



Standards of Practice for Pediatric Palliative Care and Hospice







Standards of Practice for Pediatric Palliative Care and Hospice

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Standards of Practice for Pediatric Palliative Care and Hospice

Preface

The National Hospice and Palliative Care Organization's (NHPCO) Standards of Practice for Hospice Programs are organized within the framework of the Quality Partners Ten Components. NHPCO's Quality Partners program utilizes the Standards of Practice as its foundation to provide a framework for quality assessment and performance improvement. 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. 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. (For additional information regarding the Standards of Practice, please visit www.nhpc.org/quality. More information on pediatric palliative care and/or hospice care can be found at www.nhpc.org/pediatrics)

Purpose

Using these standards as a guide to service provision programs will develop best practices to:

- ◆ Deliver safe, effective, high quality care for children¹ 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;
- ◆ 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.

¹Throughout this entire document, "children" refers to patients in the perinatal period, infancy, childhood, adolescence, and young adulthood.





What is Pediatric Palliative and Hospice Care?

Pediatric palliative and/or hospice care is both a philosophy and an organized method for delivering individualized care to **children with life-threatening conditions**. This care focuses 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/or hospice care is 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/or hospice care affirms life by supporting the child's and family's goals for the future including hopes for cure, life prolongation and/or improvement in quality of life. This care is not meant to hasten death, nor to 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 interdisciplinary team including the child, family and caregivers. Effective pediatric palliative and/or 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.





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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 parents' employment and strain family relationships and finances.
- ◆ Children do not have a legal voice, as adults do. In most situations, parents 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.



- ◆ The 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. Millions of children living in the United States may be exposed, with their families, to unsafe environments which put them at high risk.²

Identifying Children for Pediatric Palliative Care and Hospice

All children with life-threatening conditions 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 and/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 and/or hospice services with or without continuing curative or disease-modifying treatments.



²Adapted from When Children Die: Improving palliative and end-of-life-care for children and their families. Committee on Palliative and End-of-Life-Care for Children and Families, Board on Health Sciences Policy; 2003. Marilyn J. Field and Richard E. Behrman, Editors.



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Diagnostic Categories³

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 infection
- ◆ Chronic or severe respiratory failure
- ◆ Renal failure (non-transplant candidates)
- ◆ Muscular dystrophy, myopathies, neuropathies
- ◆ Severe short gut, TPN-dependent

³Reference: Association for Children with Life Threatening or Terminal Conditions and Their Families, Royal College of Paediatrics and Child Health, 1997.



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*)



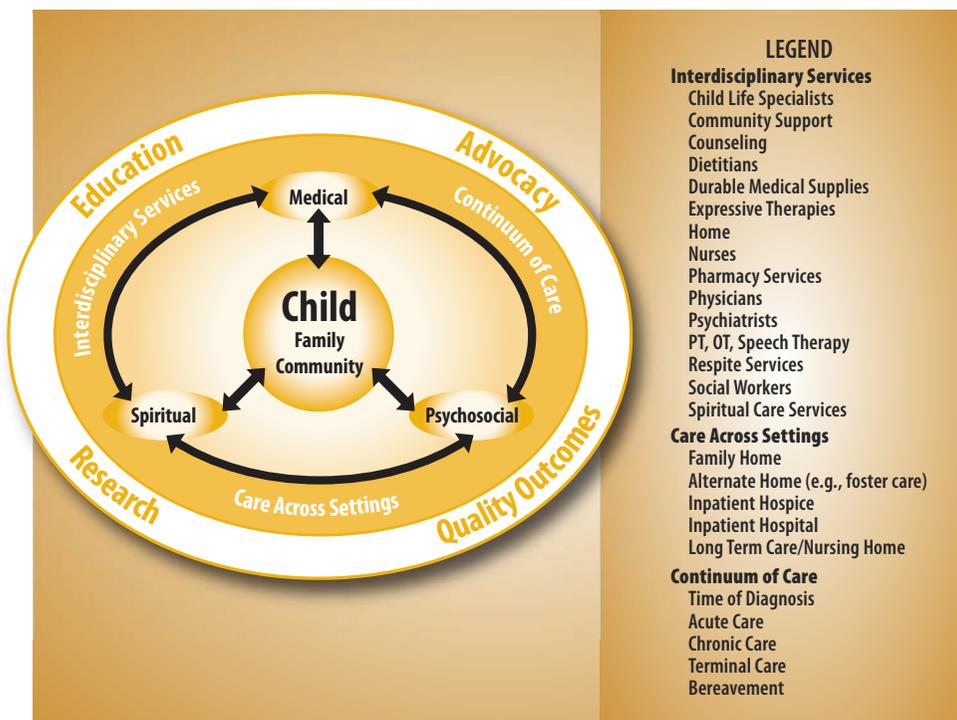


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Model of Care

The following model emphasizes the continuum of care necessary to support children and families as they move among systems and sites of care. To support the concept of “family centered care,” the child and family are the focal point in this construct. The model also depicts a holistic care model and its interrelationship to the core across the continuum. For clarity, the legend further defines interdisciplinary services, care settings, and the continuum of care for children and their families.

Pediatric Palliative Care Model⁴



⁴Model developed by National Hospice and Palliative Care Organization’s Children’s Project on Palliative/Hospice Services (ChiPPS). All rights reserved.



Pediatric Standards

Patient and Family Centered Care

Principle

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.

Standards

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.



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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 dying or its possibility.

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 a full range of clinical and educational resources that meet the needs of each child served regardless of age, cognitive and educational ability.

PPC-PFC 1.5

The 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.



Practice Examples

- ◆ Prior to admission, the palliative care and/or hospice team assesses the family communication system, with history of condition and what conversations have taken place between 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.
- ◆ 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.
- ◆ 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.



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PPC-PFC 2

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

PPC-PFC 2.1

Methods to address loss, anticipatory grief, and bereavement are age-appropriate and include information about the needs of dying and grieving children at all developmental stages.

PPC-PFC 2.2

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

PPC-PFC 2.3

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 2.4

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



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 and develop strategies for bereavement support for the child's classmates.
- ◆ The younger sibling of a child with terminal neurodegenerative disease is enrolled in a sibling support group.
- ◆ 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.



Standards of Practice for Pediatric Palliative Care and Hospice

Ethical Behavior and Consumer Rights

Principle

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

Standards

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 take into account the child's and the family's cultural or religious values, the parents'/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 suicide or euthanasia 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 about disclosing information to the child.

PPC-EBR 1.8

When resolution is not achieved, 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.



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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 this conversation; in addition to providing support and reassuring both parents, the interdisciplinary team will make pain and symptom management a priority in his care.
- ◆ Parents are encouraged to weigh the benefits and burdens of a tracheostomy for their 13 year-old child who has Duchenne's Muscular Dystrophy. The interdisciplinary team makes suggestions about how they can include their teenager in the decision-making process.
- ◆ 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 parents are unwilling to discuss likelihood of death.



PPC-EBR 2

The interdisciplinary team provides guidance 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 parental 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, parents 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, parents/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 parental approval to include these children in the decision-making process, thus allowing them to exercise independence.



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PPC-EBR 2.5

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

PPC-EBR 2.6

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 doesn't follow his rules.
- ◆ A 15 year-old is refusing to undergo a Phase I drug trial. Conflict arises when the parents 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 dissent is respected.
- ◆ Parents request continued mechanical ventilation in the pediatric 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 regular respirations. After discussion with the family, the infant is extubated and dies in the mother's arms.
- ◆ While advance directives are not legally binding for children in most states, the interdisciplinary team assists the terminally-ill child and family, who wishes to remain at home, to complete and disseminate a written advance care plan describing the child and family's goals and preferences at the end of life.



Standards of Practice for Pediatric Palliative Care and Hospice

Clinical Excellence and Safety

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.

Standards

PPC-CES 1

Clinical care will be guided by the ethical principles of beneficence, nonmaleficence and promotion of the best interests of the child.

PPC-CES 1.1

In the absence of pediatric medical expertise, the palliative care and/or hospice organization will develop a collaborative consultative relationship with pediatric providers and/or a tertiary healthcare facility to support provision of care suited to the unique needs of pediatric patients.

PPC-CES 1.2

A primary care coordinator for all pediatric patients is identified.

PPC-CES 1.3

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

PPC-CES 1.4

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 goals of care should be avoided.

PPC-CES 1.5

Members of all disciplines providing direct services to children will complete annual competencies in pediatric pain and symptom management.



PPC-CES 1.6

Utilization of age-appropriate assessment tools is confirmed in all documentation.

PPC-CES 1.7

Pain and all distressing symptoms will be assessed on every visit, by each discipline.

PPC-CES 1.8

Families, and the child as age-appropriate, will be 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.

PPC-CES 1.9

A pediatric physician and/or pharmacist is available for consultation to the interdisciplinary team as needed.

PPC-CES 1.10

Adequate doses of analgesics are administered 'around the clock' and not only on an 'as-needed' basis. Additional doses are given to treat breakthrough pain, or predicted intermittent exacerbation.

PPC-CES 1.11

When indicated, a sufficient dose and an appropriate pharmacologic formulation (for example, sustained-release preparation or continuous infusion) is chosen to enable children and their families to sleep through the night, without waking in pain or waking to take their medications.

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.



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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 phone weekly or more frequently if needed with the pediatric specialists to adjust dosing and solicit support.
- ◆ A 7 year-old has trouble seeing and can't 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. 1 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 two 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. Mom uses the music intervention in addition to his pharmacologic regimen to comfort him daily.
- ◆ A 15 year-old refuses to continue palliative radiation because getting out of bed in the morning causes him too much pain. His nurse suggests starting his breakthrough dosing before even getting out of bed. He begins this routine, and is able to finish the radiation course which decreases his tumor burden and his pain. With this response he is able to stop the continuous IV meds temporarily, go back on oral opioids, and return to school to finish the school year.



Inclusion and Access

No pediatric-specific additions to this standard are suggested. Please refer to NHPCO's Standards of Practice.

Organizational Excellence

Principle

Flexibility in pediatric program design and service delivery facilitates access to services for children. A pediatric palliative care and/or hospice model that offers multiple support services over time and across settings ensures enhanced access for this underserved population.

Standards

PPC-0E1

Pediatric programs may serve patients in the perinatal period, infancy, childhood, adolescence and young adulthood. The program must have policies and procedures in place to address all developmental, physical, social, psychological and spiritual needs of children served.

PPC-0E 1.1

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

PPC-0E 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.



Standards of Practice for Pediatric Palliative Care and Hospice

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 makes every effort to ensure 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.

PPC-OE 2

The program partners with community agencies and others that provide resources for children.

PPC-OE 2.1

The program partners with local schools.

PPC-OE 2.2

The program partners with social service agencies.

PPC-OE 2.3

The program partners with specialty healthcare agencies.

PPC-OE 2.4

The program partners with faith groups in the community.



Workforce Excellence

Principle

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.

Standards

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

Pediatric-specific training is completed by all staff caring for children with life-threatening conditions.

PPC-WE 1.2

Volunteers directly working with children or their families are also trained in developmental needs, family dynamics, communication challenges, and pain and symptom management.

PPC-WE 1.3

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.





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PPC-WE 1.4

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 1.5

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

PPC-WE 1.6

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

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

- ◆ 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 NHPCO Pediatric Curriculum, Pediatric ELNEC, IPPC, EPEC, and the Harvard PCEP.
- ◆ The nurse manager works with the clinical nurse 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.
- ◆ A pediatric resource library is maintained and is accessible to all staff, volunteers, patients, and family members.
- ◆ Staff utilize current editions of texts such as *Nursing Care of Infants and Children* (Whaley and Wong) and *Pediatric Home Healthcare* (American Academy of Pediatrics) to develop pediatric policies and procedures for a program expanding its services to children.
- ◆ Volunteer retention efforts include putting into place: individual support mechanisms; mentoring or "buddying" systems with experienced, competent peer volunteers; changing assignments when the program's, child's or family's needs are not met; providing ongoing feedback and recognition events; and facilitating communication and camaraderie with other interdisciplinary team members (e.g., *support groups, telephone calls, flyers, closure of care, meeting with volunteer coordinator, etc.*).





Standards of Practice for Pediatric Palliative Care and Hospice

Standards

Principle

Palliative care and/or hospice programs adopt the NHPCO Standards of Practice for Hospice Programs, and utilize the appendix “Standards of Practice for Pediatric Palliative Care and Hospice” as the foundation for their pediatric care.

Compliance with Laws and Regulations

No pediatric-specific additions to this standard are suggested. Please refer to NHPCO’s Standards of Practice.

Stewardship and Accountability

No pediatric-specific additions to this standard are suggested. Please refer to NHPCO’s Standards of Practice.





Performance Measurement

Principle

The program develops, defines and utilizes a systematic approach to improving 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.

Standards

PPC-PM1

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-PM1.1

Measures of children's clinical outcomes are developed.

PPC-PM1.2

All adverse events are documented and investigated.

PPC-PM 1.3

All medication errors are documented and investigated.

PPC-PM 1.4

Resource utilization is analyzed.

PPC-PM 1.5

Child and family satisfaction surveys are developed and sent to families.



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Practice Examples

- ◆ The organization develops focus groups or professional pediatric advisory groups which meet regularly to gain feedback about services provided and to review quality standards and compliance. Consumers are represented in these groups.
- ◆ Patients with indwelling central catheter lines are monitored monthly for the development of line infections.
- ◆ On-call logs are kept daily, and compliance with the organization's response time standard is monitored monthly.
- ◆ 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.
- ◆ A home safety checklist is developed to ensure a home environment that is safe for a developmentally-disabled child.



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Acknowledgments

The National Hospice and Palliative Care Organization gratefully acknowledges the commitment of the Children’s Project on Palliative/Hospice Services (ChiPPS) in establishing the *Standards of Practice for Pediatric Palliative Care and Hospice* and extends our gratitude and appreciation to Susan Huff, for leading the project.

In addition, we extend our gratitude to the following ChiPPS Workgroup members and NHPCO staff that assisted in the development of the standards.

ChiPPS WORKGROUP

SARAH FRIEBERT	MARIA RIGGS
MARY JO GILMER	DAVID STEINHORN
STACY REMKE	SUZANNE TOCE

NHPCO STAFF

KATHY BRANDT	LIN SIMON
JOHN MASTROJOHN III	GWYNN SULLIVAN

Development of the Standards of Practice for Pediatric Palliative Care and Hospice was made possible through the efforts of the National Hospice Foundation and generous gifts from:

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 BRICKSON DIAMOND
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