



# Guidance on Forgoing Life-Sustaining Medical Treatment

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Pediatric health care is practiced with the goal of promoting the best interests of the child. Treatment generally is rendered under a presumption in favor of sustaining life. However, in some circumstances, the balance of benefits and burdens to the child leads to an assessment that forgoing life-sustaining medical treatment (LSMT) is ethically supportable or advisable. Parents are given wide latitude in decision-making concerning end-of-life care for their children in most situations. Collaborative decision-making around LSMT is improved by thorough communication among all stakeholders, including medical staff, the family, and the patient, when possible, throughout the evolving course of the patient's illness. Clear communication of overall goals of care is advised to promote agreed-on plans, including resuscitation status. Perceived disagreement among the team of professionals may be stressful to families. At the same time, understanding the range of professional opinions behind treatment recommendations is critical to informing family decision-making. Input from specialists in palliative care, ethics, pastoral care, and other disciplines enhances support for families and medical staff when decisions to forgo LSMT are being considered. Understanding specific applicability of institutional, regional, state, and national regulations related to forgoing LSMT is important to practice ethically within existing legal frameworks. This guidance represents an update of the 1994 statement from the American Academy of Pediatrics on forgoing LSMT.

Pediatric health care is practiced with the goal of promoting the best interests of the child. Treatment is generally rendered under a presumption in favor of sustaining life. However, as medical and surgical technologies advance, pediatricians, parents, and other family caregivers may need to consider when it is ethically supportable or advisable to use available interventions to sustain the life of a child who is severely ill. In individual patients, they may conclude that continued treatment beyond maximizing comfort is no longer in the best interests of the child and instead redirect treatment toward limitation or withdrawal of

## abstract

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interventions that are deemed more burdensome than beneficial.

Many deaths in pediatric and neonatal critical care units are preceded by decisions agreed on by the medical team and family to withhold or withdraw life-sustaining medical treatment (LSMT).<sup>1-4</sup> This statement provides guidance for decision-making and communication about withholding and withdrawing LSMT and directs physicians toward American Academy of Pediatrics' (AAP) statements that promote optimal end-of-life care for children.<sup>5-7</sup> This statement is presented in the context of health care in the United States today, in which continuing LSMT is assumed to be the desire of the patient or family unless forgoing treatment is specifically discussed, agreed on, and ordered.

In this statement, LSMT refers to any therapy known to extend survival or for which a strong consensus exists that it may. LSMT includes interventions such as assisted ventilation, medically administered nutrition and hydration, renal replacement therapy, vasoactive infusions, or implanted electronic instruments, such as cardiac defibrillators or ventricular assist devices. In some instances, LSMT also refers to treatments such as transfusions, supplemental oxygen, and medications such as antibiotics, insulin, and others.

A treatment that has been considered for a patient but not begun is said to have been "withheld." One that was started and then discontinued was "withdrawn." The term "forgoing" refers to the process of either withholding or withdrawing.

The terms "burden" and "burdensome" are used in this guidance to refer to the adverse symptoms and suffering experienced by the child in association with particular medical and surgical interventions.

## PRINCIPLES

### Best Interests

As endorsed by professional organizations in North America and Europe, ethical decision-making concerning providing or forgoing LSMT for children is guided by the patient's best interests.<sup>8-10</sup> Acknowledging that the phrase "best interests" is highly subjective and may be difficult to define in any given situation, it remains important to maintain the centrality of patient interests when developing goals of care.

### Balancing Benefits and Burdens

Applying the best interests standard leads to favoring interventions that are likely to provide greater benefit than burden for the child and discouraging the initiation or continuation of interventions that are likely to lead to greater burden than benefit.<sup>11,12</sup> The burdens to the child of greatest salience in this context are those that endure or recur despite maximal attempts at palliation and prevention. Such burdens may include pain, unwanted or lengthy restrictions on activity (by using pharmacological or physical means), anxiety, fear, isolation, or other life changes that cause distress to the child.

Some treatments unlikely to benefit patients in the long-term have short-term positive effects that encourage patients, physicians, and other caregivers to provide those interventions despite a lack of firm evidence of efficacy over time. Whether such interventions should be considered "futile" or "nonbeneficial treatment"<sup>13</sup> has been the subject of debate.<sup>14</sup> Some groups caution against "broadly characterizing a treatment as 'futile' or 'non-beneficial'"<sup>10</sup> and recommend instead that physicians clarify how each treatment option, including decisions to forgo LSMT, may or may not promote established goals of care.

Interventions that have no chance of achieving the intended physiologic benefit are considered "physiologically futile." Some scholars have argued that physicians should provide treatments that are physiologically futile if intractable disagreements with families occur.<sup>15</sup> Others find the practice ethically problematic in that it "adds burden for the patient" and "may involve a form of deception, through 'pretending' that a treatment has potential for physiological benefit when it does not."<sup>10</sup> According to a joint statement by 5 professional organizations concerned with the care of those with critical illness, physicians should not provide such interventions in the rare situation in which they agree, after a deliberative and inclusive process, that the intervention would be physiologically futile.<sup>16</sup>

One approach to evaluating the benefit-burden balance of life-prolonging interventions is referred to as "provisional intensive care."<sup>12</sup> In such situations, time-limited trials of LSMT are initiated, then withdrawn after a prespecified period of time if they have failed to contribute to improvement in the patient's status or are found to impose greater burden than benefit. It may remain difficult for caregivers and physicians alike to discontinue LSMT at the end of such a trial, even when consensus exists around lack of net benefit of the intervention, particularly if withdrawal is associated with a sense of personal culpability for the patient's death. Despite the different emotional and psychological meanings that withholding and withdrawing LSMT may have, they are widely considered to be ethically and morally equivalent.<sup>6,8</sup>

Children in states of extremely critical illness associated with virtually no chance of recovery may be perceived by their families

and/or physicians to be suffering significantly, despite exhaustive attempts to palliate pain and other symptoms. In these circumstances, forgoing burdensome LSMT may be considered ethically advisable. The AAP and other organizations<sup>8-10</sup> support continuing palliative measures intended to manage pain or suffering in all instances.

## PROCESS GUIDANCE

### Physician Roles

The ethical duties of veracity and fidelity call physicians to share “complete, honest and unbiased information with patients and their families on an ongoing basis and in ways they find useful and affirming.”<sup>17</sup> Beneficent actions also include efforts to identify individuals, groups, and other resources that can provide support to the patient and family. When physicians engage in partnerships characterized by shared decision-making around goals of care, it can reduce the often overwhelming burden on families and adolescents contemplating difficult treatment decisions, including those that involve forgoing LSMT.<sup>18</sup>

Pediatricians may graduate from training feeling uncomfortable discussing end-of-life care or taking part in its planning.<sup>19-21</sup> Given the importance of communication skills when discussing forgoing LSMT, pediatricians may wish to improve these skills through focused training, collaborative work with a range of pediatric medical subspecialists and pediatric surgical specialists, mentorship by colleagues whose communication skills are highly valued, and resources offered by a range of professional organizations.<sup>22</sup> This is equally important for pediatric subspecialists, pediatric surgeons, providers of acute care and pediatricians in the medical home.<sup>23</sup>

Treating children with life-limiting conditions may create significant moral distress for members of the care team. Physicians who, on moral grounds, decline to participate in limitation or withdrawal of LSMT should continue to fulfill the “duty of care”<sup>10</sup> to the child until they are able to arrange for care by another physician. Guidance can be found in the 2009 AAP statement on claims of conscience.<sup>24</sup>

### Involving Children and Families

Children and families are recognized as integral members of the health care team, as participants in development of all aspects of the health care plan, and as shared owners of that plan.<sup>17</sup> Parents and family caregivers generally are regarded as best able to appreciate the best interests of the child,<sup>9</sup> which is the central framework for ethical decision-making concerning treatment options in pediatrics, including decisions to forgo LSMT, based on goals of care. Parents, guardians, and adolescents involved in developing the plan of care will benefit from receiving information and resources necessary to help them anticipate what decisions may lie ahead. Supports may include explanations and images, updates about an evolving course of illness, and a commitment from providers to listen to families’ questions, needs, and values.

According to standards of practice promoted by the National Hospice and Palliative Care Organization, every child has a right to “open and honest” communication of “age-appropriate information about his or her illness, as well as potential treatments and outcomes, within the context of family decisions”<sup>9</sup> and to be “given the opportunity to participate in decisions affecting his or her care, according to age, understanding, capacity, and parental support.”<sup>9</sup> These recommendations, reflected in guidelines issued by

other professional organizations in North America and Europe,<sup>8,10</sup> call for physicians to seek assent, and take into consideration dissent, of older children and adolescents who demonstrate some health care decision-making capacity, “while ensuring the child’s best interests remain at the core of decisions.”<sup>9</sup>

The AAP recognizes that “some pediatric patients, especially older adolescents and those with medical experience because of chronic illness, may possess adequate capacity, cognitive ability, and judgment to engage effectively in the informed consent or refusal process for proposed goals of care.”<sup>25</sup> As Diekema has written, others may not “truly possess sufficient capacity to make life-altering medical decisions,” such as declining LSMT.<sup>26</sup>

### Communicating Resuscitation Status

When attempted resuscitation is not warranted clinically or desired in inpatient settings, specific orders written in the medical record typically take the form of “do not attempt resuscitation” (DNAR) orders, also called “do not resuscitate” or “allow natural death” orders. Progress notes that accompany these orders typically indicate prognosis and describe the content of discussions with the family and the medical team, the expressed wishes of the patient and family decision-makers, any issues that remain unresolved, and recommendations of the treating team and consultants.<sup>8,10</sup> This practice promotes more widespread understanding among members of the health care team of the considerations informing decisions to forgo attempts at resuscitation.

Physicians who treat children need to be aware of institutional policies, regional and state health regulations, and federal legislation pertaining to forgoing LSMT. As 1 example, in some institutions, family caregivers

are asked to sign orders to forgo LSMT, creating potentially stressful demands on family caregivers who are already anticipating the death of their child. In others, verbal agreement, or simply allowing the action after discussion with the treatment team, is sufficient.

The developing autonomy of children and adolescents to express preferences and wishes for care and remembrance around the end of life may be supported by the use of tools such as “Voicing my Choices,”<sup>27</sup> “Personal Resuscitation Plans,”<sup>28</sup> and “Child and Family Wishes,”<sup>29</sup> originally derived from adult-oriented advance care plans.

One of the decisions that may emerge from these discussions with children and families is for the physician to write an out-of-hospital DNAR order. These orders are supported in many but not all states.<sup>30,31</sup> When parents or guardians feel strongly about affirming the child’s DNAR status, providing documentation to emergency medical responders in the field and hospital emergency departments will increase the likelihood their wishes will be respected. Parents and legal guardians should be reassured they can rescind out-of-hospital DNAR orders at any time or make the decision not to present the forms to emergency responders.

Some children with DNAR orders are candidates for interventions under deep sedation or general anesthesia, aspects of which would be considered resuscitative in other contexts. To best support goals of care, the AAP and other national organizations endorse the concept of “required reconsideration” of DNAR orders in the process of informed consent for surgery or anesthesia<sup>32</sup> and assert that continuing a DNAR order intraoperatively and perioperatively may be ethically supportable in some circumstances.

### **Disagreements Concerning Forgoing LSMT**

Family decision-makers may disagree with medical recommendations to forgo LSMT because of different perceptions and expectations about the child’s current and future quality of life, different interpretations of the prognosis, or religious and culturally based beliefs that influence their sense of what is in the child’s best interests. The AAP and other organizations support addressing these considerations with the utmost regard for families’ viewpoints, continuing a process of respectful and honest information sharing as the patient’s condition and the family’s understanding evolve over time.<sup>8–10,16,17</sup> Differences between family caregivers or between the care team and child and/or family decision-makers can be approached by using basic principles of negotiation and conflict resolution and support from pastoral care providers and consultants in palliative care or ethics.<sup>8,9,16</sup> If a family agrees to discontinuation of LSMT but requests a delay to allow others to visit the child, reasonable accommodations, guided and limited by the interests of the patient, may allow for closure.

Typically, physicians may obtain permission to provide LSMT from either lawful parent. In some states, however, permission to withdraw or withhold LSMT must be provided by both parents unless one has been designated the sole legal guardian for health care decisions or the child has another legal guardian. Although legal requirements may differ from state to state, ethical considerations with regard to forgoing LSMT are identical across state lines.

Physicians and the care team may consider whether it is appropriate to forgo LSMT despite family objections when the anticipated benefits of LSMT are minimal and the perceived burden of suffering remains substantial even after

exhaustive attempts have been made to palliate pain and other adverse symptoms. Although this may be ethically supportable in rare circumstances of extreme burden of treatment with no benefit to the patient beyond postponement of death, state regulations may require consent from guardians. At this point in time, it is legally permissible in at least 1 state for physicians to withdraw LSMT against family wishes.<sup>33</sup> Some hospitals have policies and procedures allowing physicians to write unilateral DNAR orders. Strategies that institutions can implement to prevent and address such conflicts are proposed in a joint statement by 5 professional organizations concerned with the care of those with critical illness.<sup>16</sup>

### **Interdisciplinary Planning and Consultation**

The care of children with medical complexity involves contributions from multiple pediatric medical subspecialists and pediatric surgical specialists, pediatricians in the medical home,<sup>23</sup> and health care professionals from many disciplines. All can provide guidance and support to family decision-makers when options to forgo LSMT are discussed.

Conversations with children and families about treatment options over which the care team is strongly divided can be stressful to family decision-makers. At the same time, understanding the range of professional opinions behind treatment recommendations is critical to informing family decision-makers (and children, in some cases), even when these views conflict. It can be challenging to manage the flow of information in ways that are minimally confusing and maximally supportive to families and professional staff.<sup>22,34</sup> Interdisciplinary meetings and consultation with palliative care specialists can promote these goals. Ethics consultation services provide



support for families and medical staff and are helpful early in the course of care and as concerns and conflicts arise.<sup>35,36</sup>

## **SPECIAL SITUATIONS**

### **Forgoing Medically Administered Nutrition and Hydration**

Medically administered nutrition and hydration constitute interventions that may be withheld or withdrawn for the same types of reasons as other medical treatments. It is considered ethically supportable to forgo medically administered nutrition and hydration when there is consensus that they do not provide net benefit to the child and thereby fail to support the child's best interests. As with the forgoing of other LSMT, parents and legal guardians should be fully involved in decision-making and be reassured that their child will continue to be provided with palliative measures to ensure comfort.<sup>6,8</sup>

### **Children With Developmental Disabilities**

The ethical foundation of decision-making concerning forgoing LSMT is the same for children with developmental disabilities as for those considered typically developing.<sup>8</sup> The approach to identifying goals of care and deriving treatment plans based on those goals, including considerations to forgo LSMT, is grounded in the consideration of each child's best interests. Some children with developmental disabilities experience associated conditions that warrant palliation. A small number of children have central nervous system impairment so substantial that questions arise as to their capacity to experience pleasure or any benefit from continued existence; these considerations figure into assessments of benefits and burdens of treatment.<sup>8</sup>

### **Infants and Children in Foster Care**

Decisions about forgoing LSMT may arise in the care of children who are in the custody of child protective services after parental rights have been terminated but before adoption has taken place. In these cases, the state and its agents, acting in loco parentis, may need medical and ethical guidance from members of the care team concerning issues with which they lack familiarity or experience. In these situations, it is ethically supportable to inform parents about end-of-life discussions, although they lack decision-making authority.

### **Suspected Abuse or Neglect**

For children whose injuries are believed to be the result of child abuse, the same medical and ethical decision-making criteria apply to forgoing LSMT as for other children, including discussion of potential organ donation with guardians and the medical examiner. Conflicts may arise for people accused of having caused the injuries or for those in an adult relationship with people who are so accused if legal charges will change depending on whether the child survives or dies. Appointing a guardian ad litem in all cases in which such conflicts are suspected promotes states' interests in protecting vulnerable citizens. Guidance from legal and ethics consultants should be sought by providers who are concerned that such conflicts raise the potential that a child's best interests are not being pursued.

### **Newborn Infants With Uncertain Prognosis**

In the care of neonates who were born extremely preterm, survived profound asphyxia, possess certain life-threatening congenital anomalies, or have multiple organ system failure, decisions to forgo LSMT may be exceptionally difficult because of the uncertainty about prognosis

during the early hours or days of life. Uncertainties are magnified by the changing limits of viability as the practice of neonatology advances and because withholding initial treatment may worsen outcomes of some infants who unexpectedly survive. The AAP supports a process of shared decision-making with the family in the approach to resuscitation and intensive care of infants born at extremely low gestational age (<25 weeks), for whom "the risk of permanent, severe neurodevelopmental and other special health care needs affect both the infant and the family and, for some parents, may outweigh the benefit of survival alone."<sup>37</sup> In the care of other high-risk newborn infants whose "prognosis is uncertain but likely to be very poor and [for whom] survival may be associated with a diminished quality of life for the child," AAP policy affirms that "parental desires should determine the treatment approach"<sup>5</sup> The AAP also asserts that a treatment should be considered "inappropriate" when it is "harmful, of no benefit, or futile and merely prolonging dying."<sup>5</sup> As in all instances beyond the neonatal period, comfort care of newborn infants is appropriate whenever a decision is made to forgo resuscitation or intensive care.<sup>37</sup>

In 1994, the US Congress amended the Child Abuse Prevention and Treatment Act of 1984 (Human Services Amendments of 1994, Pub L No. 103-252) to require state child protective services agencies to develop and implement mechanisms to report to a government agency treatment withheld from infants on the basis of disability, except in any of the following situations: (1) when an infant is chronically and irreversibly comatose; (2) when providing the treatment would merely prolong dying, would not be effective in ameliorating or correcting all of the infant's life-threatening conditions, or would be

futile in terms of the infant's survival; or (3) when the treatment would be virtually futile and inhumane.<sup>38</sup> It is important to recognize that this legislation pertains exclusively to infants, is intended to prevent discrimination on the basis of disability alone, and may not always be consistent with approaches that compassionately consider each child's evolving medical condition and best interests.<sup>39,40</sup> The Child Abuse Prevention and Treatment Act is directed at states, not individual physicians, and it does not provide direction on what actions state governments and agencies should then take when a possible violation is reported. Understanding specific applicability of institutional, regional, state, and national regulations related to forgoing LSMT is important to practice ethically within existing legal frameworks.

### Death by Neurologic Criteria

Recommended processes for the diagnosis of death by neurologic criteria in children and infants have been updated over time. Physicians should use current processes and be aware of state statutes and institutional policies that may restrict the determination of death by neurologic criteria in certain circumstances. They are encouraged to offer the time and guidance needed to help families understand that once death by neurologic criteria has been determined, their child has met legal criteria for death.<sup>41</sup> Families' religious beliefs and practices should be acknowledged during the process of determining death by neurologic criteria, and physicians should be knowledgeable about state laws that may honor exemptions to this determination. The process of discontinuing interventions that sustain oxygenation and tissue perfusion in a child whose death was determined by neurologic criteria, although fundamentally different from withdrawing LSMT,

may be experienced similarly by families and clinicians. In addition, it is important for pediatricians to be aware of regulations about reporting imminent death to organ-procurement agencies and the need, in some instances, to sustain organ support until appropriateness for organ recovery has been established.

### RECOMMENDATIONS

When decisions to forgo LSMT are being contemplated, compassionate care for children who are severely ill and their families is enhanced by attention to the following considerations:

1. Although there is a presumption in favor of sustaining life in most circumstances, forgoing LSMT is ethically supportable when the burdens of treatment outweigh the benefits to the child;
2. Understanding specific applicability of institutional, regional, state, and national regulations related to forgoing LSMT, including the Child Abuse Prevention and Treatment Act, is important to practice ethically within existing legal frameworks;
3. Respectful, truthful, and thorough communication between members of the treatment team, the medical home, the patient, and family decision-makers supports the process of shared decision-making across care environments and throughout the evolving course of the child's illness;
4. Perceived disagreement among the team of professionals may be stressful to families. At the same time, professional opinions behind treatment recommendations are critical to informing family decision-makers, even when these views conflict;

5. Each child is entitled to "open and honest" communication of "age-appropriate information about his or her illness, as well as potential treatments and outcomes, within the context of family decisions" and to be "given the opportunity to participate in decisions affecting his or her care, according to age, understanding, capacity, and parental support."<sup>9</sup> The child's participation can be enhanced through the use of care-planning tools;
6. Ethics consultation may be useful to the health care team and to families when ethical concerns about forgoing LSMT are raised or require clarification;
7. Ethical approaches to managing disagreement between the views and wishes of family caregivers and/or between family decision-makers and the health care team can be approached by using basic principles of negotiation and conflict resolution and addressed with support from spiritual care providers and consultants in palliative care or ethics;
8. Reasonable accommodation for the timing of forgoing LSMT may be given to families to allow family members to gather, but the utmost care is warranted to avoid prolonging suffering of the patient;
9. It may be ethically supportable to forgo LSMT without family agreement in rare circumstances of extreme burden of treatment with no benefit to the patient beyond postponement of death;
10. Medically administered nutrition and hydration, like other LSMTs, constitute interventions that may be withheld or withdrawn when there is consensus that they do not provide net benefit to the child and thereby fail to support the child's best interests;

11. The AAP endorses the concept of “required reconsideration” of DNAR orders in the process of informed consent for surgery or anesthesia. It may be ethically appropriate to continue DNAR orders intraoperatively and perioperatively if this is consistent with goals of care;
12. Physicians who decline to participate in limitation or withdrawal of LSMT on the basis of their own moral, religious, or personal beliefs should continue to care for the child until they are able to arrange for care by another physician;
13. Ethical and medical decision-making in certain special situations, including the care of children with developmental disabilities, children who are in foster care, and children whose injuries are believed to be the result of child abuse, are guided by the same principles as decision-making for other children;
14. For some newborn infants who were born at extremely low gestational age (<25 weeks), survived profound asphyxia, possess certain life-threatening congenital anomalies, or have multiple organ system failure, the AAP recognizes that “prognosis is uncertain but likely to be very poor,”<sup>5</sup> and survival may be accompanied by a high risk of “permanent, severe neurodevelopmental and other special health care needs” and diminished quality of life.<sup>37</sup>

In such instances, it is ethically supportable for decisions about forgoing LSMT, developed in a context of shared decision-making with professionals involved, to be determined by parental preferences, except when requested treatments are judged to be of net harm, “of no benefit, or physiologically futile and merely prolonging dying”<sup>5</sup>; and

15. Physicians should use current processes for the diagnosis of death by neurologic criteria and be aware of pertinent state statutes and institutional policies.

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#### ABBREVIATIONS

AAP: American Academy of Pediatrics

DNAR: do not attempt resuscitation

LSMT: life-sustaining medical treatment

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