

# AMERICAN ACADEMY OF PEDIATRICS

Committee on Bioethics and Committee on Hospital Care

## Palliative Care for Children

**ABSTRACT.** This statement presents an integrated model for providing palliative care for children living with a life-threatening or terminal condition. Advice on the development of a palliative care plan and on working with parents and children is also provided. Barriers to the provision of effective pediatric palliative care and potential solutions are identified. The American Academy of Pediatrics recommends the development and broad availability of pediatric palliative care services based on child-specific guidelines and standards. Such services will require widely distributed and effective palliative care education of pediatric health care professionals. The Academy offers guidance on responding to requests for hastening death, but does not support the practice of physician-assisted suicide or euthanasia for children.

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ABBREVIATION. AAP, American Academy of Pediatrics.

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In modern society, we expect children to outlive their parents. However, 53 000 children in the United States die every year from trauma, lethal congenital conditions, extreme prematurity, heritable disorders, or acquired illness.<sup>1</sup> The causes of death in children are substantially different from the causes of death in adults; thus, palliative care guidelines that are appropriate for adults are often inappropriate for children. For children living with life-threatening or terminal conditions, medical professionals are obligated to ensure that medical technology is used only when the benefits for the child outweigh the burdens. An infant or child will benefit from palliative care when no treatment has been shown to alter substantially the expected progression toward death.

Palliative care seeks to enhance quality of life in the face of an ultimately terminal condition. Palliative treatments focus on the relief of symptoms (eg, pain, dyspnea) and conditions (eg, loneliness) that cause distress and detract from the child's enjoyment of life. It also seeks to ensure that bereaved families are able to remain functional and intact. Hospice care refers to a package of palliative care services (including, for example, durable medical equipment, and both diagnostic and therapeutic interventions), generally provided at a limited per diem rate by a multidisciplinary group of physicians, nurses, and other personnel, such as chaplains, health aides, and bereavement counselors.

The recommendations in this statement do not indicate an exclusive course of treatment or serve as a standard of medical care. Variations, taking into account individual circumstances, may be appropriate.

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Palliative care includes the control of pain and other symptoms and addresses the psychological, social, or spiritual problems of children (and their families) living with life-threatening or terminal conditions.<sup>2,3</sup> The goal of palliative care is the achievement of the best quality of life for patients and their families, consistent with their values, regardless of the location of the patient.<sup>4</sup> The American Academy of Pediatrics (AAP) has previously addressed the limitation or withdrawal of life-sustaining medical treatment.<sup>5-7</sup> Specific strategies for palliative management of pain, dyspnea, agitation, nausea, vomiting, seizures, depression, anxiety, grief, and other symptoms can be found in other sources.<sup>8-11</sup>

### PRINCIPLES FOR PALLIATIVE CARE

The AAP calls for the development of clinical policies and minimum standards that promote the welfare of infants and children living with life-threatening or terminal conditions and their families, with the goal of providing equitable and effective support for curative, life-prolonging, and palliative care.<sup>12</sup> The following principles serve as the foundation for an integrated model of palliative care.

#### Respect for the Dignity of Patients and Families

The provision of palliative care for children includes sensitivity to and respect for the child's and family's wishes. In consultation with the child's parent or guardian, the plan of care incorporates respect for the terminally ill child's preferences concerning testing, monitoring, and treatment. Consistent with this principle of respect, information about palliative care should be readily available and parents may choose to initiate a referral to a pediatric palliative care program. The needs of families must be attended to both during the illness and after the child's death to improve their ability to survive the ordeal intact.

#### Access to Competent and Compassionate Palliative Care

In addition to alleviating pain and other physical symptoms, physicians must provide access to therapies that are likely to improve the child's quality of life.<sup>13</sup> Such therapies may include education, grief and family counseling, peer support, music therapy, child life intervention or spiritual support for both the patient and siblings, and appropriate respite care. Respite care, the provision of care to an ill child (in his or her usual state of health) by qualified caregivers other than family members, allows the family

time to rest and renew, whether for hours or days, on a schedule, or intermittently as needed. Families may benefit from the provision of respite care throughout a child's illness, not only near the end. Appropriate pediatric respite care is often lacking, but is considered by many families to be essential for their continued integrity and ability to care for the ill child, siblings, and themselves. Ideally, the patient's pediatrician, family physician, pediatric subspecialist, or surgeon will offer to continue to care for the child, while making a timely referral to palliative and hospice care. Palliative care programs should assist the child's usual medical caregivers in maintaining an ongoing role in the child's care.

### **Support for the Caregivers**

Health care professionals must be supported by the palliative care team, their colleagues, and institutions in dealing with the child's dying process and death. Institutional support may include paid funeral leave, routine counseling with a trained peer or psychologist, and regularly scheduled remembrance ceremonies or other interventions such as inviting bereaved families to return and celebrate with staff the deceased child's life.

### **Improved Professional and Social Support for Pediatric Palliative Care**

Regulatory, financial, and educational barriers often bar families from access to pediatric palliative care services. Professional and public education may foster awareness of the need for, and value of, pediatric palliative care and lead to efforts to remove bureaucratic and economic obstacles to its availability.

### **Continued Improvement of Pediatric Palliative Care Through Research and Education**

Clinical research concerning the effectiveness and benefits of pediatric palliative care interventions and models of service provision should be promoted. In addition, information about pediatric palliative care that is already available must be effectively disseminated and incorporated into education and practice.

## **AN INTEGRATED MODEL OF PALLIATIVE AND CURATIVE TREATMENT**

The AAP supports an integrated model of palliative care "in which the components of palliative care are offered at diagnosis and continued throughout the course of illness, whether the outcome ends in cure or death."<sup>8</sup> It is difficult to determine which children may benefit from palliative care. If palliative care is reserved for children who are dying or have a terminal condition, other patients who may benefit from these services may not receive them. Time of death is often difficult to predict. If the nearness of death is used to determine if children receive palliative care, some children may die without the benefits of individualized family-centered palliative care. With a broader definition that includes children living with a life-threatening condition, all children who need palliative care may benefit. In addition,

aspects of an integrated palliative care approach, including symptom management and counseling, may prove beneficial when provided early in the course of a child's illness.<sup>11</sup>

Curative treatments seek to reverse the disease process, whereas palliative treatments focus on relieving symptoms, regardless of their impact on the underlying disease process. Rigid distinctions between curative, life-prolonging, and palliative interventions may hinder the appropriate provision of palliative care to children living with a terminal condition. Physicians and family members may exhaust all curative options before they consider palliative care, which delays the timely introduction of palliative care or referral to palliative care specialists. Finally, it may be difficult to define individual therapies as either curative or palliative. For example, mechanical ventilation often is viewed as a life-prolonging or curative therapy that should be forgone with palliative care. However, such support, especially noninvasive forms of positive pressure ventilation, may provide symptomatic relief from dyspnea and significantly improve a child's quality of life.

Moreover, the assumption that there is no place for palliative care until all curative options have been exhausted may interfere with an early discussion of palliative issues, including limitations of unduly burdensome interventions at the end of life. Parents and children may infer that a discussion of issues such as do not resuscitate orders or comfort care is equivalent to "giving up." Such inferences may inhibit family members from voicing fears and concerns about the burdens of life-prolonging interventions and the dying process. Communication with patients and families about these concerns must be done with respect and empathy. An explanation of the usefulness of specific therapies, such as cardiopulmonary resuscitation, and a discussion of the value of advance directives to ensure that treatments that have become burdensome are not used, can be comforting to families. The ability of health care professionals to communicate difficult messages well can be learned through directed education and practice.

## **DEVELOPING A PALLIATIVE CARE PLAN**

As no one person can provide all the necessary support for the child and family, palliative care is best provided using an integrated interdisciplinary approach. The provision of palliative care for children involves a partnership between the child, family, parents' employer(s), teachers, school staff, and health care professionals, including nurses, chaplains, bereavement counselors, social workers, primary care physicians, subspecialty physicians, and consultants. Physical, emotional, psychosocial, and spiritual/existential domains of distress must be addressed. The child should participate to the fullest extent possible, given his or her illness experience, developmental capacities, and level of consciousness. Regardless of the prognosis, respect for the child requires that he or she be given a developmentally appropriate description of the condition along

with the expected burdens and benefits of available management options, while soliciting and listening to the child's preferences.<sup>14</sup> For example, burdens may include time away from home and friends; benefits may include participation in research studies based on an altruistic motive.<sup>15</sup> The discussion should focus on what interventions, from the child's and family's perspective, will be of the most benefit.

Each available diagnostic or therapeutic intervention needs to be considered within the context of the goals and expectations of the child and family. The decision to forgo certain treatments means that only those selected interventions are withheld or withdrawn. As the goals of therapy change with the progression of the child's condition or disease, the desirability of some interventions may change. Early interdisciplinary discussion and planning facilitates the smooth integration of these changes. The relief of pain and anxiety is an essential aspect of palliative care, and should be addressed throughout the course of illness. In some instances, pain relief may free a child to participate more fully in his or her final days, weeks, or months of life. Openness to the day-to-day experience of the child and flexibility in considering all options that may palliate distressing symptoms and conditions are essential when developing a treatment plan. *The goal is to add life to the child's years, not simply years to the child's life.*

#### WORKING WITH PARENTS OF DYING CHILDREN

While acknowledging uncertainty, a pediatrician needs to provide a realistic appraisal of prognosis and the range of time in which death is likely to occur. Pediatricians should support parental expression of the disappointment, anger, grief, and suffering associated with the child's illness. Acknowledging grief is often the first step toward facing the reality of the child's illness. Such acceptance may help parents focus on the quality of the child's remaining life.<sup>16</sup> Most importantly, the pediatrician needs to reassure the parents and child of the continued involvement and support of caring, skilled clinicians throughout the child's life, as well as after death. Fear of abandonment and isolation, especially during a child's long illness, is a major concern to chronically ill or dying children and their families.<sup>17</sup>

The place where death occurs, whether in an intensive care unit, another area of the hospital, another institution, or at home, may depend on such factors as the wishes of the child and family, the physical layout and visitation policies of the alternative sites, the desire and ability of staff to remain involved, and the availability of other caregivers such as bereavement counselors and clinicians with palliative care expertise. Whether death is anticipated or unexpected, pediatricians are expected to help support parental grief and guilt as parents struggle to cope with their fundamentally incomprehensible loss. The family must have the opportunity to carry out important family, religious, and/or cultural rituals and to hold the child before and after death.<sup>18</sup> Members of the extended family, friends, primary care physicians, and religious advisors are

to be included, if the family chooses. These individuals can support the family and each other during this time of crisis and in bereavement. A handwritten note of sympathy from the pediatrician or attendance at the funeral can be healing for the family and the physician. In addition, an opportunity for either organ and/or tissue donation when feasible, and an explanatory meeting with the pediatrician to share the results of a limited or full autopsy, may provide some comfort for a grieving family.

The death of a child who has been chronically ill presents added challenges. Parents grieve the loss of the expected normal child from the time of diagnosis of a condition likely to result in disability and childhood death. Often, these parents may find it difficult to accept the reality of impending death, perhaps because previous predictions proved inaccurate. For some parents, continued hope for cure, no matter how unlikely, may be an important coping mechanism or may conform with deeply held religious or cultural beliefs.

#### WORKING WITH CHILDREN

As many children with chronic, life-shortening illnesses are now living into adolescence and young adulthood, the pediatrician needs to acknowledge the child's own recognition of the likelihood of premature death, to help the child communicate his or her wishes, and to plan for the child's death.<sup>19</sup>

The pediatrician should assist parents in understanding and supporting the siblings of the ill child, all of whom are affected by the child's condition and eventual death. Parents are to be supported in attending to the needs of the ill child and siblings while acknowledging the sadness that results from life-threatening illness. The child should be reassured that he or she has done nothing wrong and is not responsible for his or her own illness or that of a sibling. Children should be encouraged to talk about feelings of anger, sadness, fear, isolation, and guilt, or to express themselves through art or music therapy.<sup>13,20,21</sup> Pediatricians should provide families with developmentally appropriate guidance about these difficult communications, encourage parents of older children and adolescents to talk together as a family about their feelings, and encourage the sharing of memories to facilitate bereavement and healing.<sup>22,23</sup> Families may benefit from the pediatrician or another member of the palliative care team participating in such family discussions. In these tragic situations, it is also helpful for the primary care pediatrician to work with the schools and other youth organizations to assist other children affected by the death of the child.

The pediatrician and the child's parents may consider the following factors when discussing death with a child: the disease experience and developmental level of the child; the child's understanding of and prior experience with death; the family's religious and cultural beliefs about death; the child's usual patterns of coping with pain and sadness; and the expected circumstances of death. The appropri-

ate time to start a conversation about a child's impending death is difficult to determine, as cultural beliefs must be respected and denial by family members may provide some relief from the overwhelming sense of loss and pain. However, avoiding this conversation ignores the fact that ill children and their siblings are usually aware of their condition. Children may maintain silence out of a desire to protect their parents, while feeling painfully isolated from those they need most.<sup>20,24</sup> Hints that a child wants to talk about death may be subtle. Open and honest communication is usually most effective in relieving the child's distress, allowing for mutual support and personal growth during the final phases of the child's life.

### HASTENING DEATH

The decision to forgo life-sustaining medical treatment does not necessarily imply an intent or choice to hasten the death of a child.<sup>25</sup> Although a child's life may be shortened by forgoing burdensome interventions or providing adequate sedation in the face of otherwise unrelieved symptoms, the goal of palliative care is to optimize the quality of the child's experience rather than hasten death. On occasion, the relief of severe, progressive symptoms such as pain or dyspnea may require a rapid escalation in the doses of administered analgesics and sedatives. If the child becomes obtunded and less responsive, parents and staff may feel that the medication is to blame, rather than the disease process—a misunderstanding that is reinforced by referring to the procedure as "terminal sedation."<sup>26–28</sup> The child's progressive deterioration and death may be attributable to the disease process, and not the medication.<sup>7,29</sup> Rarely, the relief of progressive symptoms may require deep sedation. Dying with dignity and without pain or distress is the primary goal.

If a child or adolescent requests euthanasia, the health care team is to respond compassionately, with a renewed focus on determining and alleviating the sources of distress, including perceptions of abandonment, depression, loneliness, physical symptoms, and communication problems. Patients and families are never to be prevented from forgoing burdensome life-sustaining medical treatment under appropriate circumstances—regardless of worry that others may view such a decision as euthanasia or suicide. With the provision of competent and compassionate palliative care, including the use of adequate analgesia and sedation for the treatment of rapidly progressive symptoms, requests to hasten death are generally abandoned. The informed decision of an adolescent or young adult patient nearing death to refuse further life-sustaining medical treatment ought to be respected; such respect does not imply the right of a patient to obtain assistance to commit suicide.<sup>30</sup>

The AAP is concerned about reports of involuntary euthanasia of infants and young children and of physician-assisted suicide of adolescents.<sup>30–32</sup> The

AAP does not support the practice of physician-assisted suicide or euthanasia for children.

### BARRIERS TO THE PROVISION OF PEDIATRIC PALLIATIVE CARE

Primary care pediatricians may be unfamiliar or uncomfortable with counseling or managing a child and family in palliative care, given the infrequency of death in most practices.<sup>33</sup> Thus, early consultation with pediatric hospice or palliative care professionals may be useful. Nevertheless, pediatricians who have established relationships with a child and family may assist in evaluating proposed interventions, help monitor the health and well-being of the siblings and family, and attend to the sometimes subtle and prolonged effects of grief on the family after the palliative care or hospice program is no longer involved.

Unfortunately, the majority of children who die have not had the benefit of palliative care services.<sup>34,35</sup> A major factor impeding pediatric palliative care is that the federal Medicare model was used to create most state Medicaid hospice benefits.<sup>36</sup> The Medicare model of hospice care was designed for adult patients with cancer, restricting admission to patients with a life expectancy of 6 months or less. This stipulation restricts the availability of hospice services to children, given the difficulty in predicting length of survival for many of the childhood diseases that result in premature death. Some hospice programs may require that patients and families agree to forgo life-prolonging or curative treatments and perhaps authorize a do not resuscitate order as a requirement for admission. Such requirements ignore the fact that many families accept the concept of hospice care only after a counseling process that is available within a hospice or palliative care program.<sup>34</sup> In addition, children living with a life-threatening or terminal condition may be receiving therapies that improve their quality of life, but are not adequately reimbursed through Medicaid hospice benefits. Treatment that generally is not reimbursed, for example, includes the use of newer, more expensive antibiotics for children with cystic fibrosis, long-term ventilator therapy for children with neuromuscular disorders, or surgical interventions that may palliate the child's symptoms. Reimbursement and regulatory policies may also preclude appropriate hospitalizations for children with life-threatening conditions. Moreover, families qualifying for Medicaid hospice benefits may lose other state-provided benefits, including dietary supplements and, more importantly, skilled home nursing care. Finally, health benefits from private insurance companies often mimic those from Medicare, and most do not have specific provisions in place for children.

Although hospice personnel are better equipped than most health care professionals to address issues surrounding terminal conditions, many hospice programs lack pediatric expertise and thus deprive chil-

dren and their families of the benefits of palliative care. Limited access to pediatric-specific palliative care and hospice services deprives children of knowledgeable health care personnel for home-based pain and symptom management. Many families may have to choose between life-prolonging or palliative care, and between pediatric or nonpediatric health care professionals, rather than have the opportunity to develop an individualized treatment plan that accounts for the specific needs of the child and family. As a result, the child living with a life-threatening or terminal condition may suffer an unnecessarily poor quality of life, leaving surviving family members with an excessively difficult bereavement.

#### MINIMUM STANDARDS FOR PEDIATRIC PALLIATIVE CARE

Excellence in pediatric palliative care is essential for hospitals and other facilities caring for children. Program development in pediatric palliative care, along with community outreach and public education, must be a priority of tertiary care centers serving children.

Minimum standards of pediatric palliative care must include a mechanism to ensure a seamless transition between settings, including at least 1 consistent caregiver, the availability of expert pediatric palliative care assistance 24 hours a day, 365 days a year, and the availability of an interdisciplinary care team with sufficient expertise to address the physical, psychosocial, emotional, and spiritual needs of the child and family. At the minimum, this team will include a physician, nurse, social worker, spiritual advisor, and child life therapist.

Although palliative care services may not be necessary for all families, the full range of clinical and educational resources must be made available. In addition, comprehensive palliative care cannot be accomplished without a designated care coordinator who can maintain continuity and ensure the care provided is consistent with the child's and family's goals despite the intermittent care and high staff turnover associated with tertiary care centers. The coordinator can ensure that the plan of care is coordinated with community care professionals to ensure a realistically achievable plan. Tertiary centers must provide community caregivers with explicit instruction in the care of the child, and appropriate pediatric palliative care consultation must be available 24 hours a day. Creative ways of coordinating care between the tertiary center and the community may involve individualized video conferencing or other forms of electronic communication. Respite for family caregivers and home nursing care are essential to maintain the integrity of families and the safety and well-being of the ill child. Finally, bereavement support must be available to the family, caregivers, and others affected by the death of a child, for as long as necessary. These essential services must be reimbursed equitably. The early inclusion of insurance

case managers on the palliative care team may assist in accomplishing some of these goals.

Nursing, medical, pastoral care, and social work curricula must include the interdisciplinary management of childhood life-threatening conditions. Practical exercises involving interdisciplinary education, including hospice visits, may best achieve this goal. In addition, attending to the needs of children who experience the death of a significant adult must be addressed. The requirement to achieve competency in these areas must be reinforced by adding questions on palliative care to professional certification examinations. The needs of the medical caregivers who provide pediatric palliative care must be recognized and actively addressed to allow them to continue to provide this rewarding but emotionally draining care.

#### RECOMMENDATIONS

1. Palliative care and respite programs need to be developed and widely available to provide intensive symptom management and promote the welfare of children living with life-threatening or terminal conditions.
2. At diagnosis of a life-threatening or terminal condition, it is important to offer an integrated model of palliative care that continues throughout the course of illness, regardless of the outcome.
3. Changes in the regulation and reimbursement of palliative care and hospice services are necessary to improve access for children and families in need of these services. Modifications in current regulations should include 1) broader eligibility criteria concerning the length of expected survival; 2) the allowance of concurrent life-prolonging and palliative care; and 3) the provision of respite care and other therapies beyond those allowed by a narrow definition of "medically indicated." Adequate reimbursement should accompany these regulatory changes.
4. All general and subspecialty pediatricians, family physicians, pain specialists, and pediatric surgeons need to become familiar and comfortable with the provision of palliative care to children. Residency, fellowship training, and continuing education programs should include topics such as palliative medicine, communication skills, grief and loss, managing prognostic uncertainty, and decisions to forgo life-sustaining medical treatment, spiritual dimensions of life and illness, and alternative medicine.<sup>33,37,38</sup> Pediatric board and subboard certifying examinations should include questions on palliative care.
5. An increase in support for research into effective pediatric palliative care programming, regulation and reimbursement, pain and symptom management, and grief and bereavement counseling is necessary. The pharmaceutical industry must provide labeling information about symptom-relieving medications in the pediatric population and provide suitable formulations for use by children.
6. The practice of physician-assisted suicide or euthanasia for children should not be supported.

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## **Palliative Care for Children**

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