



Standards of Practice for Pediatric Palliative Care

Quality improvement resource

2022 Edition



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Leading Person-Centered Care

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Introduction

Introduction

The palliative care and hospice interdisciplinary team provides family-centered care that includes the child and family as one unit of care, respecting individual preferences, values, and cultural beliefs, with the child and family active in decision-making regarding goals and plan of care. The family and caregivers have the right to be informed about the illness, potential treatments, and outcomes.

This appendix to the NHPCO Standards is a guide for palliative and/or hospice programs providing care to patients in the perinatal period, infancy, childhood, adolescence, and young adulthood; regardless of whether care is delivered in the home, hospital, long-term care or a respite facility. Throughout this entire document, “children” refers to patients in the perinatal period, infancy, childhood, adolescence, and young adulthood (young adulthood encompasses individuals over 18 years). It may also serve as a guide to pediatric programs developed within a hospice, home health, hospital, or state agency.

It should be understood this document does not stand alone and is designed as a pediatric-specific appendix to the existing NHPCO Standards of Practice for Hospice Programs. Information on pediatric palliative care and/or hospice care can be found at www.NHPCO.org/Pediatrics.

- Deliver safe, effective, high-quality care for children^{1,2} and their families;
- Enhance effective identification of and response to family needs, including the specifics of care required for children of all ages;
- Improve knowledge, skills, and support for care providers; and
- Identify unmet needs in care delivery so that organizations may expand their services or develop partnerships with other care providers to fill these gaps and address challenges found in providing care to children and their families.

What is Pediatric Palliative and Hospice Care?

NHPCO uses the National Consensus Project’s definition of palliative care: beneficial at any stage of a serious illness, palliative care is an interdisciplinary care delivery system designed to anticipate, prevent, and manage physical, psychological, social, and spiritual suffering to optimize quality of life for patients, their families, and caregivers. Palliative care can be delivered in any care setting through the collaboration of many types of care

¹ Children refers to patients in the perinatal period, infancy, childhood, adolescence, and young adulthood (young adulthood encompasses individuals over 18 years).

² Caregiver includes any individual who serves as the primary caregiver(s) or decision maker for the child (biological parent, foster parent, guardian etc.)

providers. Through early integration into the care plan of seriously ill people, palliative care focuses on improving quality of life for both the patient and the family. Palliative care is a framework that encompasses hospice care which is focused on end of life.

Pediatric palliative and hospice care are both a philosophy and an organized method for delivering individualized care to children with life-threatening conditions. Both palliative and hospice care focus on enhancing quality of life for the child and family, preventing and/or minimizing suffering, optimizing function, and providing opportunities for personal and spiritual growth. As such, it can be provided along with concurrent life-prolonging or curative care or as the main focus of care. Pediatric palliative and hospice care are achieved through a combination of active and compassionate therapies intended to comfort and support the child, as well as family members and other significant people in the child's life. Effective management of pain and other distressing symptoms, together with psychosocial and spiritual care, are of critical importance beginning at diagnosis and continuing throughout the entire course of a child's life and beyond. Therapies should take a holistic approach, assisting children and families in fulfilling their physical, psychological, social, developmental, educational, and spiritual goals while remaining sensitive to personal, cultural, and religious values, beliefs, and practices.

Pediatric palliative and hospice care affirm life by supporting the child's and family's goals for the future including hopes for cure, life prolongation and improvement in quality of life. This care is not meant to hasten death or prolong suffering; instead, it aims to guide and assist the child and family in making the best decisions possible for whatever time they have remaining together. Pediatric palliative care is planned and delivered through the collaborative efforts of an IDT including the child, family, and caregivers. Effective pediatric palliative and hospice care also provides support for caregivers, allowing them to work through their own reactions to the situations they encounter without duplication of healthcare services.

How Does Pediatric Palliative Care and Hospice Differ from Palliative Care and Hospice for Adults?

- Children are not small adults. Developmental differences among infants, children, and adolescents that affect diagnosis, prognosis, treatment strategies, communication, and decision-making processes present challenges to adult providers who do not have training or experience in caring for children.
- Children's general physiologic resiliency complicates predictions about their future. Many children who die are born with rare medical conditions, with associated uncertainty in diagnosis, prognosis, and medical management.
- Many communities do not have enough children with life-threatening medical conditions to acquire sufficient clinical expertise in their evaluation and management, including end-of-life care. As a result, seriously ill children and their families often travel far from home for treatment. This approach fragments care and removes children from their logistical, emotional, and spiritual sources of support and may disrupt caregivers' employment and strain family relationships and finances.
- Children do not have a legal voice, as adults do. In most situations, caregivers have legal authority to make decisions about medical treatments for their child. Most states will not recognize a formal advance directive signed by a minor, even a minor living independently.

- Many problems facing children with life-threatening medical conditions and their families, and many shortcomings in end-of-life care, are embedded in broader social, economic, and cultural problems.
- Children are members of many communities, including neighborhoods, places of worship and schools. Their continuing role in these communities should be incorporated into their plans of care. School is an integral part of their lives, and it is essential they have ongoing opportunities for education and peer interactions.
- Grief associated with a child's death has devastating, long-term implications for the entire family and extended community. Siblings have unique needs during an illness and after a child's death. Children and young families are especially vulnerable to misunderstandings related to differences in language, cultural experiences, and values about life, illness, death, and medical or non-medical therapies.



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Identifying Children for Pediatric Palliative Care and Hospice

Identifying Children for Pediatric Palliative Care and Hospice

All children with serious illness deserve excellent pediatric palliative care either as the primary treatment, or concurrent with disease-modifying or curative therapies. Delays in the provision of pediatric palliative care strategies and services are associated with increased physical, emotional, and spiritual suffering of children and their families.

However, prognosis and optimal management of severe chronic illness, in addition to life-threatening conditions in children, are coupled with high levels of uncertainty. Furthermore, families and healthcare providers may find the possibility of death difficult to accept. When determining whether to recommend palliative care or hospice services, even as disease-modifying treatment continues, one approach is to ask the question: "Do you expect this child to live to adulthood?" or "Would you be surprised if this child died in the next year?" The following are four groups of diagnostic categories with examples of the types of patients who should be afforded palliative care or hospice services with or without continuing curative or disease-modifying treatments.

Diagnostic Categories

Group 1

Life-threatening conditions for which curative treatment may be feasible but can fail, where access to palliative care services may be beneficial alongside attempts at life-prolonging treatment and/or if treatment fails.

- Advanced or progressive cancer or cancer with a poor prognosis
- Complex and severe congenital or acquired heart disease
- Trauma or sudden severe illness
- Extreme prematurity

Group 2

Conditions where early death is inevitable, where there may be long periods of intensive treatment aimed at prolonging life, allowing participation in normal activities, and maintaining quality of life (e.g., life limiting conditions).

- Cystic fibrosis
- Severe immunodeficiencies
- Human immunodeficiency virus (HIV) infection
- Chronic or severe respiratory failure
- Renal failure (non-transplant candidates)
- Muscular dystrophy, myopathies, neuropathies
- Severe short gut, Total Parenteral Nutrition (TPN)-dependent

Group 3

Progressive conditions without curative treatment options, where treatment is exclusively palliative after diagnosis and may extend over many years.

- Progressive severe metabolic disorders, (e.g., metachromatic leukodystrophy, Tay-Sachs disease, severe mitochondrial disorders)
- Certain chromosomal disorders, (e.g., Trisomy 13 and 18)
- Severe osteogenesis imperfecta subtypes
- Batten disease

Group 4

Irreversible but non-progressive conditions with complex healthcare needs leading to complications and likelihood of premature death.

- Severe cerebral palsy
- Prematurity with residual multi-organ dysfunction or severe chronic pulmonary disability
- Multiple disabilities following brain or spinal cord infectious, anoxic or hypoxic insult or injury
- Severe brain malformations, (e.g., holoprosencephaly, anencephaly)



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Clinical Excellence and Safety
(PPC CES)

Clinical Excellence and Safety (PPC CES)

Principle

Health professionals providing pediatric palliative care and/or hospice have a responsibility to pursue comfort aggressively and minimize the child's physical, psychosocial, and spiritual pain and suffering in keeping with safe practice, acceptable standards and patient/family agreement.

Standard:

PFC 1: Hospice services are available twenty-four (24) hours a day, seven (7) days a week.

PPC CES 1.1 The hospice organization seeks collaborative relationships with pediatric specialists to address unique needs of the patient based on age or diagnosis.

PPC CES 1.2 Pain management is patient/family centered to improve quality of life (e.g., sleeping through the night, fatigue management, and decrease of pain).

PPC CES 1.3 A primary care coordinator (e.g., case manager, nurse navigator, etc.) for all pediatric patients is identified.

PPC CES 1.4 A plan for anticipated pain and symptom management is part of every plan of care.

PPC CES 1.5 Pain prevention and treatment should be anticipated for all procedures or interventions related to the plan of care. Procedures or interventions not related to the family's goals of care should be avoided.

PPC CES 1.6 Team members providing direct services to children will complete annual competencies, at a minimum, on pediatric pain and symptom assessment and management, and growth and development as appropriate per discipline.

PPC CES 1.7 Utilization of age-appropriate assessment tools are noted in all documentation.

PPC CES 1.8 Pain and all distressing symptoms are reported on every visit, by each discipline (including volunteers).

PPC CES 1.9 Families and the child, as age-appropriate, are educated about pain and symptom assessment and management as it relates to their child's plan of care. Education materials are made available at time of admission and/or when pain and symptoms occur, in a manner that is easily understood by the family.

PPC CES 1.10 A pediatric physician and/or pharmacist is available for consultation to the interdisciplinary team as needed, 24 hours-a-day, 7-days-a-week.

PPC CES 1.11 Adequate doses of analgesics are administered as prescribed by the physician and not only on an 'as-needed' basis. Around the clock dosing of analgesics is recommended for pain that is experienced for more than Additional doses are given to treat breakthrough pain or predicted intermittent exacerbation.

PPC CES 1.12 The appropriate opioid dose is the dose that effectively relieves pain and is not based solely on doses per body weight.

PPC CES 1.13 Age-appropriate, non-pharmacologic therapies are an integral part of the pain and symptom management plan of care.

Practice Examples:

- A rural palliative care and/or hospice program primarily caring for adults is asked to provide care for a child with spinal muscular atrophy who has significant respiratory distress. As they have no pediatric providers, they develop a collaborative consultative relationship with pediatric palliative care providers at a tertiary children's hospital 100 miles away. The nurse and/or medical director communicates by Microsoft Teams weekly or more frequently if needed with the pediatric specialists to adjust medication dosing and solicit support.
- A program with limited experience caring for children develops a collaborative relationship with a pediatric provider such as a pediatric hospice, palliative care program and/or tertiary children's hospital to participate in telehealth/virtual consultation visits.
- A 7-year-old has trouble seeing and cannot make out the FACES pain scale normally used for assessment. Instead, the nurse determines this child clearly understands the concept of numbers and uses 5 marbles instead. One marble in his hand indicates no pain, and all 5 taking up his entire palm indicate the worst pain ever. The nurse suggests leaving the marbles at his bedside for every caregiver to use.
- A 2-year-old with end-stage congenital heart disease continues to suffer (despite an aggressive pain regimen), exhibiting respiratory distress, restlessness, and anxiety. He is calmed with the addition of a music therapy intervention, allowing his mother to rest, take a shower and put him down literally for the first time in days. The patient's mother uses the music intervention in addition to his pharmacologic regimen to comfort him daily.
- Clinical policies and procedures are developed and implemented for the care of children of any age, including perinatal consultations for a pregnant mother whose fetus has been diagnosed with a life-limiting condition. Policies and procedures reflect evidence-based perinatal and pediatric practice and guide the provision of care by all disciplines.
- A primary adult hospice provider is interested in establishing a pediatric hospice program and develops a collaborative agreement with the local children's hospital for competency training in pain and symptom assessment and management
- The hospice ensures that caregivers of a pediatric hospice patient inform the local fire department that a seriously ill child resides in the home and stickers are placed on the patient's bedroom window to alert fire responders in the event of a fire.



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Compliance with Laws and Regulations (CLR)

Compliance with Laws and Regulations (CLR)

Principle

Every hospice/palliative care program ensures compliance with applicable laws, regulations, and professional standards of practice, implementing systems and processes that prevent fraud and abuse.

Standard:

PPC CLR 1: The organization maintains full compliance with legal and regulatory requirements and standards of practice, including, but not limited to, the incorporation of concurrent care for pediatric patients under the Concurrent Care for Children Requirement (CCCR) pursuant to Section 2302 of the Affordable Care Act (ACA).

Practice Example:

- The American Academy of Pediatrics (AAP) issues an updated position statement on pediatric hospice and palliative care. The hospice/palliative care program has an existing structure to evaluate the current position statement to ensure that the hospice is compliant with all current outlined recommendations.

Standard:

PPC CLR 2: Hospices and palliative care programs should use the best available scientific evidence in determining eligibility for pediatric patients since prognosis is uncertain for most life-limiting pediatric diagnoses/conditions. Programs should have a systematic way to document this process and on-going evaluation and should involve pediatric expertise in prognostic determination as required.

Standard:

PPC CLR 3: The hospice maintains a comprehensive, timely, and accurate clinical record of services provided in hospice and palliative care settings for each patient and family.

PPC CLR 3.1 A standardized format is used to document the services provided in all care settings. This format includes fields and elements unique to special populations, especially pediatrics.

PPC CLR 3.2 Documentation in the hospice clinical record includes assent by the pediatric patient (age dependent by state) for admission into the hospice program, if appropriate and allowed by the caregivers/ legal guardian(s).

PPC CLR 3.3 Documentation tools in the clinical record should be age appropriate.

Practice Examples:

- An assessment of patients under 18 years of age is conducted to determine the extent to which they can participate in decision making.
- The hospice maintains up-to-date information on age-appropriate state advance directive forms (Allow Natural Death (AND), Do Not Resuscitate (DNR), Physician Orders for Life-Sustaining Treatment (POLST)), Medical Orders for Life-Sustaining Treatment (MOLST), etc.) and provides guidance and assistance to families to assist with their completion.



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Ethical Behavior and Consumer Rights (PPC EBR)

Ethical Behavior and Consumer Rights (PPC EBR)

Principles

Bioethicists consider four basic principles of health care ethics for care/practice to be considered “ethical” and that care/practice must respect all four of McCormick et al.’s principles.

- **Autonomy** – Requires the patient have self-sufficiency of thought, purpose, and action when making decisions about their health care. The decision-making process must be free of strong-arming or persuasion.
- **Nonmaleficence** – Requires that healthcare providers not intentionally create a harm or injury to the patient, either through acts of commission or omission.
- **Beneficence** – Healthcare providers have an obligation to be of benefit to the patient, as well as take steps to prevent and to remove harm from the patient.
- **Justice** – Refers to everyone having an equal opportunity. This principle seeks to eliminate discrimination in healthcare.

The best interests of the child shall be the primary consideration in decision making.

Standard:

PPC EBR 1: Staff communication with the child and family is open and honest, in accordance with each child’s level of understanding. Without full disclosure, the child and family cannot participate in decision making about treatment choices. When, what, and how to disclose information to children must consider the child’s and the family’s cultural or religious values, the caregiver(s)/guardian’s choices of what the child can be told, and the child’s capacity and desire to understand.

PPC EBR 1.1 Every child has equal access to palliative care and/or hospice, irrespective of the family’s financial circumstances.

PPC EBR 1.2 Children are not subjected to treatments that impose undue burden without potential benefit.

PPC EBR 1.3 Every child receives effective pain relief and symptom management, incorporating the use of pharmacologic and non-pharmacologic methods.

PPC EBR 1.4 Every child is treated with dignity and respect and is afforded privacy.

PPC EBR 1.5 The needs of adolescents and young people and their role in decision making are addressed and planned for, well in advance.

PPC EBR 1.6 The practice of physician-assisted death (PAD) is not supported or endorsed.

PPC EBR 1.7 The principles of negotiation and conflict resolution are used to address disagreements among or between healthcare providers, the child, and the child's family.

PPC EBR 1.8 When resolution is not achieved to an identified conflict, the interdisciplinary team enlists the assistance of a cultural interpreter/advisor, chaplain and/or an ethics consultant.

PPC EBR 1.9 In the event of an ethics consult, the team meets afterwards, with the family and/or child present (as preferred by the child and his/her family) to discuss options, and to assist in implementing changes to the plan of care.

Practice Examples:

- Parents are fearful of how to speak to their 8-year-old son about dying. They are counseled about ways to present the information, anticipating his questions and known fears. The team offers to be present, if the parents wish, during the conversation; in addition to providing support and reassuring both parents, the interdisciplinary team make pain and symptom management a priority in his care.
- A family is counseled that it is ethically acceptable to discontinue TPN for their baby when it has become clear that continued intravenous feeding as death nears is causing additional symptoms of respiratory discomfort.
- A Hmong elder is contacted to assist in discussions about treatment options for a Hmong toddler who is a motor vehicle accident victim and whose caregivers are unwilling to discuss likelihood of death.

Standard:

PPC EBR 2: The interdisciplinary team provides guidance and education to the child/family in choosing medically- and ethically appropriate treatment options that are consistent with their values and beliefs. Team members should not attempt to influence families to make decisions that are not compatible with their values. Children with chronic illness often have a level of understanding greater than would be assumed based on their age.

PPC EBR 2.1 Every child is given the opportunity to participate in decisions affecting his or her care, according to age, understanding, capacity and caregiver support. Emphasizing competence or capacity to assent or dissent, rather than the age of the child, allows children to participate in decisions regarding their care whenever possible and appropriate.

PPC EBR 2.2 While most children under the age of 18 have no legal decision-making rights, they should be included in decision making according to their capacity. For children without complete decision-making capacity, caregivers or guardians make decisions based on the best interests of the child, assisted by the interdisciplinary team.

PPC EBR 2.3 For older children who demonstrate some healthcare decision-making capacity, caregivers/guardians and the interdisciplinary team should share age-appropriate information, seek assent, and take into consideration dissent, while ensuring the child's best interests remain at the core of decisions.

PPC EBR 2.4 For adolescents under the age of 18 who demonstrate healthcare decision-making capacity, every effort must be made to obtain caregiver (guardian) approval to include these children in the decision-making process, thus allowing them to exercise independence.

PPC EBR 2.5 Patients who are over the age of 18 years who are cared for by pediatric programs are treated as adults. Guardianship should be verified by teams for patients over 18 who do not possess decision-making capacity.

PPC EBR 2.6 Emancipated minors with demonstrated capacity have the legal right to participate in all decisions regarding their medical care.

PPC EBR 2.7 There is an established process for anticipating, identifying, and resolving conflict, including consultation with specialists and/or a bioethics committee.

Practice Examples:

- A school-age child is given choices of timing, room location, analgesia, and distraction techniques for blood draws. He is quite calm when all conditions are met but becomes hysterical when a new nurse does not follow his rules.
- A 15-year-old is refusing to undergo a Phase I drug trial. Conflict arises when the caregivers do not support this decision. The interdisciplinary team consults with the family's priest and the team chaplain to assist with decision making and plan of care. The adolescent's decision is respected.
- Parents request continued mechanical ventilation in the pediatric intensive care unit (ICU) for their infant with a severe brain malformation. In response, the interdisciplinary team recommends a time-limited trial, and suggests consultation with another pediatric intensivist and/or ethics committee consultation. A time-limited trial is negotiated. At the end of the trial, the infant remains without spontaneous respirations. After discussion with the family, the infant is extubated and dies in the mother's arms.
- While advance directives are not yet legally binding for children, the interdisciplinary team assists the terminally ill pediatric patient and family, who wish to remain at home, to complete and disseminate an age-appropriate written advance care plan describing the child and family's goals and preferences at the end of life. Providers should follow written goals of care or preferences.
- A pediatric hospice team meets a 19-year-old with a severe intellectual disability, cerebral palsy and end-stage scoliosis causing respiratory failure, who is on a ventilator in the pediatric ICU at the local tertiary care center. Advance care planning has not been discussed with the patient previously, and he is unable to communicate. Prior to planning transfer and extubation to allow the young man his natural death at home, the team verifies that his parents have established guardianship.



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Inclusion and Access (PPC IA)

Inclusion and Access (PPC IA)

Principles

Hospice and palliative care providers promote inclusiveness and access to programs and services regardless of race, ethnicity, color, religion, sex (including gender identity, sexual orientation, and pregnancy), disability, age, disease, disability or genetic information, or other characteristics.

Standard:

PPC IA 1: Hospice and palliative staff and volunteers are oriented to the special needs of children in hospice and palliative care service and their families and communities.

Practice Examples:

- Contacts are made with specialty physicians (e.g., cardiovascular, pulmonary, neurology, and other pediatric specialists) to facilitate the referral of patients as appropriate.
- A task force and/or advisory group is formed to develop ways to increase minority and under-served populations' access to hospice/palliative care. The minority group or population is represented on the task force or advisory group.
- The hospice and palliative care organization develops or integrates age- and developmentally appropriate forms and assessments.

Standard:

PPC IA 2: Bereavement care must include age-appropriate bereavement services for children (e.g., siblings) who lose loved ones.

PPC IA 2.1 The hospice and palliative care program demonstrates efforts to promote the community's understanding of grief and loss across all age groups.

Practice Examples:

- The organization maintains an up-to-date list of local counselors who are who are trained and certified in working with children's bereavement issues in an age-appropriate manner.
- Community educational programs are sponsored in partnership with other community organizations, funeral homes, schools, educational programs, healthcare agencies, etc.

Standard:

PPC IA 3: The organization's leaders continually review the services provided by the organization to ensure that the needs of minority pediatric populations are being met.

Practice Examples:

- A survey process exists to identify community needs at regular intervals; input is solicited from representatives of all constituencies in the community, including children of different ages.
- The hospice and palliative care program collaborate with pediatric medical treatment facilities (MTFs) to ensure quality care for eligible patients.
- A pediatric hospice and palliative care program establish a Spanish-speaking volunteer program, pairing members of the community hospice and palliative care patients. Specialized training is given to the volunteers, who share companionship and activities. Regular debriefings are scheduled with the volunteers, as well as special remembrance services and bereavement counseling for volunteers whose patient dies.

Standard:

PPC IA 4: Access to pediatric hospice and palliative care is enhanced by collaborating with community organizations to promote coordination of care.

Practice examples:

- The hospice and palliative care program collaborate with a pediatric MTFs to ensure quality care for eligible patients.
- Contacts are made with specialty physicians (e.g., cardiovascular, pulmonary, neurology, and other pediatric specialists) to facilitate the referral of patients as appropriate.



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Organizational Excellence (PPC OE)

Organizational Excellence (PPC OE)

Principles

Pediatric program design and service delivery are founded on a culture of quality, accountability, and service excellence within an organization that values collaboration and communication and ensures ethical business practices.

Standard:

PPC OE 1 Pediatric programs may serve patients in the perinatal period, infancy, childhood, adolescence, and young adulthood, as well as adult survivors of pediatric diseases. The program must have policies and procedures in place to address developmental, physical, social, psychological, and spiritual needs of children of all ages.

PPC OE 1.1 Care by providers trained in pediatric palliative care and/or hospice is available 24 hours a day, 7 days a week.

PPC OE 1.2 Families have a key contact person to assist with coordination of care, and they are instructed on how to contact the team in the event of a crisis or if they have needs after designated business hours.

PPC OE 1.3 Coordination of care among the interdisciplinary team, the family, and all sites of care occurs regularly and is discussed routinely at interdisciplinary team meetings.

PPC OE 1.4 Pediatric palliative care and/or hospice services are accessible to children and families in a setting that is appropriate to their needs and resources.

PPC OE 1.5 Respite care is recognized as a valuable need and the team ensures that families have access to respite care in their own home and/or in a home-away-from-home setting or facility with pediatric interdisciplinary care.

Practice Example:

- Program develops quality Initiatives based of established quality practice standards and guidelines.
- The perinatal/pediatric palliative care provider is not working in a silo. They must coordinate and communicate with the mother's obstetrician who is managing the pregnancy. The group, including the family, the obstetric care providers and the pediatric and perinatal/pediatric palliative care providers and members of the interdisciplinary team such as social worker and child life specialist need to communicate with each other about such things as:
 - Monitoring (fetal heart rate, ultrasound, amniocentesis, fetal lung maturity testing, etc.) before delivery
 - Plans to intervene, or not (and to what extent), in the event of fetal distress
 - Advance planning for resuscitation, or not, and to what extent, of the baby once born

- Advance planning for bonding of the baby with their parents once born
 - How it will be determined whether resuscitation is in order, and for how long, versus spending that precious time with the family
 - Preparation for memory and legacy opportunities
 - Assisting with coordinating care across care settings
 - Facilitating communication with family if requested by parent(s)
 - Assisting with sibling understanding and grief
 - Referral for grief support for all family members
- The hospice or palliative care interdisciplinary team works with the primary care team, the patient, and family to determine capacity of patient, confirm guardianship if patient is 18 or over without capacity, determine decision-makers, establish patients assent if developmentally able, establish short and long-term goals of care of patient and family (individually or separately as they may be different), to create an interdisciplinary plan of care. Assessment should include patient and families understanding of condition and prognosis, developmental level of patient and family members, understanding of services available and their meaning, psycho-social needs, spiritual and environmental assessments.

Standard:

PPC OE 2: The program partners with community agencies and others that provide resources for children, including respite care.

Practice examples:

- The program partners with local schools.
- The program partners with social service agencies, including county- and state-based aid programs and Title V programs (e.g., Early and Periodic Screening, Diagnostic and Treatment (EPSDT)).
- The program partners with specialty healthcare agencies and providers.
- The program partners with faith groups in the community.
- The program partners with community support services, such as wish-granting organizations.



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Patient and Family-Centered Care
(PPC PFC)

Patient and Family-Centered Care (PPC PFC)

Principles

The palliative care and/or hospice interdisciplinary team provides family-centered care that includes the child and family as one unit of care, respecting individual preferences, values, and cultural beliefs, with the child and family active in decision making regarding goals and plan of care.

Standard:

PPC PFC 1: The goals of the child and family are foremost at the center of all services provided.

PPC PFC 1.1 Services should be available to all children and families who are referred, regardless of their financial or health insurance status.

PPC PFC 1.2 Family is defined as the persons who provide physical, psychological and spiritual comfort to the child, and who are close in knowledge, care and affection – regardless of genetic relationships. Family members may be biological, marital, adoptive, custodial relations, friends, as well as pets. Parents, siblings, grandparents, schoolmates, and others are part of the child’s community who may need particular support.

PPC PFC 1.3 All aspects of care are provided in a manner that is sensitive to: the child’s developmental stage; the personal, cultural, and spiritual beliefs and practices of the child and family; and their preparedness to deal with significant decline or the possibility of dying.

PPC PFC 1.4 The child has the right to age-appropriate information about his or her illness, as well as potential treatments and outcomes, within the context of family decisions. The program has trained staff and access to clinical and educational resources that meet the needs of each child served regardless of age, cognitive and educational ability.

PPC PFC 1.5 The patient, family and caregivers have the right to be informed about the illness, potential treatments, and outcomes.

PPC PFC 1.6 Decisions are made by the family, including the child to the level of his/her capacity, in collaboration with the interdisciplinary team and additional service providers.

PPC PFC 1.7 The interdisciplinary team identifies the patient’s family’s beliefs and philosophies in addition to those of the pediatric patient and does its best to honor both sets of beliefs in all care decisions.

PPC PFC 1.8 The interdisciplinary team promotes opportunities for personal growth and fulfillment of reasonable goals, and to find meaning according to the preferences of the patient, recognizing that the pediatric patient’s growth may be based on developmental stage.

Practice Examples:

- The palliative care and/or hospice team assesses the family communication system, with history of condition and what conversations have taken place among acute or primary care provider, child (according to his/her capacity) and family or caregiver.
- The interdisciplinary team has access to tools and resources to share age-appropriate information with the child and family, including pediatric-appropriate advance directive information.
- Admission policy supplemental materials include pediatric-specific conditions not limited to cancer diagnoses and including complex medical conditions. Resource lists include NHPCO, AAP, and disease-specific organizations/websites, Courageous Parents Network.
- The interdisciplinary team meets the child and family with the acute care or primary care provider present to review plan of care and develop goals together. If possible and appropriate.
- A 5-year-old child is diagnosed with stage IV neuroblastoma. Although the child will be undergoing surgery and starting chemotherapy, the palliative care team is called and is introduced to the family by the oncologist as a resource for support when the child will be ready to go home. The social worker from the palliative care team collaborates with the oncology team, and frequently makes visits while the child is in the hospital to build relationships prior to discharge home.
- The interdisciplinary team has resources available to facilitate baptism or other religious or non-religious rituals for the patient/family to fulfill spiritual faith goals.

Standard:

PPC PFC 2: The interdisciplinary team members implement interventions identified in the plan of care.

PPC PFC 2.1 The palliative and/or hospice interdisciplinary team includes the availability of a professional, such as a child life specialist, licensed marriage and family counselor, licensed clinical social worker, or psychologist, who has special skills in communicating with children in a developmentally appropriate manner on issues related to adjustment to illness, loss, and grief.

PPC PFC 2.2 The pediatric plan of care is documented, updated regularly, and communicated to all team members involved in providing care and services to the patient and family, including referring and involved clinicians, and the patient and family themselves.

PPC PFC 2.3 The plan of care for pediatric patients takes into consideration family members, including siblings, grandparents, and key community members/support (e.g., teachers, schoolmates, aides, therapists) and provides resources to these supporting groups as needed.

PPC PFC 2.4 The plan of care takes into consideration physical, emotional, spiritual, psychosocial, cultural, practical, developmental, educational, medication, and equipment needs. The plan of care also takes into consideration the home environment of the family.

Practice Examples:

- The pediatric plan of care includes changes related to functionality in the community (e.g., ability to attend school or participate in hospital or home-bound activities). Plan of care must also incorporate siblings and community systems and include notification procedures (with appropriate permission caregiver/guardian) with new changes related to decline.
- During team meetings, specific interventions related to a pediatric patient including sibling and community support are discussed and expertise is sought, if necessary, competencies are not immediately available to the team.
- The pediatric plan of care is revised if the child has significant change or enters active decline or active end of life to include support to siblings, extended caregivers, and community.
- The interdisciplinary team works with caregivers and siblings of the pediatric patient, especially as signs of decline become imminent.

Standard:

PPC PFC 3: Comprehensive anticipatory loss, grief and bereavement support methodologies are offered as an integral component of care to the child and all family members at admission into the program.

PPC PFC 3.1 Methods to address loss, anticipatory grief and bereavement will be provided for the family members at all developmental stages.

PPC PFC 3.2 Educational materials describing children's grief and supportive strategies for bereaved children are made available to family members.

PPC PFC 3.3 Partnerships among palliative care providers and community agencies (e.g., schools, faith communities) are established to facilitate outreach and support for children affected by loss.

PPC PFC 3.4 The needs of siblings are an integral part of each child/family plan of care.

PPC PFC 3.5 Routine bereavement services are available and offered to the family and caregivers for a minimum of 13 months regardless of risk factors, including age-appropriate bereavement services for children who are affected by the death of a family member.

Practice Examples:

- While the child is enrolled in a palliative and/or hospice program, a member of the team visits the classroom or school (with permission of family) to assist classmates to understand treatment and how they may be helpful to the student and family.
- Following the death of a high school student from cancer, the bereavement counselor from the program and the school counselor meet to develop bereavement support strategies for the child's classmates.
- The younger sibling of a child with terminal neurodegenerative disease is enrolled in a sibling support group.
- The interdisciplinary team uses child life, expressive therapy and psychosocial team members to identify anticipatory grief issues for children, siblings and families facing a child's death.

- A child life specialist or social worker makes visits to the home with siblings and the sick child prior to death, to create a memory book of favorite vacations together. Siblings review the memory book months later in support group.
- A 17-year-old loses her twin and asks to participate in the washing of the body and to put on makeup for her sister before the body leaves the home, remembering "she never left home without makeup." Later in a bereavement counseling session, this sibling remarks that she will always remember this as the most intimate moment with her sister, and that she appreciated being a part of preparing the body after her sister's death.
- The palliative and/or hospice staff help the patient and family complete advance directives, including making tools available that are appropriate for younger patients, such as My Wishes and Five Wishes. The interdisciplinary team fosters communication between the medical team and hospice/palliative team to support mutual understanding of goals.
- The hospice staff works with the funeral home prior to death to facilitate the least traumatic patient transfer possible. (This may include not covering child's face until transportation is out of sight, allowing for a caregiver to carry child out of home to vehicle if desired, encouraging caregivers to allow siblings to have the opportunity to see child and say good-bye, not zipping the child into a funeral bag, and allowing the family to escort their child to the funeral). The hospice team must be knowledgeable of the local restrictions and laws regarding death of a minor at home and prepare family accordingly prior to death.
- Recognizing that bereavement needs for families losing a child are different, the hospice sets up a protocol to allow bereavement services to continue for two years when a child dies.
- The organization provides grief and bereavement support for staff members.



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Performance Measurement
(PPC PM)

Performance Measurement (PPC PM)

Principles

The program develops, defines, and utilizes a systematic approach to ascertain and improve performance. This approach is authorized and supported by the program's governing body and leaders. The approach assures that information is collected and analyzed, actively uses performance measurement data to foster quality assessment, performance improvement and is specific to pediatric patients being served.

Standard:

PPC PM 1: The palliative care and/or hospice organization has a quality improvement plan in place to measure and evaluate services rendered to children and their families.

PPC PM 1.1 Validated measures of children's clinical outcomes are implemented, using available standard measures or those developed or adopted by the program if gaps exist.

PPC PM 1.2 All adverse events are documented and investigated; results of inquiries are communicated throughout the organization's leadership and disseminated to clinical personnel to ensure that similar events do not recur.

PPC PM 1.3 All medication errors are documented and investigated. Correction measures are implemented based on investigation results, such that possibilities for future errors are minimized.

PPC PM 1.4 Resource utilization is analyzed; results of analysis are used to guide appropriate and equitable distribution of available resources.

PPC PM 1.5 Child and family satisfaction surveys are developed (de novo or adapted from reliable and appropriate sources) and sent to families to complete. Measures are implemented to maximize response rates. Results of completed surveys are shared with management and clinical personnel, as appropriate, so that improvements can be made in ongoing and future care. Unsatisfactory results are addressed directly with involved team members, and patients and families are contacted and updated regarding performance improvement plans.

Practice Examples:

- The organization develops focus groups or professional pediatric advisory groups which meet regularly to offer and review feedback about services provided and to analyze quality standards and compliance. Consumers, including teenagers, are represented in these groups.
- Patients with indwelling central catheter lines are monitored for the development of line infections according to evidence-based recommendations.
- On-call logs are analyzed, and compliance with the organization's standard is monitored.
- Family satisfaction surveys specific to care provided to children and families are sent during the child's care and/or after death and the results are aggregated and analyzed. Positive feedback is conveyed directly to the involved care team; constructive feedback is also shared, and process or system implications are addressed.
- A home safety checklist is developed to ensure a child's home environment is as safe as possible.



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Stewardship and Accountability
(PPC SA)

Stewardship and Accountability (PPC SA)

Principles

Pediatric palliative care and/or hospices have an organizational leadership structure with access to relevant expertise (skills/knowledge) in pediatrics palliative/hospice care.

Standard:

SA 1: There are administrative policies that define the roles and responsibilities of the pediatric specialists, committee, consultant, or team.

Practice Examples:

- Written policies define the composition and organization of the interdisciplinary team(s). These policies reflect flexibility in team composition for different specialty populations.
- The organization includes pediatric expertise and representation on compliance committees and budget development proceedings.



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Workforce Excellence (PPC WE)

Workforce Excellence (PPC WE)

Principles

The organization's leadership develops and monitors systems to ensure that pediatric palliative care and/ or hospice interdisciplinary team members, including volunteers, are adequately trained, staffed, and supported to provide the services offered by the program, and that sufficient support is in place for staff to engage in routine self-care.

Standard:

PPC WE 1: All staff caring for children receive pediatric-specific orientation, training, mentoring, development opportunities, and continuing education appropriate to their roles and responsibilities.

PPC WE 1.1 Physicians directing pediatric palliative care programs have board-certification or are board-eligible in pediatrics or family medicine and/or hospice and palliative medicine. Expectations for board certification after a given period of board eligibility should be specified by the individual organization.

PPC WE 1.2 The manager of a pediatric hospice and palliative care program should, at a minimum, be a registered nurse with a background in pediatric care and training in hospice and palliative care.

PPC WE 1.3 All staff providing hospice and palliative care for children have verifiable training and experience in pediatric hospice and palliative medicine and achieve certification where available.

PPC WE 1.4 Volunteers directly working with children or their families are suitably screened and trained in developmental needs, family dynamics, communication challenges, and pain and symptom management.

PPC WE 1.5 When pediatric providers are not available within an organization, partnerships or consultative agreements are established with those in the community and/or at tertiary healthcare centers who are experts in working with children and adolescents.

PPC WE 1.6 Clinical policies and procedures are developed and implemented for the care of children of any age. Policies and procedures reflect evidence-based pediatric practice and guide the provision of care of by all disciplines.

PPC WE 1.7 On-call or after-hours staff are competent to take pediatric calls and provide pediatric care.

PPC WE 1.8 Pediatric consultative support is made available to staff as needed 24 hours/day.

Practice Examples:

- Hospice incorporates pediatric education into the new hire and annual training for all hospice employees, such as After-Hours staff caring for children on evenings, nights, and weekends, admission nurses, Inpatient Hospice Units/Houses, as well as other supporting teams/departments (Quality, Clinical Software, Finance). Curriculum

should include at least similarities and differences between pediatric and adult hospice patients, child growth and development, main diagnoses and usual course of illness, pain and symptom management guidelines, grief support at appropriate development levels and concurrent care. Reference and resource material should be readily available for all staff.

Standard:

PPC WE 2: Pediatric visit frequency and length of visit is assessed and adjusted to reflect the needs of both the child and family in the plan of care.

Practice Examples:

- When establishing the Plan of Care and visit frequency, the Interdisciplinary Group assesses the child's physical condition and psycho-social-spiritual needs including the need of visits around the child and family's schedules; such as school, extracurricular activities, and other family functions/activities. This may mean the nurse visits the patient and family in the evening to allow both parents to be present for the visit or the Social Worker and/or Child Life Specialist visits in the later afternoon once the siblings get home from school

Standard:

PPC WE 3: The hospice or palliative care program develops and implements age- appropriate competency programs for all staff and volunteers responsible for direct patient care activities.

Practice Examples:

- A community palliative care and/or hospice program primarily caring for adults works with a children's hospital to standardize pediatric pain assessment and management tools.
- A palliative care and/or hospice program caring for several children a year sends their staff to conferences with pediatric-specific hospice or pediatric palliative care content.
- Examples of training curricula include Pediatric End-of-Life-Nursing Education Consortium (ELNEC), Education in Palliative & End-of-Life Care (EPEC)-Pediatrics, and the Harvard Palliative Care Education and Practice (PCEP).
- The nurse manager works with the clinical nurse specialist or a clinical nurse educational specialist at a pediatric palliative care and/or hospice to implement pain and symptom assessments of infants and non-verbal children.
- The program has a contractual arrangement with a staff agency that has pediatric-trained staff available to provide coverage when an employee is ill or requires a change in assignments. It is preferred that the palliative care and/or hospice program maintain adequate staff that are pediatric trained as a first plan of action when an employee is ill or requires a change in assignments.
- A pediatric resource library is maintained and is accessible to all staff, volunteers, patients, and family members.
- Staff utilize current educational and evidence-based pediatric resources—including textbooks, established curricula and up-to-date journal articles—to develop policies and procedures for programs expanding services to children.

- Volunteer retention efforts include establishing: individual support mechanisms; mentoring or “buddying” systems with experienced, competent peer volunteers; assignment changes when the program’s, child’s or family’s needs are not met; ongoing feedback and recognition events; and facilitation of communication and camaraderie with other interdisciplinary team members (e.g., support groups, telephone calls, flyers, closure of care, meeting with volunteer coordinator, etc.).
- A community hospice or palliative care program adjusts the caseloads and productivity expectations of the pediatric palliative care/hospice nurse and social worker to meet the needs of the pediatric patient and family.
- The hospice has access to pediatric physicians to collaborate, consult, and provide recommendations on appropriate pediatric treatments.



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Pediatric Advisory Council Standards Workgroup Members

Holly Davis, MS, APRN
AVP Clinical Services
Hospice & Palliative Care Charlotte Region

Oralea Marquardt
Youth and Family Grief Counselor
Treasure Coast Hospice

Christy Torkildson, PhD, RN, PHN, MSN
Lead, MSN-Public Health Nursing Program
College of Nursing & Health Care Professions

Jennifer Mangers, MS
Child Life Specialist
Journey Care

Michelle Goldbach
Administrator/Director of Clinical Operations
Kindred Hospice

NHPCO Pediatric Advisory Council Staff Liaisons

Hope Fost, MPH

NHPCO Staff

Judi Lund Person, MPH, CHC
Hannah Yang Moore, MPH



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National Hospice and Palliative
Care Organization

NHPCO

1731 King Street
Alexandria, VA 22314

tel. 703.837.1500 | nhpco.org