

**SPECIALIZED CLINICAL SERVICES****HOSPICE AND PALLIATIVE CARE****INTRODUCTION**

Pediatric palliative and/or hospice care are increasingly important components of the continuum of care for hospitalized children. As both a philosophy and an organized method for delivering care, these approaches to care focus on the relief of physical, psychosocial, and spiritual suffering experienced by infants, children and adolescents and the family/caregiver who face a life-threatening condition. The guiding philosophy includes comfort and quality of life, while at the same time sustaining hope despite the likelihood of death. The goals of this type of care include enhancing choices, relieving pain and suffering and ensuring the best quality of care for the child and family/caregiver during the stages of living, dying and grief and bereavement. Care may be provided at home, in an inpatient hospice setting or within a traditional hospital setting. Palliative care services are most easily accessible in the traditional intensive care and hospital settings. Resources for treatment of dying children outside of these settings may be quite limited and vary by geographic location. Pediatric hospitalists therefore are often in the best position to provide both leadership and clinical roles for children requiring these services. Pediatric hospitalists should be able to access available palliative and hospice services and must be comfortable managing ethical dilemmas encountered in the inpatient setting related to care of the dying patient.

**KNOWLEDGE**

*Pediatric hospitalists should be able to:*

- Define the terms palliative and hospice care and describe the similarities and differences between them.
- Give examples of children who may be appropriate for hospice and palliative care services.
- Describe why pediatric hospice and palliative care are optimally provided by an interdisciplinary team consisting of a pediatrician, pediatric nurse, social worker, chaplain, home health aide, and others.
- Compare and contrast multidisciplinary with interdisciplinary team dynamics.
- Describe why the decision related to forgoing potentially life-sustaining treatments or the withdrawal of life support often are best made before a child becomes critically ill.
- Discuss the elements of a treatment plan for relief of suffering, including appropriate consultations (such as palliative care, pain service, physiatrists, and others) and therapies (such as complementary medicine, pain medications, and others).
- Explain how elements of palliative treatment and curative treatment may simultaneously occur during the course of treatment of a child's life limiting illness.
- Identify local, regional, and national resources for pediatric palliative and hospice care that are accessible to patients, the family/caregiver, and healthcare providers.
- Describe the role and composition of a hospital Ethics Committee as it relates to patient and family/caregiver decisions regarding end-of-life decisions.
- Describe the processes involved in writing "Allow Natural Death (AND)" orders, pronouncing a person dead, completing a death certificate, discussing autopsy and donor mandates and options, and accessing immediate support for family/caregiver and staff.

**SKILLS**

*Pediatric hospitalists should be able to:*

- Proactively identify opportunities for appropriate referral to and utilization of hospice and palliative care services.
- Communicate "bad news" effectively and provide opportunities for patients and the family/caregiver to be introduced to palliative care or hospice services when appropriate.
- Manage ethical dilemmas encountered in the inpatient setting related to care of the dying patient.
- Integrate cultural issues in discussions and management of end of life issues.
- Effectively adapt communication methods to varying age and developmental stages to assure understanding of chronic illness, death and dying.
- Recognize and manage pain and other common symptoms causing distress for patients and the family/caregiver at the end of life.
- Correctly prescribe medication and non-medication therapies in collaboration with appropriate consultants.

**ATTITUDES**

*Pediatric hospitalists should be able to:*

- Create awareness for the importance of pediatric palliative and hospice care.
- Demonstrate awareness and acceptance of palliative care approaches, which may include alternative and/or complementary medical therapies.
- Role model ethical behavior at all times.
- Identify personal attitudes toward end of life care from a physical, psychosocial and spiritual perspective.
- Recognize when personal perspective and bias may influence care for dying patients.
- Identify gaps in personal knowledge, skills and attitudes regarding palliative care and utilize opportunities for professional education to address them.
- Collaborate with the interdisciplinary team, subspecialists and the primary care provider to ensure coordinated longitudinal care for children receiving palliative or hospice services.

**SYSTEMS ORGANIZATION AND IMPROVEMENT**

*In order to improve efficiency and quality within their organizations, pediatric hospitalists should:*

- Engage in organizational efforts to provide pediatric hospice and palliative care education for interdisciplinary teams.
- Create or help sustain a pediatric perspective for hospital Ethics Committees.
- Collaborate with hospital administration and community partners to ensure efficient access to appropriate consultants necessary for success of these programs for children.
- Advocate for development of pediatric hospice and palliative care resources in their hospital and their community.

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