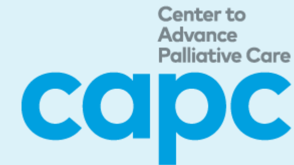
Pediatric Palliative Care Practice Examples from the NCP Clinical Practice Guidelines, 4th Edition



This chart highlights pediatric-specific practice examples drawn directly from each of the eight domains of the National Consensus Project's Clinical Practice Guidelines for Quality Palliative Care, 4th Edition. The examples reflect how interdisciplinary teams across diverse care settings can apply the guidelines to improve outcomes for seriously ill children and their families.

Domain	Pediatric Practice Example (from NCP Guidelines 4th ed.)
Domain 1 Structure and Processes of Care	*Practice Example D1-B* Staff at a **community hospital** identify a trend in after hours and weekend utilization of the emergency department (ED). A significant proportion of patients they see are seriously ill children with symptom issues following a hospitalization at the pediatric hospital, which is 30 miles away. The local hospice has a large home-based pediatric palliative and hospice program, with just one board-certified hospice and palliative medicine pediatrician. The hospital's pediatric service partners with a large community pediatric practice and the hospice pediatric physician, to implement a collaborative quality improvement initiative. Outcomes include staff education for hospital ED personnel, the development of decision-support tools for symptom management, processes to clarify after-hours access to specialty palliative care, and a community resources guide specifically for families with seriously ill children.
Domain 2 Physical Aspects of Care	*Practice Example D2-C* A **large multi-site, multi-specialty community pediatric practice** cares for children with neurological disease, muscular dystrophy, and cystic fibrosis. Ongoing review of their quality metrics identifies that parent satisfaction has been decreasing, particularly related to symptom management for children who have

Domain	Pediatric Practice Example (from NCP Guidelines 4th ed.)
	been hospitalized and are discharged home. In response, the practice invests in training several advanced practice providers as "palliative care champions" to support patients with serious illness and to facilitate care coordination when they are hospitalized. The practice initiates a palliative care clinic one day per week at rotating sites attended by a consulting palliative medicine physician to collaborate with the palliative care champions. The quality improvement plan strengthens the practice relationships with home care and hospice, with a goal of better care coordination for their patients.
Domain 3 Psychological and Psychiatric Aspects of Care	*Practice Example D3-D* A pediatric palliative care team at a **tertiary children's hospital** developed a collaborative practice with the pediatric oncology program to optimize well-being of children throughout their cancer care trajectory. When a young girl with newly diagnosed metastatic cancer developed severe anxiety in the presence of clinicians, the palliative care team worked with the child and her parents to gain trust and assess the causes of her distress. The palliative team collaborated with child life specialists and the pediatric clinical psychologist to address the child's anxiety, using a combination of play therapy, art therapy, relaxation techniques, and medication. The child's mother played an integral role in helping the team to adjust strategies based on the child's needs in the hospital, clinic, and home settings. Co-therapy sessions were facilitated to help the child and her identical twin process their feelings and anxiety as the disease advanced, providing opportunities for the child to identify and communicate what was most important to her at end of life.
Domain 4 Social Aspects of Care	*Practice Example D4-B* A **children's hospital** has recognized the need to expand palliative care integration beyond the current inpatient palliative care team. Social workers and

Domain	Pediatric Practice Example (from NCP Guidelines 4th ed.)
	child life therapists in the outpatient setting already conduct an in-depth psychosocial assessment of every new patient and family within 14 days of the start of outpatient care. This information is recorded in the outpatient medical record and has not been available to inpatient teams, yet it has great importance in managing transitions of care. The hospital commits to implementing a single electronic medical record for inpatient and outpatient care. Representatives of the psychosocial outpatient team begin attending the inpatient palliative care interdisciplinary team meetings to enhance communication and information sharing. Patients admitted who will not be seen in follow-up in the hospital clinics receive the in-depth psychosocial assessment while hospitalized. A process to routinely identify these patients and to share this information with the healthcare providers who will be seeing the patient and family after discharge is under development.
Domain 5 Spiritual, Religious and Existential Aspects of Care	*Practice Example D5-C* A **pediatric oncology** program has recruited a physician dually boarded in oncology and palliative medicine, along with a pharmacist skilled in the pharmacology of symptom management. Staff and family caregiver education in symptom management improves rapidly. At the monthly staff meeting, several individuals acknowledge these improvements but request attention to the spiritual care of the children and families they serve. The staff feels poorly equipped to address the needs of parents and families from diverse religious traditions. They feel unsure of how to respond effectively to the spiritual experiences children may report, such as communication with deceased relatives, visits from "angels," and awareness of their impending death. The pediatric oncology program adopts improved spiritual care as a goal for the next quarter, using the NCP Guidelines as a framework for its quality improvement plans. The 0.20 FTE professional chaplain assigned to this unit leads these efforts, including the development of strategies to

Domain	Pediatric Practice Example (from NCP Guidelines 4th ed.)
	standardize spiritual assessment of all children and their families and a focus on incorporating spiritual care in the plan of care. While resources are stretched in this setting, the team believes that the combined efforts of all the staff, including child psychology, art and music therapy, and child life specialists, can make a major improvement in spiritual care.
Domain 6 Cultural Aspects of Care	*Practice Example D6-F* A large **pediatric tertiary care hospital** provides palliative care to a diverse patient population. To better serve patients and families whose primary language is not English, the team partners with the medical interpreter services department to provide education on palliative care topics. The team meets with the interpreter prior to patient and family encounters to prepare the interpreter for the topics that will be discussed. In addition, an interpreter is assigned primary responsibility for palliative care patients and is a member of the weekly palliative care interdisciplinary rounds. Palliative care team members have found incorporating medical interpreter services into the IDT to be extremely helpful, and it has resulted in improvements in patient- and family communication and increased cultural sensitivity. Incorporating the interpreter into the palliative care team offers opportunities for additional support for the interpreter staff, for debriefing for both the team and the interpreter staff, and enhanced cultural competency for IDT members.
Domain 7 Care of the Patient Nearing the End of Life	*Practice Examples D7-A & D7-C* D7-A: A large **children's hospital** recognized that all units, particularly those caring for children with a higher risk of death, should provide excellent palliative care. The perinatal and neonatology teams provide training for all staff in palliative care, and a team of prenatal/neonatal clinicians, including social work, physicians, nurses, child life, and chaplaincy, have become the leaders for this care. This

Domain	Pediatric Practice Example (from NCP Guidelines 4th ed.)
	team has developed protocols for symptom management, and converted a hospital room dedicated to imminently dying infants to provide privacy and support. A comprehensive perinatal and pediatric bereavement program provides support to grieving parents, siblings, and grandparents, including follow-up through the first year after the baby's death. D7-C: A **pediatric neurology practice** serves a large population of children with severe neuromuscular diseases and brain tumors. Many of these children utilize the emergency department in the last month of life, and often die in the hospital, emergency department or ICU. Once hospitalized, the children and families receive support from an inpatient palliative care service, but at discharge there are few resources available to them. In consultation with the palliative care service, the neurological practice recruits an advanced practice registered nurse certified in hospice and palliative care. The nurse works with the inpatient service to create protocols for symptom management, and improve support for parents caring for children at home. This leads to a more active collaboration with home health and home hospice agencies and both agencies commit to rapidly scaling their capacity to care for pediatric patients, particularly those with end-of-life needs.
Domain 8 Ethical and Legal Aspects of Care	*Practice Examples D8-E & D8-F* D8-E: A **hospital-based pediatric palliative care** team was approached by members of the PICU care team, who expressed that they were often uncomfortable with the ethical and legal implications of withdrawal of life-sustaining therapies. The PICU care team did not feel that issues including decision-making capacity of the patient, disclosures to the child, staff moral distress, and sedation of the imminently dying were consistently addressed prior to withdrawing the therapies. A multidisciplinary group, including members of the children's hospital Ethics Committee, was convened to initiate the standardization

Domain	Pediatric Practice Example (from NCP Guidelines 4th ed.)
	of the withdrawal of life-sustaining therapies process. The process included structured huddles using a new withdrawal of life-sustaining therapies checklist to document decision-making in the medical record in real time — ensuring presence of child life, chaplaincy and social work, anticipatory symptom management strategies, and confirmation with medical decision-maker and, if appropriate, the patient. Following these interventions, staff reported improvement in team communication and reduction of distress surrounding withdrawal of life-sustaining therapies. D8-F: A **community pediatric palliative care** team routinely assesses parental and child/adolescent preferences regarding goals of care. A teen with advanced cancer disclosed to the team that he no longer wanted chemotherapy and was ready to die, but he did not want to disappoint or anger his parents. The palliative care team acknowledged the teen's honest expression of his wishes and provided support. With his permission, the team coordinated goals of care discussions with the parents separately, and subsequently with the parents and teen together. The palliative team also drew upon the expertise of their child life specialist, the teen's oncology team at the hospital, along with the hospital's pediatric ethics committee to facilitate a new plan that honored all family members' needs.

Source: National Consensus Project for Quality Palliative Care. Clinical Practice Guidelines for Quality Palliative Care, 4th edition. Richmond, VA: National Coalition for Hospice and Palliative Care; 2018. https://www.nationalcoalitionhpc.org/ncp.

Last Reviewed Date: 4/9/2026

Created By: Megan Hesketh, MHA
Reviewed By: Connie Dahlin, MSN, ANP-BC, ACHPN, FPCN, FAAN