics, 8*, 556. https://doi.org/10.3389/fped.2020.00556

Derrington, S., Broden Arciprete, E. G., Lin, M. C., Oczkowski, S. J. W., Alladin, A., Anani, U. E., Borchik, A. K., Collins, C. A., Delgado-Corcoran, C., Dickerman, M. J., Harrod, C. G., Henner, N., Kon, A. A., Lewis-Newby, M., Lord, B. T., Masters, A. A., McCarthy, S., Moynihan, K. M., Munoz-Blanco, S. M., . . . DeCourcey, D. D. (2026). Society of Critical Care Medicine 2026 guidelines on the care and management of pediatric and neonatal intensive care patients at the end of life. *Pediatric Critical Care Medicine, 27*(4), 518–536. https://doi.org/10.1097/PCC.0000000000003914

Diekema, D. S., Botkin, J. R., & Committee on Bioethics. (2009). Clinical Report: Forgoing medically provided nutrition and hydration in children. *Pediatrics, 124*(2), 813–822. https://doi.org/10.1542/peds.2009-1299

Dombrecht, L., Chambaere, K., Beernaert, K., Roets, E., De Vilder De Keyser, M., De Smet, G., Roelens, K., & Cools, F. (2023). Components of perinatal palliative care: An integrative review. *Children*, *10*(3), 482. https://doi.org/10.3390/children10030482

Druml, C., Ballmer, P. E., Druml, W., Oehmichen, F., Shenkin, A., Singer, P., Soeters, P., Weimann, A., & Bischoff, S. C. (2016). ESPEN guideline on ethical aspects of artificial nutrition and hydration. *Clinical Nutrition, 35*(3), 545–556. https://doi.org/10.1016/j.clnu.2016.02.006

Fonville, V., & Perrin, M. (2026). Lactation during perinatal bereavement from the perspective of families and support providers: A scoping review. *Journal of Human Lactation*. 42(1), 49–62. https://doi.org/10.1177/08903344251389584

Hellmann, J., Williams, C., Ives-Baine, L., & Shah, P. S. (2013). Withdrawal of artificial nutrition and hydration in the neonatal intensive care unit: Parental perspectives. *Archives of Disease in Childhood. Fetal and Neonatal Edition, 98*(1), F21–F25. https://doi.org/10.1136/fetalneonatal-2012-301658

Lichtenthal, W. G., Roberts, K. E., Donovan, L. A., Breen, L. J., Aoun, S. M., Connor, S. R., & Rosa, W. E. (2024). Investing in bereavement care as a public health priority. *The Lancet. Public Health, 9*(4), e270–e274. https://doi.org/10.1016/S2468-2667(24)00030-6

Loganathan, P., Simpson, J., Boutcher, P., Cooper, A., Jackson, A., & Benson, R. J. (2018). Home extubation in a neonate. *Pediatrics, 142*(1), e20172845. https://doi.org/10.1542/peds.2017-2845

Kang, Z. L., Tay, K., & Chong, P. H. (2025). Should clinically assisted hydration and nutrition ever be withdrawn for a neonate with a chronic non-progressive neurological condition? A case study. *Children, 12*(3), 287. https://doi.org/10.3390/children12030287

Martín-Ancel, A., Pérez-Muñuzuri, A., González-Pacheco, N., Boix, H., Espinosa Fernández, M. G., Sánchez-Redondo, M. D., Cernada, M., Couce, M. L., & en representación del Comité de Estándares, Sociedad Española de Neonatología. (2022). Perinatal palliative care. *Anales de Pediatría (English Edition)*, *96*(1), e1–e7. https://doi.org/10.1016/j.anpede.2021.10.003

Mendes, J. C., & Justo da Silva, L. (2013). Neonatal palliative care: Developing consensus among neonatologists using the Delphi technique in Portugal. *Advances in Neonatal Care, 13*(6), 408–414. https://doi.org/10.1097/ANC.0000000000000037

Moore, D. B., & Catlin, A. (2003). Lactation suppression: Forgotten aspect of care for the mother of a dying child. *Pediatric Nursing, 29*(5), 383–384.

Mohammadi, A., Gholami, M., Jandaghian-Bidgoli, M., & Abdi, F. (2025). Impact of neonatal palliative care on neonates, their parents, and nurses: A systematic review. *Palliative Care and Social Practice, 19*, 26323524251326103. https://doi.org/10.1177/26323524251326103

National Consensus Project for Quality Palliative Care. (2018). *Clinical practice guidelines for quality palliative care, 4th edition*. National Coalition for Hospice and Palliative Care. https://www.nationalcoalitionhpc.org/wp-content/uploads/2020/07/NCHPC-NCPGuidelines_4thED_web_FINAL.pdf

National Hospice and Palliative Care Organization. (2023, June). *NHPCO pediatric facts and figures: 2023 Edition*. https://allianceforcareathome.org/wp-content/uploads/NHPCO_Pediatric_Facts_Figures_2023.pdf

Postier, A., Catrine, K., & Remke, S. (2018). Interdisciplinary pediatric palliative care team involvement in compassionate extubation at home: From shared decision-making to bereavement. *Children, 5*(3), 37. https://doi.org/10.3390/children5030037

Raed, M., Grossoehme, D. H., Brown, M., & Friebert, S. (2019). Hospital to home transport at end of life: Survey of clinician experience. *Palliative Medicine, 34*(3), 424–429. https://doi.org/10.1177/0269216319870641

Sieg, S. E., Bradshaw, W. T., & Blake, S. (2019). The best interests of infants and families during palliative care at the end of life: A review of the literature. *Advances in Neonatal Care, 19*(2), E9–E14. https://doi.org/10.1097/ANC.0000000000000567

Sorrentino, G., Thekkan, K. R., Genna, C., Aite, L., Ragni, A., Bevilacqua, F., Dall'Oglio, I., Roberti, M., Tiozzo, E., & Gawronski, O. (2025). The implementation and impact of narrative diaries in neonatal intensive care units: A scoping review. *Nursing in Critical Care, 30*(2), e13281. https://doi.org/10.1111/nicc.13281

Vesely, C., & Beach, B. (2013). One facility’s experience in reframing nonfeeding into a comprehensive palliative care model. *Journal of Obstetric, Gynecologic, & Neonatal Nursing, 42*(3), 383–389. https://doi.org/10.1111/1552-6909.12027

Winter, S. M. (2000). Terminal nutrition: Framing the debate for the withdrawal of nutritional support in terminally ill patients. *American Journal of Medicine, 109*(9), 723–726. https://doi.org/10.1016/s0002-9343(00)00609-4

Wojtkowiak, J., & Mathijssen, B. (2022). Birth and death: Studying ritual, embodied practices and spirituality at the start and end of life. *Religions, 13*(9), 820. https://doi.org/10.3390/rel13090820

Wool, C., & Catlin, A. (2019). Perinatal bereavement and palliative care offered throughout the healthcare system. *Annals of Palliative Medicine, 8*(Suppl 1), S22–S29. https://doi.org/10.21037/apm.2018.11.03

World Health Organization. (2020, August 5). *Palliative care* [Fact sheet]. https://www.who.int/news-room/fact-sheets/detail/palliative-care

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