Pediatric Oncology
Palliative and
End-of-Life
Care Resource

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# Contents

**Preface** ......................................................... vi
**Introduction** .................................................. vii
**Acknowledgments** ............................................. viii

## Section 1 Palliative Care
- Entry Into the Palliative Care System .......................... 1
- Financial Resources ............................................ 3

## Section 2 Pain Management
- Cardiovascular Symptom Management ............................ 13
- Overview of Arrhythmias ......................................... 15
- Palpitations ................................................................ 15
- Sinus Bradycardia ................................................... 16
- Supraventricular Tachycardia ...................................... 17
- Superior Vena Cava Syndrome ...................................... 18
- Gastrointestinal Symptom Management ........................... 20
- Anorexia and Cachexia ............................................. 20
- Constipation ................................................................ 21
- Dehydration .................................................................. 22
- Diarrhea .................................................................... 22
- Hiccups (Singulatus) .................................................. 25
- Nausea and Vomiting ................................................ 25
- Hematologic Symptom Management ............................... 29
- Anemia ..................................................................... 28
- Bleeding and Hemorrhage .......................................... 29
- Integumentary Symptom Management .............................. 33
- Diaper Dermatitis .................................................... 33
- Dry Skin .................................................................... 34
- Pressure Ulcers (Decubiti) ........................................... 36
- Pruritis ..................................................................... 38
- Treatment-Related Skin Irritation and Breakdown .............. 40
- Tumor Necrosis and Fistula ........................................ 41
- Neurological Symptom Management .............................. 42
- Agitation .................................................................... 42
- Deterioration and Acute Confusion ............................... 43
- Dysphagia .................................................................. 45
- Fatigue ..................................................................... 46
- Fever ....................................................................... 48
- Increased Intracranial Pressure ...................................... 49
- Insomnia and Sleep Disturbance .................................... 50

**Section 3 Management of Physical Symptoms**
- Myoclonus and Tremors ............................................ 51
- Seizures .................................................................... 52
- Spinal Cord Compression ......................................... 53
- Weakness and Impaired Mobility ................................. 54
- Pulmonary Symptom Management ............................... 56
- Agonal Respirations ................................................ 56
- Cough ..................................................................... 57
- Dyspnea ................................................................... 58
- Pulmonary Edema ..................................................... 60
- Secretions .................................................................. 61
- Wheezing ................................................................... 62
- Renal and Metabolic Symptom Management ................. 63
- Decreased Urine Output (Oliguria) ............................... 63
- Urinary Frequency and Incontinence ............................. 64
- Hematuria .................................................................. 65
- Hypercalcemia ......................................................... 66
- Syndrome of Inappropriate Antidiuretic Hormone ........... 67
- Urinary Retention ..................................................... 70

**Section 4 Complementary and Alternative Therapies** ......... 71

**Section 5 Management of Psychosocial Issues** ............... 77
- Anxiety .................................................................... 79
- Children, Death, Grieving, and Mourning ...................... 85
- Communication Challenges ....................................... 89
- Cultural Considerations ........................................... 92
- Spiritual Distress ...................................................... 97
- Depression ............................................................. 104
- Medical Decision Making When the Child Is a Minor, Emancipated Minor, or Young Adult ................................. 107
- Parental Coping ....................................................... 113
- Parental Grief and Mourning ..................................... 117

**Section 6 Professional Caregiver Issues** ....................... 121
- Therapeutic Relationships and Professional Boundaries .... 123
- Professional Grief and Mourning ................................. 125

**Section 7 Care as Death Nears** ................................... 129
- Nearing Death ........................................................ 131
- Care Following the Child’s Death ................................. 133
- Funeral Arrangements .............................................. 134

**Index** ..................................................................... 135
Introduction

This Resource is organized by sections representing critical aspects of pediatric oncology end-of-life and palliative care. For specific symptoms or issues within each section, the following elements are presented:

- Definition(s)—meaning of essential terms
- Causes and/or influencing factors—underlying etiologies; factors affecting presentation, severity, outcome of symptom or issue
- Overview of care—context, goals, and rationale for recommendations
- Recommendations—assessment, interventions, and/or management, including special considerations
- References—cited works
- Supporting materials—tables, figures, or exhibits.

Individual symptoms and issues are listed alphabetically in the index. It is important to consider that most symptoms or issues rarely occur in isolation.\(^1\)\(^4\)

Palliative care begins at the time of cancer diagnosis and continues throughout the illness trajectory. When children are not expected to survive their disease, palliative care continues through the dying process and the bereavement period. The Resource is not intended to replace the recommendations of the treating physician, but is intended to serve as an adjuvant resource.

REFERENCES

SECTION 1

Palliative Care
1.1 Entry Into the Palliative Care System  Deborah A. Lafond, MS PNP-BC CPON®

DEFINITION
Palliative care for children is the active, total care of the child’s body, mind, and spirit and extends to providing support to the family. It begins when illness is diagnosed and continues as long as the child is receiving care, regardless of whether treatment is directed at the disease, and, for the family, through bereavement if the child dies.

CAUSES AND INFLUENCING FACTORS
Children with life-threatening illnesses, such as cancer, face an unpredictable course characterized by periods of stability marked by intervals of serious illness, which ultimately may lead to death. Palliative care should be integrated early during the course of care for those patients with serious, life-threatening illnesses with unpredictable courses as well as those who have predictable trajectories of progression, such as (a) diagnosis of hematologic or oncologic disease; (b) evidence of advanced or progressive disease; (c) high-risk disease with poor prognosis for cure; (d) event-free survival (EFS) ≤50% (e.g., brain stem glioma, stage IV neuroblastoma, acute myelogenous leukemia); and (e) serious, complex, comorbid disease with poor prognosis for adequate symptom control. Insufficient reimbursement for coordinating pediatric palliative services is a significant obstacle to effective interdisciplinary care, although professional and legislative attempts to address such barriers are ongoing.

OVERVIEW OF CARE
Palliative care represents holistic, child-, and family-centered care, provided by an interdisciplinary team in the hospital, outpatient, or home settings, which aims to enhance quality of life by addressing the physical, psychosocial, and spiritual consequences of illness and treatment. The goals of care change as the child’s and family’s needs change. Ideally, palliative care begins at diagnosis with a life-threatening illness and continues through and after death with the provision of bereavement care to surviving family members.

<table>
<thead>
<tr>
<th>ASSESSMENT</th>
<th>INTERVENTIONS AND MANAGEMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Assess for the following:</strong></td>
<td><strong>Nonmedical</strong></td>
</tr>
<tr>
<td>• Child’s and family’s readiness to learn</td>
<td>• Introduce the simultaneous provision of cure-directed treatment and palliative care as close to the time of diagnosis as possible. Discuss roles of primary treatment team, palliative care, home care, and hospice providers and provide contact information as appropriate.</td>
</tr>
<tr>
<td>• Child’s and family’s understanding of child’s illness and prognosis</td>
<td>• Discuss the principles of palliative care as indicated.</td>
</tr>
<tr>
<td>• Child’s and family’s goals and expectations</td>
<td>• Present all available treatment and palliative goals and options.</td>
</tr>
<tr>
<td>• Family’s ability to provide care, including use and operation of any required equipment</td>
<td>• Discuss likely effects of disease and various treatments, including hospitalization, clinic visits, invasive procedures, and physical and emotional effects.</td>
</tr>
<tr>
<td>• Cultural and spiritual beliefs and needs related to illness, dying, and death</td>
<td>• Clarify misconceptions (e.g., related to illness, treatment, prognosis).</td>
</tr>
<tr>
<td>• Onset, duration, and severity of pain and other symptoms</td>
<td>• Determine child and family’s preferred decision-making style. (See Section 5.7: Medical Decision Making When the Child Is a Minor, Emancipated Minor, or Young Adult, p. 107.)</td>
</tr>
<tr>
<td><strong>Consider the following, based on child’s status:</strong></td>
<td>• Clarify child and family’s goals and reassess on an ongoing basis.</td>
</tr>
<tr>
<td>• Laboratory and radiological tests specific for diagnosis and symptoms, only if course of care will be altered by results.</td>
<td>• Provide written materials and facilitate child and family’s demonstration of skills as indicated (e.g., symptom management, medication administration, equipment management).</td>
</tr>
<tr>
<td>• At the time of entry into palliative care (or may be deferred to a later point in the illness trajectory as determined by the needs of child and family), refer to (if not already established as team members):</td>
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</tr>
<tr>
<td>- Spiritual care providers</td>
<td>- Spiritual care providers</td>
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<tr>
<td>- Child life department</td>
<td>- Child life department</td>
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<tr>
<td>- Social worker</td>
<td>- Social worker</td>
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<tr>
<td>- Psychologist</td>
<td>- Psychologist</td>
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<tr>
<td>- Pain team and hospice and palliative care team (if available).</td>
<td>- Pain team and hospice and palliative care team (if available).</td>
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<tr>
<td>• Provide anticipatory guidance as disease progresses (e.g., signs and symptoms of disease progression and dying process; See Section 7.1: Nearing Death, p. 131.)</td>
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Assessment

Interventions and Management

- Conduct Advanced Care Planning (ACP) with interdisciplinary team. (See Section 5.7: Medical Decision Making When the Child Is a Minor, Emancipated Minor, or Young Adult, p. 107.)
- Notify primary team members, including primary care provider if not part of ACP team, of the child and family’s goals of care and the tenets of the advanced-care plan.
- Discuss impact on family (e.g., parental and sibling stress, financial concerns).
- Reassure child and family that primary treatment team members will continue to be involved in care during end-stage disease or provide referral to hospice services as appropriate.
- Provide psychosocial and spiritual support as indicated. (See Section 5.4: Cultural Considerations, p. 92, and Section 5.5: Spiritual Distress, p. 97.)
- Facilitate opportunities to promote positive communication among child, family, and providers. (See Section 5.3: Communication Challenges, p. 89.)
- Refer to bereavement specialist for funeral and bereavement support when it is clear the child will not survive his or her disease or earlier in the trajectory of illness to assist other family members with anticipatory grief.

Medical

- Provide pharmacologic and nonpharmacologic interventions for pain and symptom management. (See Section 2: Pain Management, p. 7.)
- Provide palliative anticancer therapies as appropriate.

Special Considerations. It is particularly critical to coordinate the simultaneous provision of cure-directed and palliative care in children at lowest likelihood of cure (e.g., those with EFS <50% [see above]) and particularly those enrolled in Phase I clinical trials who generally experience a very low response rate.10 (See Box 1.1.1.)

Box 1.1.1. Precepts of Palliative Care for Children and Adolescents

My Wishes, a booklet to help children communicate with their family and healthcare providers (HCPs) about how they wish to be cared for should they become seriously ill, www.agingwithdignity.org/mywishes.html
Five Wishes, a booklet to help adolescents and young adults communicate with their family and HCPs about how they wish to be cared for should they become seriously ill, in English, http://agingwithdignity.org/5wishes.pdf (also available in Spanish)
Children’s Hospice International, Program for All-inclusive Care for Children and Their Families, www.chionline.org
National Hospice and Palliative Care Organization, www.nhpco.org

References

DEFINITION

Financial resources are any available source of wealth or reserve that can be drawn upon when needed and may include wages; personal checking and savings; trusts; stocks; bonds; third-party reimbursement benefits, including private insurance, Medicare, Medicaid, and Social Security; as well as charitable organizations and agencies whose mission includes helping families of ill children.

CAUSES AND INFLUENCING FACTORS

The factors that may influence the financial resources of a family requiring palliative care include (a) medical benefits (and out-of-pocket expenses); (b) proximity of care to home (e.g., transportation, lodging costs); (c) socioeconomic status; (d) hospital policies (e.g., free or discounted meals, parking for parents); (e) employment status (e.g., ability to work or time off related to care for the child); (f) eligibility for assistance programs; and (g) community support (e.g., faith community, fundraising). The child and family requiring palliative care may experience changes in lifestyle that affect their financial resources. Time needed to care for the child may affect employment status, which in turn, may affect benefits and available cash reserves.

OVERVIEW OF CARE

The financial costs of pediatric palliative care, as well as fears regarding financial security, can place additional burdens on families. Unlike adults, children often receive therapies such as blood transfusions, nutrition, and chemotherapy near the time of death. These therapies provide increased quality of life for pediatric patients; however, they do not fit within the current reimbursement structures, and, therefore, insufficient reimbursement can become a significant obstacle to effective interdisciplinary care. Palliative care and hospice services are underdeveloped for children when compared to adult services and may be fragmented among many providers. Coordination of care and referral to resources should begin early in the treatment plan to help minimize financial stressors.

ASSESSMENT

Assess for the following:
- Ability of primary family wage-earner(s) to continue paid employment
- Adequacy of medical benefits (e.g., insurance, government programs, charitable organizations)
- Availability of respite benefits
- Other sources of income or assistance.

INTERVENTIONS AND MANAGEMENT

Assist parents in identifying financial resources for palliative care services
- Private medical insurance; identify a contact at the insurance company and provide assistance to parent(s) in clarifying benefits and negotiating services.
- Employee benefit programs (e.g., employee help funds, leave share) and financial assistance programs; many employers have programs where employees can donate paid time off.
- Sources of personal funding (e.g., use of savings, Individual Retirement Account); evaluate feasibility of using these resources versus the potential risks.
- Fundraising opportunities and availability of assistance from family’s place of worship as indicated.
- Payment plans to individual care providers to meet deductibles and/or care not covered.
- Recommend that parents maintain a log or folder of all medical (e.g., prescriptions, hospital stays) and nonmedical (e.g., parking, meals, travel) expenses related to treatment for tax preparation.
- Facilitate family members’ contact with potential sources of information and financial support, including
  - institution-based and/or insurance company case manager
  - hospital/clinic financial counselor
  - financial planner
  - insurance assistance programs
  - governmental assistance programs (e.g., State Children’s Health Insurance Program, Consolidated Omnibus Budget Reconciliation Act, Americans with Disabilities Act, Family Medical Leave Act, Medicaid, Supplemental Security Income)
  - illness-specific organizations (e.g., American Cancer Society)
  - regional charitable organizations (e.g., American Legion)
  - medication assistance programs (e.g., www.needymeds.com, www.pparx.org, individual pharmaceutical company programs)
- Discuss plan for funeral expenses and facilitate discussion with funeral director when it is clear the child is not going to survive his or her disease and based on the readiness of the family. (See section 7.3: Funeral Arrangements, p. 134.)

Special Considerations. For a comprehensive database of regional and national financial resources, see the following Web sites: CureSearch, www.curesearch.org/resources/resourceservice.aspx?ServiceId=1; Children’s Hospice and Palliative Care Coalition, www.childrenshospice.org/benefit/links-to-resources.
REFERENCES