



# Guidance for Pediatric End-of-Life Care

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THE SECTION ON HOSPICE AND PALLIATIVE MEDICINE

The final hours, days, and weeks in the life of a child or adolescent with serious illness are stressful for families, pediatricians, and other pediatric caregivers. This clinical report reviews essential elements of pediatric care for these patients and their families, establishing end-of-life care goals, anticipatory counseling about the dying process (expected signs or symptoms, code status, desired location of death), and engagement with palliative and hospice resources. This report also outlines postmortem tasks for the pediatric team, including staff debriefing and bereavement.

## STATEMENT OF NEED

Each year, approximately 45 000 infants, children, and adolescents (ages 0–19 years) die in the United States.<sup>1</sup> More than half of these deaths are in children younger than 1 year, and many are attributable to congenital disorders or prematurity.<sup>1</sup> Medical problems diagnosed in the first year of life may become complex chronic conditions and continue to contribute to pediatric mortality, even as unintentional injury becomes the most common cause of death through childhood and adolescence.<sup>2</sup>

This clinical report aims to outline practical components of quality end-of-life care with a focus on the final hours, days, and weeks of the child or adolescent's life. This information is meant to serve as a pediatric palliative care (PPC) primer for general pediatricians, hospitalists, and pediatric specialists caring for dying patients and their families. Considerations are offered for the time leading up to death, as death nears, and after death. Throughout this report, the term "family" is used to be inclusive of parents and extended family and friends. Additionally, throughout this report, the terms "child" and "adolescent" are used to be inclusive of pediatric patients from birth through 21 years of age, and specific age or developmental groups are highlighted where relevant.

## BACKGROUND

Some pediatric deaths happen within minutes to days of the cause (eg, unintentional injury, extremely preterm birth, catastrophic illness). Others occur days to years after an initial diagnosis or injury,

## abstract

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particularly as access to life-prolonging treatments (from novel medications to organ transplantation to home mechanical ventilation) alters disease trajectories and contributes to chronic medical complexity. Patterns of health before death in children and adolescents with medical complexity include: (1) cumulative complications with steady decline; (2) decline followed by a period of relative stability before further decline; or (3) widely fluctuating health status (repeatedly “defying the odds”).<sup>3</sup> Such trajectories complicate prognostication and family preparation for end of life.

Most children and adolescents in the United States die in hospitals after withholding, not escalating, or withdrawing life-sustaining treatments.<sup>4-6</sup> Approximately 20% of pediatric deaths occur in the emergency department,<sup>2</sup> a circumstance so unique and challenging because of lack of prior preparedness as to warrant its own statement.<sup>7</sup> A growing majority of inpatient pediatric deaths are among patients with medical complexity,<sup>4,5</sup> although more of these families are opting for end-of-life care at home.<sup>8,9</sup>

The American Academy of Pediatrics (AAP) emphasizes the importance of the medical home in the provision of family-centered care.<sup>10</sup> Tapping into the strength of the trusted longitudinal relationship provided by the medical home, particularly for those with medical complexity, benefits the patient and family, regardless of the location or circumstance surrounding the end of life. Notably, when access to home-based pediatric hospice care is limited, the medical home may take a leading role in providing quality end-of-life care.

Emerging pediatric data reveal that, similar to adults, racial and ethnic disparities exist in the end-of-life

experiences of children and adolescents.<sup>11,12</sup> There is compelling evidence that children and adolescents who are Black, Indigenous, and people of color have limited access to specialty care centers and providers and are receiving more intense interventions at the end of life as compared with their white counterparts.<sup>12-14</sup> Studies in pediatric oncology and patients with complex chronic medical conditions show that hospice enrollment rates are low and in-hospital death rates are high for children and adolescent who are Black, Indigenous, and people of color, and those with fewer resources.<sup>15,16</sup>

#### LAYING THE GROUNDWORK FOR END-OF-LIFE MANAGEMENT

Conversations with patients and families about goals for end-of-life care occur in a variety of settings, from prenatal visits to outpatient clinic appointments, home-based care settings, and intensive care units. All such conversations warrant a partnership among the pediatricians and other pediatric providers, patients, and families with a culturally sensitive and trauma-informed approach, recognizing that preferences about end-of-life care are often deeply rooted in family and community experiences of illness and death. Iterative conversations involving the medical home facilitate the delivery

of goal-concordant care, as do components such as palliative care engagement, shared decision making, formal advance care planning (ACP), and discussion of code status.

#### Palliative Care Engagement

The crucial partnership between patients and families with their pediatric primary health care teams can be complemented through the involvement of subspecialty PPC. The AAP first endorsed a commitment to palliative care with a policy statement in 2000,<sup>17</sup> and the reach of pediatric palliative care programs has grown since that time.<sup>18,19</sup> The AAP recommends specialty PPC “should be consulted for advanced clinical treatments and complicated decision making and for social and spiritual needs beyond what the primary care team can provide.”<sup>20</sup> Palliative care teams can help to optimize complex pain and symptom care, quality of life, appraisal of prognosis, conversations about shifting goals, and family and care team support. Consultation with a specialty palliative care team is often about facilitating communication and/or providing decision-making support.<sup>21</sup> Multiple studies have assessed the communication needs of families of children and adolescents with life-threatening conditions.<sup>22-30</sup> Some of the key communication needs are summarized in Table 1.

**TABLE 1.** Communication Needs of Families of Children and Adolescents With Life-Threatening Conditions

<ul style="list-style-type: none"> <li>• Straightforward information: full disclosure allows families to better comprehend the issues and feel prepared</li> <li>• Coordinated and consistent communication: families fear not knowing what is going on and want clinicians to help connect-the-dots using consistent and unambiguous language</li> <li>• Respecting the family-child relationship and families’ unique knowledge of the child or adolescent</li> <li>• Faith, hope, and meaning-making</li> <li>• Time to ask questions</li> <li>• Ready access to staff members, including physicians (for information and support)</li> <li>• Genuine expression of kindness and compassion from staff, including treating the child or adolescent as an individual and exploring the family’s emotions</li> <li>• Resources for addressing conflicting goals and values</li> </ul>
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Several national organizations advocate for the early involvement of palliative care teams for those with serious illness.<sup>31,32</sup> Early involvement allows for rapport building and establishing family-driven, value-based care as the palliative care team journeys with patients and families facing an uncertain future that may include death. How the patient is involved in this rapport building varies depending on the patient's age and abilities. Models of palliative care exist from the perinatal setting<sup>33-35</sup> to working with adolescents and young adults.<sup>36-38</sup> Even when early involvement of a palliative care team has not occurred (or was not possible), engagement during end-of-life care can still add value for patients, families, and staff.

### Shared Decision Making

As noted in the AAP policy statement on forgoing life-sustaining therapies, when clinicians engage in partnerships characterized by shared decision making (SDM), it can reduce the often overwhelming burden on children and families contemplating end-of-life care.<sup>39</sup> The SDM process includes exploring patient and family values, providing medical information in an individualized way, and then recommending a treatment course to align with what matters most to the patient and family.<sup>28,40</sup> SDM at the end of life requires attention to cultural and community norms, religious beliefs, impact on siblings and extended family, and prior experiences with death. Inclusion of the adolescent patient in SDM at the end of life requires a particular skillset.<sup>41</sup> The importance of SDM is also heightened for children and adolescents with complex medical conditions or disabilities, as outlined in its own AAP clinical report.<sup>42</sup> Engaging continuity care clinicians is key for these patients, as their families may have faced multiple

serious decisions over time and may benefit from clinicians who can place the end-of-life considerations in the context of those prior decisions.

### Advance Care Planning

In the ideal form, pediatric ACP addresses SDM before a clinical and emotional crisis and is offered for all patients with a life-threatening illness. ACP requires the clinician, family, and patient (when developmentally appropriate) to review the natural course of the disease and predicted quality of life while exploring patient and family hopes, worries, goals, and values.<sup>43</sup> ACP discussions should be documented in the medical record and have unique billing codes. A comprehensive advance care plan may include legal forms (eg, advance directive or durable power of attorney for patients 18 years and older), medical orders regarding life-sustaining therapies, and more informal planning, to convey the goals of care if the child or adolescent were to become critically ill. The written advance care plan allows for iterative conversations to unfold as the clinical course of the patient evolves.

Even when the disease trajectory is uncertain, articulating the spectrum of possible outcomes allows for an "anticipatory guidance approach" to ACP.<sup>44</sup> In the setting of prenatal uncertainty, for example, ACP may involve a birth plan outlining family goals for a variety of potential scenarios before, during, and after birth.<sup>45,46</sup> For adolescents and young adults, ACP may be incorporated into discussions about transitioning out of the pediatric health care system.

Parents report feeling more prepared for final days if ACP discussions have occurred and are less likely to have decisional regret.<sup>47</sup> However, barriers to such discussions still exist, particularly related to clinician concerns about parental readiness.<sup>48,49</sup> Clinicians may be reluctant to challenge families' hopeful patterns of thinking; however, research with parents reveals duality, parents can remain hopeful and simultaneously want to prepare for a range of possible outcomes.<sup>50</sup>

Whenever a trigger for ACP is identified (Table 2), clinicians can acknowledge that "we are in a different place now" with the patient's care, and then offer

**TABLE 2.** Child or Adolescent and Family Triggers for Initiating or Revisiting Advance Care Planning

<p>Condition-focused triggers include:</p> <ul style="list-style-type: none"> <li>• Serious fetal diagnosis</li> <li>• A catastrophic injury</li> <li>• New diagnosis of a condition with a poor prognosis</li> <li>• When disease-directed treatment is no longer effective</li> <li>• Incomplete response to escalating medical care or life support</li> <li>• Disease progression or relapse</li> <li>• Increase symptom burden and/or secondary complications</li> <li>• Increasing periods of time spent unwell or in the hospital</li> <li>• Reaching the age of majority and as a component of transition</li> </ul> <p>Family cues include statements about:</p> <ul style="list-style-type: none"> <li>• Wondering what will happen if intensive care is not provided for an infant at birth</li> <li>• Not wanting "heroic measures" to be taken</li> <li>• Acknowledgment that prior goals may be unachievable</li> <li>• Change in quality of life</li> <li>• Concerns about suffering</li> <li>• The child seeming "not his or herself anymore"</li> <li>• The death or critical illness of another child known to the family</li> </ul>
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**TABLE 3.** Key Components of Pediatric Advance Care Planning

- Build a partnership with family
- Discuss prognosis and predictions for the future
- Explore the patient and family's values related to quality of life (recognizing and respecting that "normal" quality of life is subjective)
- Assess goals and worries and global family strengths, values, and needs
- Understand family concepts of what it means to be a "good parent"<sup>55,112</sup>
- Articulate the possible treatment benefits and burdens, and weigh the implications of these with the patient and family
- Offer treatment recommendations, including how to respond should treatments become too burdensome, or the patient's condition deteriorates
- Explore child and family preferences for the final days, such as symptom management, resuscitation efforts, and location of death

regooling.<sup>43,51</sup> The ACP discussion requires an awareness of the patient and family's communication needs, the components of SDM, and the impact of relevant treatment options on illness trajectory. There is a growing body of literature recommending ACP practices in pediatrics, especially for children and adolescents with medical complexity (Table 3).<sup>43,52–55</sup> Several ACP guides have been studied with the adolescent and young adult population in particular, including the Lyon Family-Centered ACP survey, the Respecting Choices interview, Five Wishes, and Voicing My Choices.<sup>56,57</sup>

### Code Status Documentation

Code status documentation includes a written medical order that delineates whether cardiopulmonary resuscitation (CPR) or intubation should be initiated in the event of pulselessness or absence of spontaneous respirations and the medical record documentation of the discussion. The nomenclature for these orders includes Do Not Resuscitate, Do Not Attempt Resuscitation, Allow Natural Death, and Do Not Intubate. Although such nomenclature offers clear direction for very specific scenarios, it does not encompass the full breadth of considerations, and may leave ambiguity for some scenarios, such as patients with existing tracheostomy and ventilator dependence or the patient with an

implantable cardioverter defibrillator.

In the last decade, most states have adopted physician or medical order for life-sustaining treatment (POLST or MOLST) forms. The POLST or MOLST forms were created to provide a more encompassing medical order (for more scenarios than pulselessness or absence of respiratory effort) and portability across settings.<sup>58,59</sup> The POLST or MOLST form remains with the patient and alters the need to reexecute orders across multiple health care settings, although the wishes expressed in the POLST or MOLST should be reaffirmed when the patient presents in a new medical setting. Although most states have POLST or MOLST forms, each state's form varies in what is included and how they are applied (especially to patients younger than 18 years). Pediatricians should be familiar with the laws and practices within their states and recognize that all such forms may be revised or revoked by the medical decision maker.

If the goal of a comfort-focused end of life becomes clear during ACP discussions, the clinician may recommend protecting the patient from interventions like CPR and intubation, which would interfere with comfort at end of life. If the patient and family indicate agreement, the clinician should (1)

clarify which resuscitative efforts should and should not be attempted; (2) complete a medical order so that the entire treatment team knows how to respond; and (3) document the discussion in the medical record. Palliative care team involvement has been shown to assist with earlier and increased documentation when CPR limitations are desired.<sup>60,61</sup> Some team members may mistakenly believe that orders limiting CPR also limit medical management beyond intubation or CPR, but they do not.<sup>62</sup> It is worth reiterating that even when CPR limitation orders are in place, clinicians still must address the role of other medical evaluations and treatments with patients and families.

### AS END OF LIFE NEARS

As death nears, consideration should be provided to the preferred place of death and, if not engaged already, the potential role of hospice. Plans should be made to identify which interdisciplinary team members will address holistic end-of-life concerns. In settings without pediatric hospice supports, the medical home may be called on to address these concerns.

### Location of Death

Helping children and adolescents and their families think about whether home, hospital, or elsewhere is the preferred location for end of life is key to meeting their goals of care at this stage. Regardless of the location, the mindset and compassion in the care delivered to the dying patient and family is fundamental.<sup>46,63</sup> Although data suggest that adults prefer to die at home,<sup>64,65</sup> the pediatric data are less definitive.<sup>66,67</sup> Some children and adolescents and their families elect to be at the hospital for end of life for a variety of reasons, including familiarity with the institution and staff and concerns about symptom



management and support at home. Dussel et al found that when families had early discussions about preferred location of death, the child or adolescent was more likely to die in the preferred location, and if that location was in the hospital, the death was more likely to occur outside of an ICU.<sup>68</sup> Even when death is likely to occur in a hospital, as for a newborn infant with a fatal condition, families and clinicians should consider which hospital makes sense, a local community hospital nearer family, or a referral center with more palliative care resources.

Patients and families may have to accept that their preferred location of death may not be achievable. Perhaps the equipment needed to sustain life for the journey home or particular medications needed to maintain comfort or other supports for the patient or family are not available where a family lives. Coordination with the palliative care team, local hospice agency, or private duty nursing agencies may be able to overcome some of these barriers if this is an important family goal. For example, palliative care or ICU staff may facilitate ambulance transport for a planned extubation, handing off care to home hospice staff for the dying process.<sup>69</sup>

### **Hospice**

Hospice is a particular form of palliative care and is both a philosophy of care and an insurance benefit, meaning that it may not be available to all. In the United States, licensed hospice agencies provide comfort-focused care to patients with probable life expectancies of 6 months or less if their disease were to follow its natural course. This care includes psychosocial and spiritual supports, medical supports, such as medications and durable medical equipment, therapeutic interventions focused on promoting

comfort and relief from distressing symptoms, and legacy-building activities.<sup>31</sup> Depending on local availability, pediatric hospice services may be provided in patient homes, in freestanding hospice facilities, in hospice rooms or units within a hospital, or in long-term care facilities. Most hospice care occurs in the home, with inpatient care reserved for advanced symptom management, family respite, or as a preferred location for end of life. Perinatal hospice is increasingly available in the United States and can be a longitudinal support across the prenatal and postnatal spectrum.<sup>33,70</sup> And although not all hospice providers feel comfortable caring for children, they may be more willing to care for adolescents (especially if they are near adult size).

In 2010, a provision of the Patient Protection and Affordable Care Act mandated that Medicaid and the Children's Health Insurance Program finance concurrent care for children and adolescents enrolled in these programs.<sup>71</sup> Concurrent care allows for patients younger than 21 years meeting hospice eligibility to receive hospice services alongside life-prolonging disease-directed therapies.<sup>17,72</sup> These patients are likely to continue to see their subspecialty medical teams, may present to outpatient clinics for infusions and transfusions, and may even be readmitted to the hospital for treatment. Close partnership between the hospice team, PPC team (if applicable), and subspecialty teams is necessary for smooth transitions between settings. Despite this mandate's potential for increasing hospice access earlier in a child's illness course, data suggest that hospice is underutilized by children and adolescents.<sup>20,73</sup> Pediatric palliative care teams may provide expert guidance to hospice staff in settings where they feel

poorly prepared because of infrequent pediatric patients.<sup>74</sup>

The medical home maintains a key role for children and adolescents enrolled in hospice. Primary care pediatricians and/or primary subspecialists (such as oncologists) may act as the physician of record for the patient receiving hospice care, maintaining their role as the provider guiding symptom management and support efforts. If the primary care provider or primary subspecialist prefers for a hospice physician to take this role, the medical home remains a key source of information about the patient and family for the hospice team.

Despite meticulous planning and strong in-home support, a comfortable death at home may be unattainable for a variety of reasons. Assuming local resources are available, patients and families should know that they can return to the hospital or access a hospice facility for end-of-life care if staying home becomes too burdensome.

### **Role for Interdisciplinary Team**

Distress and suffering can escalate for the patient, family, and care team as end of life nears, and this time period may be sharply recalled by families for years to come.<sup>22,75,76</sup> The wrap-around support of an interdisciplinary team is needed to address the physical, spiritual, social, emotional, and psychological needs of the child or adolescent and the family. The PPC team incorporates the interdisciplinary expertise of physicians, nurses, social workers, case managers, spiritual care providers, bereavement specialists, child life specialists, and others who are all experienced in end-of-life care.<sup>20,31</sup> Engaging these supports early is important so that patients and families can develop trusting relationships with team

members.<sup>22,63</sup> For families of neonates, this might include collaboration with the obstetrical providers who came to know the family before birth.<sup>33</sup> In settings without pediatric palliative care or hospice access, the medical home may be a patient and family's best source of wrap-around, interdisciplinary supports.

Many patients and families lean heavily on their spirituality and faith at the end of life.<sup>23,30</sup> Significant diversity in spirituality and faith practices exists, and teams may need additional resources to mitigate a family's spiritual suffering.<sup>23,25,75</sup> Hospital chaplains and the family's spiritual supports can be engaged to provide support in prayer or religious rituals and to enhance clinician integration of spiritual perspectives.<sup>25,29,30,75</sup>

### **PROVIDING CARE IN THE FINAL DAYS**

Intensive supports are often needed in the final days of life, whether the child or adolescent is in the hospital or at home. Tasks at this time include reviewing medical interventions to limit or stop, talking with families about what dying is likely to look like, attending to symptom management, and discussing postmortem care, including questions about organ and tissue donation.

### **Plans for Life-Sustaining Medical Treatment**

Life-sustaining medical treatments (LSMTs), such as mechanical ventilation, can be acute supports for children with brief illnesses or chronic supports for children and adolescents with medical complexity. As prognosis worsens, clinicians must recognize when these technologies may be prolonging dying. Families appreciate clear recommendations that account for their child or adolescent's diagnosis, prognosis,

goals, and degree of pain and suffering<sup>77</sup> using the components of SDM outlined earlier. Language is important; clinicians should avoid talking about "withdrawing care" or "withdrawing support," because care and support continue regardless. Instead, language should focus on forgoing treatments and interventions that do not promote comfort.

Clinicians will need to clarify how LSMT, such as ventilator support, medically provided nutrition and hydration, vasoactive medications, or renal replacement therapies, may or may not promote the goals of care as death nears.<sup>39</sup> As highlighted in the AAP policy statement on forgoing life-sustaining medical treatment, "forgoing LSMT is ethically supportable when the burdens of treatment outweigh the benefits to the child."<sup>39</sup> A helpful question to elucidate the shift between benefit and burden may be, "Are we doing this to the child or for the child?"

Decisions to stop tube feeding or intravenous nutrition or hydration for a dying child or adolescent are ethically equivalent to decisions to forgo other LSMT, although they can feel different,<sup>78</sup> given cultural norms and emotions around providing food and nutrition to children. The 2009 AAP report on forgoing medically provided nutrition and hydration in children outlines situations in which the burden of medically provided nutrition may outweigh the benefit, including when they only prolong or add morbidity to the dying process. A study with parents who opted to forgo artificial nutrition and hydration found that parents were satisfied with their decision and greatly benefited from clinician assurances that the patient was dying of their disease, not from lack of nutrition.<sup>79</sup> The decisions to forgo medically provided nutrition and hydration should not preclude

offering the food for comfort or pleasure; many infants are comforted by nonnutritive suckling.

Many of these decisions are values based, and there can be different opinions within families and within clinical teams about what is "right" or "best" for an individual child or adolescent. Without opportunities for reflection and discussion, this can lead to conflict and moral distress. Early involvement of ethics consultants can be helpful in such scenarios.

### **Preparing for the Dying Process**

Many families want clinicians to prepare them for what their child or adolescent is likely to experience as death approaches, and their recollection of their child or adolescent's death will remain fresh for years to come.<sup>23,76</sup> Older pediatric patients may want to know about the dying process, and failure to address their worries may lead them to withdraw.<sup>80</sup> The approach to these conversations must be tailored to the individual patient and family.<sup>22</sup> Some patients and families want very detailed information shared early; others want only "big picture" information as death nears.<sup>81</sup> Simply asking "What are you worried about?" or "How much information is helpful at this time?" or "Would it be okay to talk about what may happen over the coming days?" is a good starting point. A patient or family may decline the discussion but will know they have permission and space to talk about it another time. Note that children and adolescents become obtunded in the final days to weeks, so earlier conversations should be had with those patients who want to talk about the dying process.

Most families value straightforward and kind communication at the end of life.<sup>23,25,28,81,82</sup> They want to know what physical changes they may see, what symptoms are

expected, and how those symptoms (especially pain) will be managed. Clinicians should highlight the uncertainty about the time until death, even following withdrawal of technology or noninitiation of neonatal resuscitation for preterm infants.<sup>69,83</sup> Giving families guideposts such as “minutes to hours” or “hours to days” can help. Some families are also ready to talk about autopsy or funeral planning before death.<sup>75,76</sup>

Given how emotionally difficult these conversations can be for families, clinicians often need to revisit end-of-life guidance more than once.<sup>76</sup> The need for repetition does not equate to denial or misunderstanding, but simply family distress. Such distress may increase as death approaches and may be verbalized in requests such as “Please do something” or “Can’t you help my child?” These statements reflect intense emotion and are not necessarily requests to alter plans of care. Clinicians can recognize and respond to the family’s emotion (eg, “I can only imagine how difficult this is for you.”) and reassure families that the team is “doing everything” to ensure their child or adolescent’s comfort and peace. Families may find it helpful to be told that their child or

adolescent’s body naturally knows the process it must take to die.

### Symptom Management

At end of life, a child or adolescent’s diagnosis, age, and ability to communicate will all play into their ability to express distress and into the clinician’s ability to interpret it. There may be variability between families and their perception of distress about the same symptom, especially as the patient becomes obtunded close to death.<sup>82</sup> This can be explored with questions like “Please tell me if anything you are seeing makes you worried.” Parents and some patients may benefit from hearing which physical signs are part of the natural dying process (Table 4) and which suggest pain or distress, such as moaning, restlessness, facial grimacing, and brow furrowing. These explanations facilitate symptom management partnership between the family, who may be with the child or adolescent consistently, and the clinical team, who may only be present intermittently.

Most pediatric research regarding end-of-life symptoms is from oncology, with most common symptoms being pain, dyspnea,

anxiety, agitation or delirium, fatigue, nausea or vomiting, and poor appetite.<sup>84,85</sup> Bereaved parents report feeling like their child or adolescent suffered “a lot” or “a great deal” from at least 1 symptom during the last month of their life and that the treatments attempted were often unsuccessful.<sup>85</sup> Families of infants may worry that pain or suffering is underrecognized because of lack of overt signs.<sup>86</sup> Pharmacologic and nonpharmacologic techniques can be combined to reduce suffering and mitigate adverse effects. Opioids and benzodiazepines are useful classes of medications to address symptoms at the end of life for children of all ages.

Some families and clinicians may worry that medications will cause oversedation or hasten death, while other families and patients may request medication administration to expedite the dying process.<sup>87</sup> The balance of adequate symptom control with sedation side effects should be routinely assessed and discussed in relation to the patient and family’s goals. Whenever possible, the preferences of children and adolescents regarding symptom control and sedation should be elicited and prioritized. Any disagreements that occur between

**TABLE 4.** Common Signs and Symptoms Naturally Occurring at End of Life

Sign or Symptom	Examples of Anticipatory Guidance: “As your child nears death, he or she . . .”	Potential Approaches
Decreased appetite	“ . . . will probably not be hungry or even thirsty because . . .”	Swabs or moisturizers for dry lips and mouth
Decreased alertness	“ . . . may sleep a lot, especially in the final days because . . .”	Child may still hear family, even if eyes closed
Changes in breathing: slow, fast, apnea	“ . . . may have changes in breathing that are generally not uncomfortable, though we will have medicines to give him or her if we are worried about comfort.”	Distressing respiratory symptoms may improve with intermittent or scheduled opiates
Noisy breathing because of oral secretions	“ . . . will swallow less, and the saliva in the back of the throat may make a noise that may sound uncomfortable to us but will not bother him or her.”	Positioning child to promote drainage; a drying agent can be used if positioning ineffective Decreasing or turning off any artificial nutrition or hydration the child is receiving
Skin changes	“ . . . will begin to feel cooler and may start to appear pale or even slightly blue.”	Monitor for signs of distress and provide reassurance that these changes are not uncomfortable to the child
Cardiac insufficiency	“ . . . will have slower and maybe irregular heart rate, and weaker pulses.”	Monitor for signs of distress and provide reassurance that these changes are not uncomfortable to the child
Loss of bowel and bladder control	“ . . . may not hold his or her urine or stool, so we will use a diaper to keep him or her comfortable.”	Prepare supplies: diapers, towels, absorptive pads, etc

patients younger than 18 years and their families about these preferences may be addressed through involvement of medical home providers, palliative care providers, or ethics consultants.

Medications at the end of life can be safely, ethically, and legally titrated in proportion to symptom burden, even if the dosing range exceeds typical parameters (eg, for patients with baseline opioid tolerance). At times, the medications and doses needed for symptom control may shorten the time to death because of their impact on sedation level and respiratory drive; such risk may be acceptable given the goal of comfort and symptom management.

However, prescribing medications with the intent to hasten death is unethical and illegal. Such requests for intentionally hastening death offer an opportunity for further conversations to explore what concerns triggered the request.

### **Organ and Tissue Donation**

As end of life nears, many patients and families actively search for meaning and purpose.<sup>25</sup> Framing organ and tissue donation in this context resonates with some adolescents and families. For those who want to learn more about organ and tissue donation in advance of an anticipated death (even prenatally), clinicians should contact their regional organ procurement organization and connect them with the family to review questions and put a plan into place. Some patients and families may also be interested in hearing about options for donating tissue for research.

For more about the regulations and process of organ donation, clinicians can refer to the AAP policy statement “Pediatric Organ Donation and Transplantation,” which highlights the federal mandate that all families of potential organ

donors be informed of the option to donate, typically by a trained “designated requestor.”<sup>88</sup> This recommendation permits the uncoupling of decisions about donation from decisions about medical goals of care, striving to avoid any perceived or real conflict of interest among medical teams.<sup>46</sup>

### **AFTER DEATH**

Once a child or adolescent dies, clinicians have essential roles in hospital- or state-required postmortem processes. They also face a new phase of family support and should anticipate debriefing needs of the staff, including members from the medical home.

### **Death Pronouncement**

Declaring the time of death can be emotional for the family and may serve as a milestone that helps them transition through grief. Clinician empathy and timely availability have a long-lasting impact on a family's grieving process.<sup>63,89</sup> The declaration of death is ideally done by a clinician familiar to the family; any uncertainties about local rules regarding authority to declare death should be resolved as early as possible. The clinician should explain to the family that they need to assess the child or adolescent. The examination itself includes auscultation to confirm the cessation of breathing and absence of heart sounds and palpation to confirm loss of carotid or radial pulse. Supplementary testing to confirm no pupillary light reflex or response to noxious stimuli (such as sternal rub) may be considered, especially if the death was unwitnessed. Declaration of death does not need to occur at the precise moment of death; if the family is holding the patient or amid intense bonding or emotion, defer the death examination until the family appears ready. Once death is confirmed, the clinician should mentally note the date and time, and

inform the family that their child or adolescent has died. Clinicians should avoid euphemisms such as “moved on” or “passed,” but should offer an expression of condolence (“I am sorry for your loss ...”) and allow time and space for the family to ask questions.<sup>90</sup>

### **Death Certificate**

The death certificate is the permanent record of death and must be completed in a timely manner, as it is necessary for burial and settlement of personal estates. Documentation details are governed by state statutes, so clinicians must be familiar with local requirements. Clinicians must document the cause of death (such as prematurity or hypoplastic left heart) as opposed to the mechanism of death (ie, respiratory failure or hypotension) as public health data are compiled from death certificates and used for statistical and research purposes.<sup>91</sup>

### **Autopsy**

All families should hear of the potential benefit of a full or a limited autopsy; some centers offer virtual autopsy. Families may pursue an autopsy for a variety of reasons. Perhaps a child or adolescent had an atypical illness course or an underdetermined diagnosis; families may hope that an autopsy will provide answers. In the case in which a child's death follows an unexpected trajectory, families and clinicians may desire an autopsy for more information about how medical care did or did not impact the outcome. Or in cases of neonatal death, an autopsy could provide information that may inform the family's decisions about future pregnancies. Some families see autopsy as a contribution to research and science and a means of building their child or adolescent's legacy. One pediatric multicenter study reported that 25% of



nonmedical examiner cases underwent autopsy.<sup>4</sup>

Clinicians must be aware of local regulations and procedures regarding autopsy, including documentation of consent, timing, the details of a full versus limited autopsy, and how to accommodate particular family requests (ie, to retain tissues for research). There are circumstances in which medical examiner or coroner involvement is mandatory, and autopsy may be required by law.

When autopsy results become available, a clinician familiar to the family should offer to review the results in the family's preferred setting (in person, via telephone, or through e-mail).<sup>46</sup> This allows the family the opportunity to learn the autopsy findings and gives space for any lingering questions about the circumstances surrounding their child or adolescent's illness and death.<sup>92</sup>

### Supporting Families

Families' needs immediately following a child or adolescent's death vary across time and setting. Sometimes the needs are conflicting, such as wanting private time alone and wanting support on hand; or wanting to remain with their child or adolescent and needing time for self-care.<sup>25</sup> Bereaved parents describe an altered sense of time and difficulty processing information about next steps.<sup>25,93</sup> The length of time families are allowed with the body of their child or adolescent in a hospital varies between institutions and states; the time allowed may be longer in home hospice. Families may benefit from hearing about the physical changes to anticipate in the hours after death. The time after death can be spent creating keepsakes to enhance the legacy building and memory making that was initiated before death (Table 5), bathing and

**TABLE 5.** Options for Memory-Making

- Participating in bedside care (eg, bathing)
- Hand or footprints or molds
- Fingerprint charms
- Locks of hair
- Artwork
- Bereavement photographs
- Videos
- Audio recording of Doppler heartbeat
- Printed heart rhythm strip
- Religious or cultural rituals
- Memory boxes with mementos

and dressing the child or adolescent, and receiving support from clinicians.

A team member should be identified to help families navigate postmortem care, including funeral planning, gathering up of the patient's belongings, leaving the physical space of the hospital or coordinating having the body transported from the home, and disposing of or returning home medical equipment.<sup>75</sup> A team member should also notify key care team members, such as the primary care pediatrician or primary specialist. With the family's permission, staff should plan to check in during the days immediately following the death to assess coping and offer support.<sup>93</sup> Many families benefit from options such as a planned follow-up meeting with the medical team or participating in an institution's memorial service.

### Funeral Attendance and Letters of Condolence

Many bereaved families attest to the clinicians who "become like family" to them.<sup>25</sup> Families value knowing that their child or adolescent is remembered and honored by clinicians, even after their death.<sup>89,94,95</sup> Clinician efforts can be particularly important to families of neonates, as the medical team may have spent more time with the infant than any extended family or loved ones. Supportive follow-up may include attending funerals,

sending letters of condolence, maintaining contact by phone or e-mail, or follow-up visits. Clinician attendance at funerals or memorial services is generally welcomed, although clinicians may have to arrange for clinical coverage or use personal time to attend.<sup>96</sup> Recommendations for written condolences include expressing genuine sympathy, sharing a memory or experience about the child or adolescent who died, and reminding the bereaved of their strengths.<sup>97,98</sup>

### Staff Debriefing

The impact of a child or adolescent's death extends to the entire inpatient and outpatient medical team that cared for that patient and family throughout the arc of their illness. Although each clinician experiences the death through his or her own belief system and experiences, there may be benefit to a collective honoring of the patient's death. Routinized pauses just after the death and staff debriefings in the hours to days following are strongly encouraged.<sup>99-101</sup> Ideal debriefings include trained facilitators and are interdisciplinary, inclusive, and voluntary.<sup>102,103</sup> The intent is a safe place for staff to reflect on their own emotions, affirm the normalcy of team emotions, honor the patient and family, and feel able to continue to care for patients.<sup>75,104,105</sup> Such debriefings are especially important in the setting of a prolonged hospital course or a hospitalization complicated by moral distress and might include facilitation by ethics consultants. "Resilience in the Face of Grief and Loss: A Curriculum for Pediatric Learners" was created by the AAP to give clinicians access to evidence-based tools aimed at supporting families, colleagues, and themselves during these difficult patient care experiences.<sup>106</sup>

## Family Bereavement Care

The National Academy of Medicine (formerly the Institute of Medicine) and the AAP have emphasized that bereavement care should be standard of care for grieving families and is a public health priority.<sup>2,20</sup> The bereavement period is defined as the adjustment that follows a person's death; grief is the complex cognitive, emotional, and social distress resulting from bereavement.<sup>76</sup> The death of a child or adolescent puts parents and siblings at increased risk for adverse physical and emotional sequelae. Families may feel the loss of connection to their second family, their child's medical team, and can benefit from the ongoing support of clinicians who solicit any lingering questions about the death or offer targeted supports.<sup>63,89,75,107</sup> Families of infants who died soon after birth may struggle with feelings that their infant's life was "not real," and extended family or friends may not know how to offer support. Family participation in events organized by medical teams, such as yearly memorial services or remembrances of a child's birthday or Mother's and Father's Day can offer some help.<sup>108</sup>

Grief does not have a finite timeline and is an adaptive process. Bereavement supports provided by hospices typically end after 1 year, although families likely continue to need support for years to come.<sup>72,109</sup> The AAP clinical reports "Supporting the Family After the Death of a Child" and "Supporting the Grieving Child and Family" offer guidance to pediatricians.<sup>110,111</sup> Components of bereavement care may include parent-to-parent supports, online bereavement groups, or grief counseling.

## CONCLUSIONS

Some children and adolescents die unexpectedly and suddenly, and others die after years of serious illness. Early advance care planning is beneficial, and the final days and weeks of life offer additional opportunities for shared decision making and revisiting goals of care. Familiarity with the medical, emotional, spiritual, and logistic elements of end-of-life care allows the pediatrician to be a comforting guide for these families. Collaboration with pediatric palliative care and hospice resources can support families and staff during pediatric end-of-life care.

## RECOMMENDATIONS

1. Palliative care ought to be engaged early, when possible, to facilitate communication and decision making with families of children and adolescents with serious illnesses. Advocacy to expand pediatric palliative care and pediatric hospice availability is important to broadening these supports for children, families, and clinicians within children's hospitals and the community.
2. Shared decision making regarding pediatric end-of-life care requires a partnership with children, adolescents, and families. They should be encouraged to share their goals and preferences so clinicians can guide choices that account for the patient and family's wishes and medical needs.
3. Pediatric advance care planning ideally begins soon after a serious diagnosis and is then revisited as the patient's condition, the available treatment options, and the goals of care evolve.
4. Families may struggle with decisions about life-sustaining medical therapies, such as

mechanical ventilation or medically provided nutrition and hydration; clinicians should help families reconcile how these therapies align with the goals of care at the end of life. Clinicians and families may consider involvement of an institution's ethics committee if there are disagreements over the best course of action.

5. Code status documentation can be an important, although not mandatory, preparation for end-of-life care. Do Not Resuscitate orders are limited to specific treatments (eg, cardiopulmonary resuscitation) in the event of a cardiopulmonary arrest and should not be assumed to reflect other treatment goals.
6. Potential options for the location of the child or adolescent's final days or hours should be discussed with the patient and family; collaboration with a pediatric hospice may expand the available options.
7. Clinicians should provide families with straightforward anticipatory guidance about the end of life: the treatments and monitoring that may or may not be continued, the physical signs of dying, and postmortem care of the patient and of the family.
8. Families value support from clinicians during and after the dying period; clinicians should be ready to offer guidance about autopsy, tissue and organ donation, funeral planning, and bereavement support.
9. Pediatric death can impact the interdisciplinary team; clinicians should be familiar with local resources for debriefing.

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## ABBREVIATIONS

AAP: American Academy of Pediatrics  
ACP: advance care planning  
LSMT: life-sustaining medical treatment  
MOLST: medical order for life-sustaining treatment  
POLST: physician order for life-sustaining treatment  
PPC: pediatric palliative care  
SDM: shared decision making

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