

Chapter 8

Advance Care Planning



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Overview of Advance Care Planning

Definition

Advance care planning is the process by which a patient and family, in consultation with healthcare providers, make decisions about current and future health care [2]. It is regarded as the gold standard for all patients facing serious illness, including the pediatric population [5]. While historically advance care planning programs and research efforts centered on adult patients, and a predominantly geriatric population [5], these efforts have expanded to incorporate children and young adults, in concordance with the growth of pediatric palliative care programs [6]. Similarly, the model for advance care planning, which in its conception focused largely on completion of advance directives, now involves discussion of goals of care, patient and family values, systems of belief, and patient prognosis as they inform patient care and medical intervention [7]. The process of advance care planning occurs as an

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ongoing conversation, rather than a discrete or finite decision, and adapts alongside the trajectory of illness, in synchrony with patient and family goals. The American Academy of Pediatrics (AAP) Policy Statement on Pediatric Palliative Care and Hospice Care Commitments, Guidelines, and Recommendations states that the palliative care clinician should “facilitate clear, compassionate, and forthright discussions with patients and families about therapeutic goals and concerns, the benefits and burdens of specific therapies, and the value of advance care planning [8].” The policy statement emphasizes the importance of engaging in advance care planning over time, as an illness and treatment course evolves, and at least annually in the care of a child with a chronic, complex illness [8]. Advance care planning should begin early in the course of illness; should be shared among the patient, family, and healthcare provider; and should occur as a structured process [9, 10].

Ethical Principles Underlying Advance Care Planning

The ethical imperative to provide compassionate patient- and family-centered care in the relief of suffering [11] extends to the care provider’s obligation to engage in advance care planning with a child and family facing serious illness. Though the process of advance care planning cannot eliminate all ethical conflict and uncertainty, it seeks to uphold the care provider’s responsibility to do good, to avoid causing harm, to respect both parental authority and patient individuality, and to provide care equitably in accordance with patient values and beliefs, regardless of means [10]. This occurs through early, honest discussions with a patient and family, framed in the context of their values and experiences and the medical recommendations of the clinical team, in order to align around the goals of care.

Of particular consequence in the field of pediatric oncology are the concepts of patient autonomy, surrogate decision-making, and the related legal doctrine of informed consent. The contemporary legal notion of patient autonomy took shape in the 1914 case, *Schloendorff v. Society of New York Hospital*, in which Justice Benjamin Cardozo ruled that: “Every human being of adult years and sound mind has a right to determine what shall be done with his own body... This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained [2].” This ruling upholds respect for persons within the medical field, particularly a patient’s right to informed decision-making, which is embodied in the process of informed consent for medical intervention. The components of informed consent include: the provision of information, an assessment of the patient’s understanding, and the patient’s capacity to make the necessary decision in the absence of coercion [12].

Within pediatrics, the application of informed consent is limited, as children are most often considered to lack the capacity to make serious medical decisions [13], with exceptions arising in the care of adolescent and young adult patients. Decision-making typically occurs through a parent or surrogate, on the basis of parental authority. Parental authority, which has in some cases been termed parental auton-

omy, hinges on parental responsibility for raising a child, parental close knowledge and understanding of the child, the responsibility to live with the outcomes of decisions made, and inherent investment in the best interests of the child [13]. However, decisions should be made with the assent of the child whenever possible. The AAP recommends that patients participate in decision-making commensurate with their developmental stage; the patient should provide assent to care when reasonable [12].

Involvement of the pediatric patient in decision-making should be promoted as part of an ethical approach to advance care planning. Such involvement requires that the care provider facilitate developmentally appropriate awareness of the patient's medical condition by discussing what can be expected from upcoming treatments and testing, assessing the patient's understanding of a clinical situation and the factors affecting patient response, and determining the patient's willingness to participate in care [12]. With development, experience, and coaching, the patient's ability to engage in the medical decision-making process as an agent in his or her health care will increase.

Communication in Advance Care Planning

Communication is at the core of successfully implemented family-centered advance care planning. The two exist inextricably. Effective advance care planning mandates and improves the quality of communication [7]; likewise, communication with patients and families depends on the discussion of the goals of care, value systems, and prognosis that structure advance care planning. A patient's values, beliefs, goals of care, and best interests are upheld through facilitating open and ongoing discussions among the patient, family, and medical care provider that are then shared with the patient's medical team and community.

Parents value communication and caring relationships with providers, especially when facing the end of their child's life [14–17]. The individual pediatric patient is intimately a part of a family, community, and social network of support that informs parent–patient decision-making. The communication necessary and inherent in effective advance care planning allows patients and families to communicate their desired care preferences with their entire medical team, and with their greater community, reducing confusion and reiteration of often difficult conversations [6]. The process of advance care planning supports end-of-life decision-making by bolstering parents' emotional supports, the quality of information provided, and medical understanding, and by enhancing the communication skills of medical providers [14].

Pediatric cancer care is based on truthful, sensitive, empathic communication with the patient, in a family-centered and child-focused approach [18]. This occurs by establishing a trusting, long-standing relationship between care provider, patient, and family and consistently employing clear, honest, and effective communication [19]. Communication may be viewed as a tool in the implementation of advance care planning and may prove a therapeutic intervention in itself. Development of the communication skills of the medical care provider has been shown to improve family outcome and experience [20].

The AAP recognizes three core elements of physician–parent–child communication. These tenets establish the groundwork for an approach to conversations in pediatric advance care planning: (1) informativeness or the quantity and quality of health information provided by the physician; (2) interpersonal sensitivity or affective behaviors that reflect the healthcare provider’s attention to, and interest in, the parents’ and child’s feelings and concerns; and (3) partnership building, or the extent to which the healthcare provider invites parents and child to express concerns, perspectives, and thoughts collaboratively [21].

Discussions focused on advance care planning are centered on patient and family goals of care, as informed by the patient’s clinical status and prognosis. The conversation takes a team-based approach, with focus on a family’s goals and achievable hopes. One such proposed conversational structure involves: (1) reviewing the major challenges confronting the child and family; (2) discussing goals and hopes; (3) discussing alternative care options; (4) examining the risks and benefits of each therapeutic option; (5) exploring tradeoffs; (6) forming a plan; and (7) planning next steps and follow-up [1]. Although the discussion might vary in structure and form, at its core it focuses on providing thorough, informative, and relevant medical information, followed by a discussion of goals of care within the context of patient and familial hopes, values, cultural and religious belief systems, and community. The developed plan is documented, and implemented, with the recognition of the ongoing nature of the advance care planning discussion.

Multiple studies have indicated the safety and importance of the inclusion of the pediatric patient in the communication process. Pediatric patients and survivors of pediatric cancers have a recognized capacity to be involved in decisions surrounding treatment and at the end of life [14, 22]. Furthermore, parents of children with cancer recognize the importance of decision-making alongside their child [23]. Children are aware of both their diagnosis and prognosis, without having been informed by an adult, and often understand more than presumed [21]. For the pediatric patient, provision of developmentally appropriate and welcomed information, inclusion in decision-making, and having choices allow an increased sense of control in the face of the chaos and fear of cancer diagnosis, as well as an enhanced sense of trust in the healthcare team [21]. The pediatric patient should not be forced to participate in advance care planning discussions, but he or she may be encouraged and supported in this endeavor through coaching and the use of developmentally appropriate language and decision-making tools [21, 24].

Timeline for Advance Care Planning

The advance care planning discussion is not discrete; it occurs in an ongoing fashion in accordance with the trajectory of illness and the evolution of a patient’s and family’s goals of care. The trajectory of pediatric illness, and that of cancer specifically, may not prove predictable; therefore, advance care planning becomes all the more important as it seeks to anticipate and prepare for both acute illness and a gradual worsening in health status. Pediatric cancer that is life-threatening may be

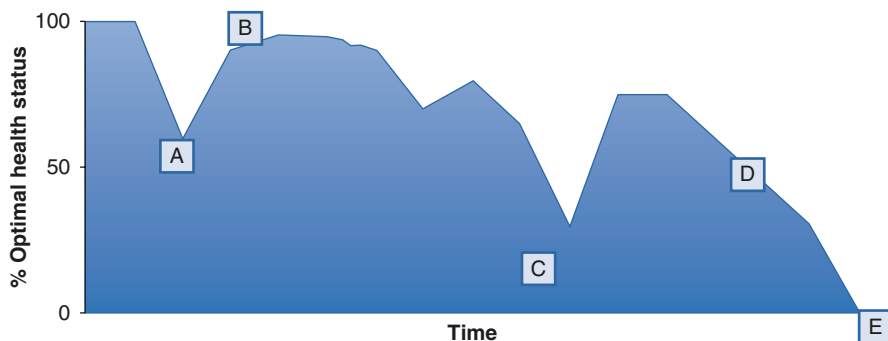


Fig. 8.1 Health status of a child with serious illness over time [1]

- A. Acute decompensation and hearing bad news
- B. Recovery and accommodating to a new life
- C. Acute decompensations and unexpected recoveries
- D. Slow decline preceding death

viewed graphically as a gradual worsening of health status from baseline marked by periods of acute illness (e.g., sepsis, significant disease progression), and subsequent improvement to a new baseline of health (Fig. 8.1). Periods of change, and of worsening health within a child's life, are associated with a higher risk of suffering [1]. As such, addressing goals of care both early in the course of illness, and again as the child faces each new challenge, continually aligns the patient, family, and healthcare team in working toward a common goal, which may evolve over time [3].

Planning for the end of life is imperative in caring for children with life-threatening cancer and their families and is the responsibility of the healthcare provider in shaping the advance care planning dialogue over time. However, given the challenges presented by prognostication and the barriers to advance planning, this discussion may occur late in the course of illness and out of immediate necessity. By contrast, when physicians and parents share the recognition that there is no longer a realistic chance for cure, earlier discussion of hospice, improved quality of care delivered by a home care team, earlier documentation of resuscitation status, and reduced cancer-directed treatment in the last month of life occur [14]. Time-appropriate prognostic communication that is family-centered and accessible to the patient allows parents to make the best possible decisions for their child and focus on quality of life, with reduction in the distress associated with uncertainty. This allows time and space for a child and parents to reframe goals and create hopes anew [25].

Barriers to Advance Care Planning

Despite recommendations to incorporate advance care planning early and often into the care of pediatric oncology patients with serious and life-threatening illness, these conversations are often documented late in illness, with resuscitation status

not documented until near the time of death [26, 27]. Inconsistent communication in advance care planning risks parental confusion, distress, and incomplete transfer of important information [26]. Historically, healthcare providers have identified unrealistic clinical expectations by parents, differences between physicians', patients', and parents' understanding of prognosis, and parental unreadiness to engage in advance care planning discussions as barriers to advance care planning. In addition, physician concern about taking away hope, physician uncertainty about prognosis, and self-doubt regarding the ability to skillfully engage in advance care planning discussions have been cited as hindrances in allowing broad-reaching advance care planning [5]. Notably, overcoming these impediments to advance care planning hinges on improved provider communication skills and education.

Parents of children with cancer remain hopeful, despite simultaneously holding expectations of poor prognosis [28]. It is within this seeming contradiction that care providers might hastily identify parental expectations as unrealistic. Yet, the exploration of the depth and breadth of parental and patient hopefulness might facilitate and support it, identifying hopes that *are* possible, and that coexist with the gravity of the prognosis [28].

Similarly, effective communication might be used to transfer information regarding prognosis from clinician to parent and patient. This can be achieved by creating an open environment for questions and assessing parents' and patients' understanding throughout the conversation. While offering specific prognostic timelines is challenging and often proves inaccurate, general timeframe estimates (i.e., days to weeks, weeks to months, months to years) might be implemented in order to convey tangible information and thus allow informed planning and decision-making [29].

Parental and patient unreadiness to participate in advance care planning has been attributed to anxiety, fear of death, fear of losing hope, lack of insight, and denial of disease severity; however, lack of readiness to engage in advance care planning should not be presumed, despite the significant emotional distress caused by pediatric cancer and illness. Patients and parents may not realize that advance care planning discussions should take place with their clinician or may not take the lead in initiating these conversations [26]. Furthermore, increased disclosure of information, particularly prognostic information, allows preservation and even enhancement of parental and patient hopes, rather than engendering false hopes and mistrust and furthering fear [28]. The honest disclosure of information in a supportive environment strengthens the trusting relationship of the patient, parent, and physician, allowing space for emotional expression, support, and thus, the preservation of hope.

Discussing poor prognosis and illness progression might take an emotional toll on the healthcare provider, posing a potential barrier to advance care planning discussions. Providers may find it helpful to consider that honest disclosure and engagement in advance care planning reduce hospitalizations, as well as deaths in the intensive care unit, and allow space for parent and family reflection and time shared meaningfully [29, 30]. Emphasis, therefore, must also be placed on fostering the education, communication skills, and resiliency of healthcare providers who have the responsibility of advance care planning.

Shared Medical Decision-Making and Advance Care Planning

Approaches to Discussing Goals of Care

Integral to the process of advance care planning is the discussion of goals of care. A goal in this context is defined as a hope for the future health and well-being of the child or young person. Dedication to significant and meaningful personal goals affords a sense of well-being and purpose [3]. Patients' and parents' goals of care will likely evolve over time [17] and may represent both short- and long-term plans for the future. In eliciting these goals through discussion, particular strategies might be implemented in order to best structure these conversations so that the care provider might listen to, support, and align with patient and family.

One such proposed method is described by the mnemonic, PERSON [4]: *perception* of current health status, *exploration* of the patient's life prior to illness, *relating* the patient's story to their present illness and important medical information, investigating *sources* of worry and fear while sharing the hopes and concerns of the medical team, *outlining* the plan moving forward, and *notifying* others, including the interdisciplinary medical team and other family members [4]. This model emphasizes the intimate nature of the conversation as a reflection of the life and legacy of the individual patient. It does not allow the discussion to be reduced to its singular components, whether resuscitation status or treatment goals. Importantly, the goals-of-care discussion considers the patient–parent–clinician triad a team and opens a space for honesty and shared hopes and worries.

Regoaling is defined as parental disengagement with initial goals and reengagement with new goals [3]. This process typically occurs sequentially over time and may involve incremental or stepwise movement toward the new set of goals (Fig. 8.2). Regoaling may occur as a child's illness worsens; however, a parent faced with the serious illness of their child may also persist—and need to persist—in the pursuit of their original goals for cure, no matter that those goals have become unattainable [3, 31]. When possible, the medical care provider can facilitate the process of regoaling, in alignment with illness trajectory, through a purposeful approach to discussing and re-discussing the goals of care. Parents expressing a mixture of positive and negative emotions surrounding their present experience may indicate a readiness to reconceive of goals of care. Exploring parental hopes, and providing suggestions for what might be possible (e.g., care at home), can support goal identification. Providing clear, direct medical information in a setting that allows time for parental acceptance, emotional expression and support, and provider assessment of parental understanding will facilitate this process, allowing for a positive experience within the discussion itself, despite saddening contexts. The relationship, honesty, safety, and emotional and social supports provided are constructive as parents face difficult transitions and decisions [3].

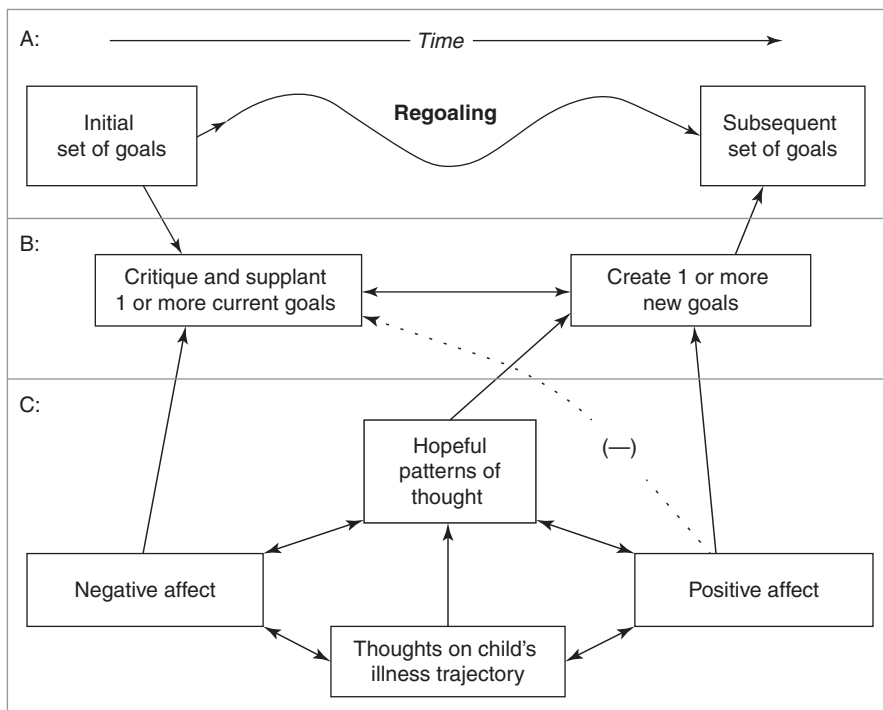


Fig. 8.2 Regoaling [3]

Factors that Influence Patient and Family Decision-Making

Children and young adults with cancer, their parents, and other family members are faced with many healthcare decisions as they endure a journey marked by both physical and emotional challenges. This process occurs under the guidance of a trusted healthcare team, and as such, an understanding of patient and parental decision-making gives the clinician the tools necessary to offer this vital support.

Parents of patients with pediatric cancer have identified the decisions to forgo further disease-directed therapy, begin phase 1 therapy, maintain or forgo mechanical support, and forgo resuscitation as the most common difficult decisions faced [14, 32]. Despite the variable nature of the particular decision at hand, multiple factors have been identified as contributing to the parental and patient decision-making process. Parents have identified information about their child's health and disease status, explained by a physician team member, as crucial. Trust in the healthcare team and support provided by the team are highly influential [23]. These findings have been mirrored in studies focused on adolescent patients, in which the medical information provided to the adolescent and the recommendations of healthcare providers and parents were given significant weight in the decision-making process [23].

Decision-making, specifically at the end of life, is affected by the flow of information, disclosure of prognosis, development of physician–patient and physician–parent relationships, patient and family preferences and goals of care, and availability of treatment alternatives. Again, paramount in this context is parental and patient trust in the clinician, identified as the most important factor in the parental decision-making process at end of life. This is more particularly described as a relationship established with a clinician who is willing to engage in end-of-life discussions framed by the background, characteristics, and experiences of the unique child and family [33].

Multiple themes have emerged within the body of literature examining the decision-making process of the pediatric cancer parent, including communication, prolongation of life, and prognostic understanding [16]. Direct, honest, accurate, and consistent information delivered in a compassionate, reassuring, and individualized manner affects parental decisions constructively. Individualized, family-centered care encompasses an understanding of patient and family values, beliefs, religion, socioeconomic circumstances, and consideration for quality of life.

Parents' decisions are further framed by the hope for more time with their child, or prolongation of life, highlighting the significance of concurrent provision of palliative and cancer-directed therapy within pediatric oncology. Communication and time function indivisibly with understanding of prognosis as decision-making factors. Communication is key in the transfer of prognostic information from clinician to parents, and well-communicated prognosis is crucial in decisions based on the hope for life prolongation [16].

Parental decision-making in the setting of incurable and progressive pediatric cancer might best be encapsulated in the conception of the “good parent” or the self-perceived role of the parent. This role has been defined by parents of children with cancer as making informed, unselfish decisions in the child's best interests, remaining by the child's side throughout illness, ensuring that the child feels cherished, teaching the child to make good decisions, serving as the child's advocate, and promoting the child's health [34]. The healthcare provider can thus seek to support parents and family members by better understanding a parent's hopes, self-identified role, and the values guiding decision-making.

The Role of the Healthcare Provider in Decision-Making and Clinician Bias

The healthcare provider enters into a partnership with a patient and family, taking up a responsibility for fostering family-centered care and shared decision-making. The care provider becomes a conduit for the transfer of prognostic information and for the discussion of potential avenues of care moving forward. The general model of shared decision-making proposes that clinician, patient, and family discuss illness trajectory and the options for treatment, including risks and benefits, with a goal of arriving together at a shared and well-understood plan [35]. Within the

framework of shared decision-making, the care provider is attuned to the individual needs of the patient and family, extending beyond medical information. A conversation occurs within the context of patient and familial hopes, goals of care, sense of meaning and spirituality, and social circumstances. The child's quality of life and depth of suffering and the parents' emotions and sense of responsibility should be attended to by the care provider engaged in discussions about serious illness [36].

The provider, therefore, works to establish a trusting and long-term relationship with the patient and family in order to provide holistic and compassionate care. Effective communication through clear, concise, and direct language in discussion of prognosis and therapeutic options aids understanding, which can be ensured through open dialogue that invites and encourages parental engagement. The clinician takes on the role of active listener [37] and collaborative communicator [38]. The concept of collaborative communication hinges on five core tasks: the establishment of a common goal or set of goals toward which collaborative effort is directed; expression of mutual respect and compassion; the development of a complete understanding of differing perspectives within the discussion; ensuring clarity and correctness of the communicated information; and the management of intra- and interpersonal processes affecting communication, reception, and understanding of information shared [38] (Fig. 8.3).

As a partner within a collaborative and reciprocal model of shared decision-making, the medical care provider strives for a sense of introspective awareness. Personal emotion and values, concern for future regret, and a sense of doubt in recommendations made can deeply affect the tenor of the discussion, alter the presentation of information, and steer the outcome away from the patient's values and goals [35]. It is important to remain mindful that acceptable patient and familial outcomes may differ from the acceptable outcomes the clinician imagines for herself or her loved ones [35, 39]. Furthermore, the clinician must be cognizant of response to patient and familial emotional expression to avoid withholding or tailoring information in a way that might prove misleading. Rather, prognostic disclosure can occur with sensitivity and preserved accuracy, in accordance with the patient's and parents' social and emotional state, in order to serve as a supportive intervention [40].

1.	Establish a common goal, or set of goals that guide a collaborative effort.
2.	Exhibit a mutual respect and compassion.
3.	Develop a sufficiently complete understanding of differing perspectives.
4.	Assure maximum clarity and correctness of what is communicated.
5.	Manage intrapersonal and interpersonal processes that effect how information is sent, received, and processed.

Fig. 8.3 Five core tasks in collaborative communication [38]

Role of Prognostic Uncertainty and Illness Trajectory in Decision-Making

Prognostic disclosure in pediatrics and pediatric oncology has evolved over the course of decades, from a predominant focus on protecting patients and families from painful information, to a growing contemporary acceptance of open communication and the concept of hope as *supported* by prognostic information [41]. Though prognostic disclosure is often an emotion-laden experience, parents of cancer patients want to be informed in order to support ongoing decision-making and to maintain hope [40, 42]. Despite growing dedication to the sensitive and compassionate discussion of prognosis, a high level of prognostic uncertainty still impedes clinician ability to accurately estimate life expectancy [43]. Furthermore, physician inaccuracy in prognostication is typically optimistic, and increasingly so as the duration of the patient–physician relationship lengthens [43]. The uncertainty of prognosis should be discussed with care and honesty in order to best support patient and familial values and overarching goals of care. One such model for discussion of prognostic uncertainty proposes first normalizing future uncertainty as a fixed concept in the human condition, then attending to patients’ and parents’ emotional responses to uncertainty, and finally helping patients and families manage the effect of uncertainty on preserving quality of life and the ability to make decisions based on the information presently known and the goals of care [44]. Refocusing on the present and preserving hope help to ensure that a patient’s goals, sense of meaning, and quality of life remain at the center of daily care.

Advance Care Planning and the Adolescent Patient

Adolescent and young adult patients diagnosed with progressive or terminal cancer require distinct consideration, as they grapple with deep physical, psychological, and emotional challenges presented both by cancer and by coming of age and agency. Adolescents with advanced cancer can participate in complex decision-making processes, including decisions surrounding the end of life, and can understand the consequences of their decisions [45]. Exclusion from desired participation in important discussions risks feelings of isolation, anxiety, and uncertainty in the adolescent patient [46].

Adolescent and young adult decisions are often relationship-based and directed by concern for others [45]. Teens value medical decision-making that is shared with parents and healthcare providers [22, 45, 47]. Adolescents with cancer report that involvement in advance care planning is helpful in reducing distress about future uncertainty and establishing realistic goals for care and quality of life [24, 48]. Adolescent and young adult involvement can also be supportive for parents and surrogate decision-makers, opening a direct dialogue on the goals of the adolescent and allowing family members to form a commitment to honor these goals [24]. At the

same time, the degree of desired involvement of the patient varies on an individual basis [22] and requires careful balancing of principles of truth-telling, nonmaleficence, parental authority, and patient need within the context of an adolescent's world and interpersonal relationships [48].

The clinician navigates a relationship between parents and the adolescent patient, seeking to provide individualized care that operates within the framework of familial dynamics, values, beliefs, and cultural practices, while keeping open channels of communication and support between patient and parents, clinician and patient, and clinician and family. Allowing parents to define their role and their conception of the "good parent" early in the clinician–parent relationship allows sensitivity to family structure and practices. Discussing a patient's worries and fears with parents while relaying that direct discussion with the patient regarding illness may reduce parental and patient suffering and distress and allows parents informed agency. Patients should direct the extent of their involvement in information disclosure, advance care planning, and decision-making. Attention should be paid to establishing a systematic approach to conversations with adolescents early in care. The use of developmentally appropriate, nonjudgmental, compassionate, and concise language, as well as the involvement of a teen's social supports, is a highly important strategy in achieving success during difficult conversations with adolescents [48].

Clinicians should consider establishing a policy of honesty and openness with families early in the care relationship, setting the expectation that this approach will continue even if the nature of discussions shifts with progression of disease and reassessment of goals of care. Although truth telling benefits most adolescents and their families, discussing the patient's and parents' hopes, worries and goals of care may identify those for whom it is not beneficial [48]. Ideally, with time, relationship-building, compassion, and sensitivity to the patient's and family's beliefs and values, a structured path for difficult conversations will be forged.

The Pediatric Patient, Decision-Making, and the Concept of Capacity

Children and young adults are recognized to have moral standing and the right to self-determination, and therefore have the right to take an active role in their own medical care [21]. In upholding this ethical standard, clinicians are compelled to engage young patients in care. Pediatric patients should be involved in health-related decision-making, in accordance with their development, using a patient- and family-centered approach [12]. This involvement becomes particularly important when the decisions to be made have no one "right" answer and depend greatly upon the patient's goals and concept of quality of life [49]. Involving children and young adults in the decision-making process seeks to uphold patient autonomy, facilitate open and honest communication, and improve the patient's understanding of care and participation in goal setting. It also serves to enhance a sense of agency or control over the perceived chaos of the experience of serious illness and respects the

capability of the pediatric patient, allowing for the development of more complex decision-making skills over time [49].

Decisional capacity can be defined as a patient's ability to make informed decisions and requires four key elements: (1) understanding, (2) appreciation of the consequences and significance of the decision, (3) reasoning or weighing the risks and benefits of various options, and (4) choice or the ability to express a value-based decision once made. Decisional capacity depends on the specific decision at hand, and therefore may shift relative to the complexity of the necessary choice [50]. Although, in most cases, pediatric patients are not deemed to have capacity for serious medical decisions, rendering parents the primary decision-makers, this concept is not absolute [13] and depends on the individual patient, the decision at hand, and (in the United States) variable state laws regarding minors' ability to consent for specific medical care or interventions [12].

Children and young adults benefit from involvement in serious conversations and medical decision-making as they, too, seek to create realistic goals for themselves and make sense of the uncertainty inherent in advanced pediatric cancer. Both clinicians and parents are responsible for creating opportunities for conversation with the young patient, seeking patient assent for medical decisions when possible and appropriate. In support of this effort, the clinician might focus on creating an open, supportive space for young patients to express themselves in a medical world often filled predominantly with unfamiliar adults. Allowing young people to approach and process conversations on their own schedule will prove beneficial, as will sensitivity to the questions, worries, and emotions of the patient. Clinicians and parents, as active listeners, can support children and young adults as they navigate illness, their sense of self, a range of emotions, and their interpersonal relationships, and establish their own framework for involvement in medical care and decisions [25].

Divergence in Goals-of-Care and Decision-Making

The experience of coping with advanced cancer brings with it a wide range of complex emotions and thoughts and a contemplation of personal values and goals that affect healthcare decisions, interpersonal relationships, and interactions. Within this, conflict or disagreement can arise surrounding medical decision-making and planning for the future. Though a divergence in views can occur between other members of the medical team, at present, focus will be placed on the clinician–patient–parent dynamic.

A diagnosis of terminal cancer and the imminent and tragic loss of the life of one's child often causes a parent to hope for a cure, despite prognosis. This hope might pervade parental decision-making, in contrast to a clinician's hope to shift toward a goal of comfort. Conversely, a clinician might propose additional cancer-directed therapy that does not coincide with parents' or patient's goals of care. The young adult patient, in particular, might express goals that differ from both parent

and clinician. Differences in opinions and beliefs, or instances of miscommunication, occur commonly within medicine and require a purposeful approach to mediation.

One such approach emphasizes addressing conflict directly, shifting focus toward the perspective of the patient and family, allowing for productive, rather than destructive, communication [51]. This approach entails the following: (1) recognizing that there is disagreement; (2) identifying a nonjudgmental starting point for discussion; (3) listening to and acknowledging the other person's viewpoint; (4) identifying the reason for conflict, and reframing it as a shared interest; (5) brainstorming options that address a shared concern; and (6) identifying options that incorporate the needs of all those involved [51]. Rather than seeking to convince a family, the clinician might focus on listening in order to understand their differing perspective and thus, work toward improved communication with the patient and family [52]. Conflict will likely not be resolved following a single conversation; however, each conversation presents the opportunity to move constructively toward resolution and toward strengthening the clinician–patient–parent relationship. When conflict resolution does not appear possible, assistance may be sought in external resources, including ethics consultation, risk management, and the involvement of another trusted healthcare provider [52].

Advance Care Planning for the End of Life

Legacy

Legacy-making is defined as a creation or performance that is remembered and that can occur either intentionally or serendipitously. Children with advanced cancer or another serious illness perceive illness and know when they are dying [53]. Similar to adults, children may attempt to put their affairs in order, may worry about and try to protect their loved ones, and will hope to be remembered [54]. The meaning, memory-making, and spirituality inherent in the ritual of the legacy project allow children and young adults to assuage these worries [55]. The act of legacy-making has been associated with an increased sense of dignity, purpose, meaning, and will to live and an improvement in suffering and depression [55]. Children and young adults find legacy work to be an outlet for self-expression and for communication about life and death. This type of project has been associated with distraction from pain and negative thoughts and reduction in caregiver stress. Legacy creation allows children with serious illness to affect the lives of others, prepare for death, and provide comfort and inspiration to loved ones [53]. Loved ones will have a tangible symbolic object, a conduit for open communication, and a means for coping with both childhood illness and death [53].

Projects may take any shape, including the creation of artwork, poetry, stories, songs, memory books, hand and foot molds, photographs, and videography.

Activities can include making a life review, taking a meaningful trip, writing letters, delegating belongings to loved ones, or meeting or talking with an important person. Patients and their families may view participation in research both in life and after death as a part of the child's legacy [56]. Although legacy work often occurs as a child nears the end of life, these projects can have greater impact when initiated early in serious illness and should be considered following diagnosis [53]. The medical care provider is in a unique position to consciously recommend and engage in legacy work with patients and can consider this very important work a part of the advance care planning effort and a means to involve the child and young adult in developmentally appropriate reflection. Involvement of child life experts, social workers, psychologists, and other team members who have a special bond with the patient will further enrich legacy work [55].

As in all work in advance care planning and with children with advanced cancer, openness and sensitivity to patients' and families' beliefs and values guide a clinician's approach to legacy-making. For some family members, legacy projects raise painful emotions. In some cases, parents interpret legacy-making as an indication that the end of life is near and, therefore, choose not to participate or feel reluctant to have their child participate [53]. Pediatric patients themselves may feel hesitant or may not want to participate in legacy-making. In such a situation, reframing to focus on the patient's life review and on serendipitous legacies already created may open the door to both intentional legacy work [55] and to meaningful reflection that positively benefits both children and their families.

Location of Care at the End of Life

Planning for the end of life and preparing for death allow families the chance to focus on meaningful time together and minimize intrusive medical interventions in sacred moments [10]. The process of advance care planning encompasses planning for the location of care at the end of life and at death, allowing both the young patient and parents to make an informed decision based on their wishes, beliefs, and customs. Although most children in the United States who die from cancer die in the hospital, the opportunity to plan the location of death may actually be more significant for a patient and family than the actual place of death [57]. Parental preparedness is cited as a significant factor in high-quality end-of-life care, and those parents presented with the chance to plan express less decisional regret surrounding place of death, regardless of the chosen location [57]. Therefore, planning for location of the end of life may reduce the risk of complicated grief. Families given the option most often choose home as the child's place of death, followed by the hospital where they received care; freestanding pediatric hospices are chosen the least often [58].

In deciding the location of death, patients and families often consider where they want to spend their precious remaining time together in the most meaningful way. The wishes of the child and young adult are strong determinants of the planned

location, as are hopes for safety and security, the support of trusted healthcare providers, the availability of specialty care, and understanding of the prognosis [59]. As such, the healthcare provider has the responsibility *not only* to engage in a timely discussion on prognosis and desired location of death but also to thoroughly explore resources available to facilitate patient and family goals for end-of-life care [60]. This might mean working closely with a home care or home hospice agency to provide comprehensive, holistic pediatric community-based palliative and hospice care [61], or providing easily accessible and consistent pediatric palliative care services. It may also entail creating an appropriate environment within the walls of a busy hospital [57, 59, 62]. Instances will arise in which the preferred location for end-of-life care and death become challenging, requiring a reevaluation and potential shift in plan; yet, maintaining open and honest communication throughout this process will allow continued focus on patient and family values and patient comfort.

Resuscitation

The implementation of formal orders to forgo cardiopulmonary resuscitation (CPR) first occurred in the 1970s in the wake of newly established resuscitation methods and reports in medical literature describing increased suffering and prolongation of death in situations in which CPR had been deemed unlikely to be beneficial [63]. In 1994, the American Academy of Pediatrics published guidelines on forgoing life-sustaining medical treatment, including CPR and “all interventions that may prolong the life of patients,” particularly when goals of care are focused on comfort [64]. CPR refers to the administration of chest compressions, vasoactive medications, and defibrillation, in conjunction with the initiation of mechanical ventilation. Orders to limit these interventions are termed Do-Not-Resuscitate (DNR) orders, or, in an effort to highlight the limited efficacy of resuscitative efforts, Do-Not-Attempt-Resuscitation (DNAR) orders [63].

Advance care planning, as a whole, describes an ongoing process of decision-making couched in the goals of care of the patient and parents, rather than the singular completion of a document detailing resuscitative planning or the instatement of a DNR order. A parent’s understanding that a child no longer has a realistic chance for cure is often delayed when compared to that of the child’s primary oncologist [65], and discussions about death with the patient and family often do not occur until the last month of life [66]. Further, initial discussions on resuscitation goals often take place during acute illness or when death has become imminent [67], limiting the patient’s ability to participate [68]. In contrast, timely discussion of resuscitation during a period of medical stability, and pre-emptive contemplation of goals should a patient’s condition worsen or improve, seeks to prevent suffering at the end of life and prolongation of the dying process when no further curative interventions remain. Early discussions may not result in a formative decision, and decisions made may shift over time in accordance with the patient’s clinical condition [69]. However, early discussion allows families the time to prepare for the

worst while continuing to hope for the best. Discussion of resuscitation requires the simultaneous and ongoing discussion of patient prognosis and familial goals of care. Parent, patient, and clinician decisions surrounding implementation of a limitation of resuscitation are guided by the hope to improve quality of life and quality of death [33].

The implementation of a DNR order or a limitation in resuscitation is relevant only in therapeutic decisions made during cardiopulmonary arrest and does not address goals of care beyond this very specific setting. Thus, resuscitation decisions make up only a single component of a greater advance care planning discussion and of a patient's and family's goals for care. Decisions to limit resuscitation in the future should not limit concurrent efforts to actively ease suffering or to initiate or continue interventions that seek to uphold goals of care in the prearrest and present state [67].

Use of Artificial Nutrition and Hydration, Blood Products, and Antibiotics at the End of Life

In addition to resuscitation, other interventions, including the use of artificial nutrition and hydration, blood products, and antibiotics, should be discussed as a part of the advance care planning process. Though these interventions are frequently instrumental in achieving the goals of cure or life prolongation, they may not align with goals of care at the end of life and, in certain situations, may pose greater risk than benefit. The AAP supports withholding and withdrawing medical interventions when expected burdens of the intervention outweigh potential benefits, in conjunction with parental decisions made in consultation with the medical team [70].

Artificial nutrition and hydration in the end stages of cancer may no longer provide comfort and can prolong the dying process. Medically administering fluids at the end of life can result in dyspnea, edema, skin breakdown, increased infection risk, electrolyte disturbance, thrombosis, and pain [70]. Discontinuing these interventions may improve comfort by decreasing respiratory secretions, cough, edema, nausea, vomiting, urinary output, and metabolic rate [70]. Furthermore, fasting has been associated with an analgesic effect produced via release of endorphins and resulting in feelings of well-being [71], as well as ketone production, resulting in hunger reduction and improved clarity of thought [72]. Dry mouth is the most common symptom associated with the suspension of artificial hydration and may be relieved by sips of fluids, artificial saliva, lip balm, and ice chips, among other methods [73]. The transition from conceptualizing nutrition and hydration as life-sustaining, to viewing it as a potential source of discomfort is challenging, particularly given the frequent emotional, cultural, and traditional practices associated with feeding a loved one. In caring for a family whose child is at the end of life and no longer receiving nutrition and hydration, a clinician might work to ease this distress through clarity of information, emotional support, and prompt attention to signs of the child's discomfort [74].

The palliative use of transfusion in young patients with advanced cancer benefits those experiencing dyspnea, weakness, fatigue, headache, or bleeding [75, 76] in the setting of anemia or thrombocytopenia. Fatigue, in particular, has been described as a source of high levels of distress in children with advanced cancer [77]. The decision to proceed with or to forgo transfusion of blood products is dependent on the individual goals of the patient and family and the balance of expected risks and benefits of the transfusion. A pediatric patient with advanced disease who is seeking quality time with loved ones and time to complete legacy projects may benefit from symptom management through transfusion, particularly if transfusion is accessible and does not require prolonged hospitalization. However, as the end of life nears, transfusion may represent a greater burden than benefit, contributing to fluid overload [78], and may be deemed invasive, and therefore inconsistent with goals of comfort.

Pediatric patients with advanced cancer are at high risk of infection because of suppressed immune function. Antibiotic use at the end of life must be considered in the context of the individual patient, familial goals of care, and the potential risks and benefits of proposed therapy [79]. Although antibiotic initiation may prolong life by resolving infection and may decrease the discomfort associated with infection-related symptoms [80], it also poses potential burdens of medication-related side effects, the need for invasive lines for administration and laboratory tests, such as blood cultures [81], and prolongation of the dying process [82].

Cumulatively, treatment decisions on implementing artificial nutrition and hydration, blood transfusion, and antimicrobial use in a young patient at the end of life are made on an individual, goal-derived basis. They are analogous to one another in the need to weigh burden with benefit within the context of patient and family goals, under the guidance of medical expertise. These decisions require the support of the medical team around the family, beginning in the contemplative stages of advanced care planning, and extending through a patient's final days.

Cancer-Directed Therapy

Parents of children with advanced cancer often hold dual goals of care in synchrony—lessening suffering and extending life [14, 65]. Although cancer-directed therapy had not historically been considered to be a part of intensive palliation and symptom management for advanced disease [83], that view has now expanded to encompass cancer control and meet nuanced patient care goals. When goals of care are no longer curative, patients and families might consider enrollment in a phase 1 or 2 clinical trial [84] or initiation of a second-line or alternate chemotherapy agent, in addition to focus on symptom-directed care. Frequently, seeking cancer- and symptom-directed therapies and supportive measures becomes integral to the

self-designated parental role, cementing the importance of the concurrent provision of cancer care [31]. Significantly, in the final 3 months of life, mild cancer-directed therapy (oral, outpatient, or minor procedure) can be associated with improved psychological well-being in children [77], hence potentially contributing to improved quality of life.

Although cancer-directed therapy may have a role in supporting a patient's quality of life, extending life, and supporting parental responsibility, such benefits occur in a setting in which continued pursuit of therapy corresponds with the patient's and family's hopes and goals, with medical recommendations. Healthcare providers are obligated to provide prognostic information to the best of their ability and to allow patients and families to make an informed decision surrounding care at the end of life. Often, when a clinician and parent recognize together that no further curative options remain, care becomes increasingly tailored to lessening suffering, and the young patient is less likely to receive cancer-directed therapy in the last month of life [65].

Autopsy and Organ Donation

Young patients with cancer and their families may consider both autopsy and organ donation as a part of a legacy [46]—a form of altruism that might allow other children and families to avoid similar suffering and loss or convey a sense of unity with families facing the same illness [85]. Through autopsy, bereaved parents might receive additional information about the patient's illness and cause of death. In some cases, information gained through autopsy offers solace in grief and a sense of meaning [85, 86]. Similarly, though cancer is often a contraindication to organ donation, the donation of corneal tissue and heart valves is commonly possible and may be perceived in a positive light by patients and families as part of an altruistic legacy [22, 87].

The discussion of both autopsy and organ donation is difficult and may be deferred as clinicians seek to reduce distress in patients and families [88]. Bereaved parents have indicated a preference for discussion of autopsy only after it has become clear that cure is no longer possible. Conversation on autopsy should be approached sensitively, bearing in mind the pain of anticipated loss. Such discussion should be undertaken by a clinician with whom the family shares a relationship, when possible, and should be informational, indicating the details of the procedure, whether autopsy would help other children in the future, whether it would help the medical team in learning about a child's cancer, and when and how parents might receive results [85, 88]. Most importantly, approach to discussing autopsy and organ donation with patients and families occurs on an *individualized* basis, with utmost sensitivity to religious beliefs, cultural practices, familial traditions, and patient and family hopes and readiness.

Practical Tools in Advance Care Planning

Pediatric Advance Care Planning Documents

This chapter champions involvement of the pediatric patient in the process of advance care planning while reinforcing the importance of clinicians' recognition of a patient's developmental stage, readiness to participate in advance care planning discussions, and familial beliefs and values. The advance directive document is a tool that can be used to facilitate a pediatric-specific approach to identifying a patient's goals of care, healthcare decisions, and conception of end of life.

The Patient Self-determination Act of 1991 mandates that all adult patients who are hospitalized or receiving long-term care receive information on advance directives and that their preferences be documented during hospitalization or long-term care admission [89]. Legally, these requirements do not pertain to most pediatric cancer patients; however, they emphasize the importance of structured, normalized advance directive use in lending voice to the preferences of the individual in anticipation of a time in which he or she is no longer able to participate actively in decision-making [90]. Adolescents have been granted legal rights in certain U.S. states to make medical decisions pertaining to routine medical care, pregnancy, substance abuse, sexually transmitted infections, parenthood, mental healthcare, marriage, homelessness, and other issues. End-of-life care has not been addressed through policy, and legal decisions have been made on a case-by-case basis, with focus placed on the best interests of the adolescent and the adolescent's capability to decide to forgo medical interventions at the end of life [91]. Given that children as young as 3 years may be aware of their prognosis, those as young as 10 years may be able to participate in discussion and decisions surrounding end-of-life care, and those as young as 14 years may have an adult-level understanding of diagnosis [22, 92], it becomes the responsibility of the medical care team to provide the pediatric patient early opportunity to document advance care plans.

Advance directives can be divided into two categories based on legal status: statutory directives, which include a living will or durable power of attorney, and non-statutory advance directives, which identify healthcare preferences or healthcare proxy in written or oral form [93]. A written or orally documented advance directive might identify a proxy, or surrogate, to make decisions based on the patient's preferences and best interests and might also delineate a patient's healthcare preferences in specific medical situations.

To proactively approach the pediatric advance directive, multiple pediatric-specific tools have been created. These include "Voicing My CHOICES™," "My Wishes," and "The Advance Care Planning Readiness Assessment" (Fig. 8.4). The adult advance care planning document, "Five Wishes," is also useful with adolescents and young adults [94]. The readiness assessment poses three questions to gauge a patient's ability and interest in engaging in advance care planning discussions: (1) would talking about what would happen if treatment is no longer effective be helpful?; (2) would talking about medical care plans in advance be upsetting?; and (3) would you feel comfortable talking or writing about what would happen if treatments are no

longer effective? [95]. “Voicing My CHOICES™,” particularly, was designed through feedback provided by adolescents and young adults about their preferred method and format for documenting expression of wishes for treatment, care, support, and how they hope to be remembered after death [46]. It depicts how the patient would like to be supported, comforted, and identify surrogates. It details life-support preferences, the patient’s spiritual wishes, addresses how the patient would like to be remembered by family and friends, and includes notes to loved ones [95].

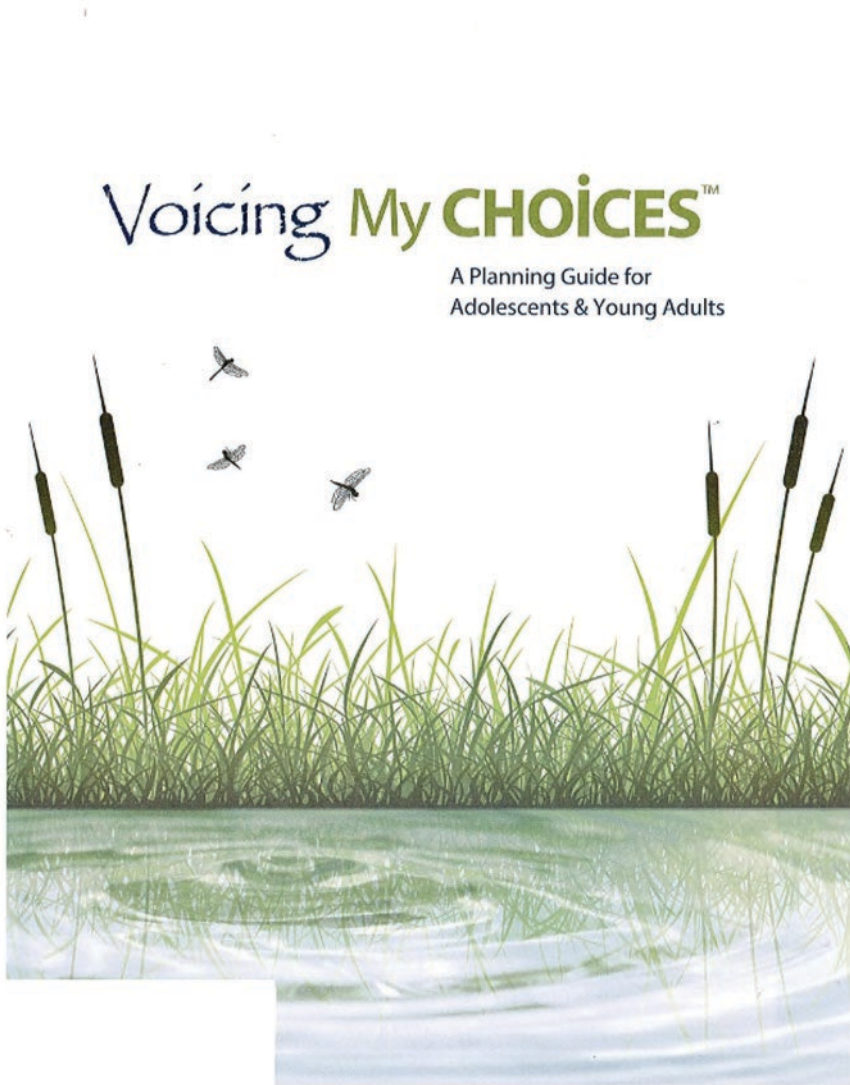


Fig. 8.4 Pediatric advance care planning sample tools. Copyright Aging with Dignity. All rights reserved



Fig. 8.4 (continued)

Involvement of the patient in advance care planning strengthens the patient's trust in family and in the healthcare team and restores the patient's voice, sense of self, and independence [46]. Working through an advance care document with a trusted health-care provider allows engagement in discussion, clarification of the document, and support through emotionally challenging sections of the document [95]. Furthermore, when a family-centered approach to the advance directive is

implemented, the active involvement of both pediatric patient and parent, or surrogate decision-maker, improves openness of communication within a family, increases congruence in patient and parent goals of care, reduces the burden of surrogate decision-making, and enables patient empowerment and preparation [24].

Orders for Life-Sustaining Treatment

Medical or physician orders for life-sustaining treatment (MOLST or POLST) are standardized, transferrable forms delineating a patient’s treatment preferences in several common life-threatening circumstances. An example of such a form can be found in Fig. 8.5. As medical orders, the MOLST or POLST form serves a separate

Directions for Health Care Professionals

Completing POST

Must be completed by a health care professional based on patient preferences, patient best interest, and medical indications.

To be valid, POST must be signed by a physician or, at discharge or transfer from a hospital or long term care facility, by a nurse practitioner (NP), clinical nurse specialist (CNS), or physician assistant (PA). Verbal orders are acceptable with follow-up signature by physician in accordance with facility/community policy.

Person with DNR in effect at time of discharge must have POST completed by health care facility prior to discharge and copy of POST provided to qualified medical emergency personnel.

Photocopies/faxes of signed POST forms are legal and valid.

Using POST

Any incomplete section of POST implies full treatment for that section.

No defibrillator (including AEDs) should be used on a person who has chosen "Do Not Attempt Resuscitation".

Oral fluids and nutrition must always be offered if medically feasible.

When comfort cannot be achieved in the current setting, the person, including someone with "Comfort Measures Only", should be transferred to a setting able to provide comfort (e.g., treatment of a hip fracture).

IV medication to enhance comfort may be appropriate for a person who has chosen "Comfort Measures Only".

Treatment of dehydration is a measure which prolongs life. A person who desires IV fluids should indicate "Limited Interventions" or "Full Treatment".

A person with capacity, or the Health Care Agent or Surrogate of a person without capacity, can request alternative treatment.

Reviewing POST

This POST should be reviewed if:

- (1) The patient is transferred from one care setting or care level to another, or
- (2) There is a substantial change in the patient's health status, or
- (3) The patient's treatment preferences change.

Draw line through sections A through D and write "VOID" in large letters if POST is replaced or becomes invalid.

COPY OF FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED.

Fig. 8.5 State of Tennessee physician order for scope of treatment [104]

A COPY OF THIS FORM SHALL ACCOMPANY PATIENT WHEN TRANSFERRED OR DISCHARGED			
Tennessee Physician Orders for Scope of Treatment (POST, sometime called "POLST")		Patient's Last Name	
This is a Physician Order Sheet based on the medical conditions and wishes of the person identified at right ("patient"). Any section not completed indicates full treatment for that section. When need occurs, <u>first</u> follow these orders, <u>then</u> contact physician.		First Name/Middle Initial	
		Date of Birth	
Section A <i>Check One Box Only</i>	CARDIOPULMONARY RESUSCITATION (CPR): Patient has no pulse <u>and</u> is not breathing. <input type="checkbox"/> Resuscitate (CPR) <input type="checkbox"/> Do <u>Not</u> Attempt Resuscitation (DNR / no CPR) (Allow <u>N</u> atural Death) When not in cardiopulmonary arrest, follow orders in B, C, and D.		
Section B <i>Check One Box Only</i>	MEDICAL INTERVENTIONS. Patient has pulse <u>and/or</u> is breathing. <input type="checkbox"/> Comfort Measures Only. Relieve pain and suffering through the use of any medication by any route, positioning, wound care and other measures. Use oxygen, suction and manual treatment of airway obstruction as needed for comfort. Do not transfer to hospital for life-sustaining treatment. Transfer only if comfort needs cannot be met in current location. Treatment Plan: Maximize comfort through symptom management. <input type="checkbox"/> Limited Additional Interventions. In addition to care described in Comfort Measures Only above, use medical treatment, antibiotics, IV fluids and cardiac monitoring as indicated. No intubation, advanced airway interventions, or mechanical ventilation. May consider less invasive airway support (e.g. CPAP, BiPAP). Transfer to hospital if indicated. Generally avoid the intensive care unit. Treatment Plan: basic medical treatment. <input type="checkbox"/> Full Treatment. In addition to care described in Comfort Measures Only and Limited Additional Interventions above, use intubation, advanced airway interventions, and mechanical ventilation as indicated. Transfer to hospital and/or intensive care unit if indicated. Treatment Plan: Full treatment including in the intensive care unit. Other Instructions: _____		
Section C <i>Check One</i>	ARTIFICIALLY ADMINISTERED NUTRITION. Oral fluids & nutrition must be offered if feasible. <input type="checkbox"/> No artificial nutrition by tube. <input type="checkbox"/> Defined trial period of artificial nutrition by tube. <input type="checkbox"/> Long-term artificial nutrition by tube. Other Instructions: _____		
Section D <i>Must be Completed</i>	Discussed with: <input type="checkbox"/> Patient/Resident <input type="checkbox"/> Health care agent <input type="checkbox"/> Court-appointed guardian <input type="checkbox"/> Health care surrogate <input type="checkbox"/> Parent of minor <input type="checkbox"/> Other: _____ (Specify)	The Basis for These Orders Is: (Must be completed) <input type="checkbox"/> Patient's preferences <input type="checkbox"/> Patient's best interest (patient lacks capacity or preferences unknown) <input type="checkbox"/> Medical indications <input type="checkbox"/> (Other) _____	
Physician/NP/CNS/PA Name (Print)	Physician/NP/CNS/PA Signature	Date	MD/NP/CNS/PA Phone Number:
	NP/CNS/PA (Signature at Discharge)		()
Signature of Patient, Parent of Minor, or Guardian/Health Care Representative			
Preferences have been expressed to a physician and /or health care professional. It can be reviewed and updated at any time if your preferences change. If you are unable to make your own health care decisions, the orders should reflect your preferences as best understood by your agent/surrogate.			
Name (Print)	Signature	Relationship (write "self" if patient)	
Agent/Surrogate	Relationship	Phone Number ()	
Health Care Professional Preparing Form	Preparer Title	Phone Number ()	Date Prepared

Division of Health Licensure and Regulation, Office of Health Care Facilities, 665 Mainstream Drive, Second Floor, Nashville, TN 37228

Fig. 8.5 (continued)

purpose from an advance directive. Life-sustaining medical treatment is defined as any intervention that prolongs the life of the patient and includes therapies such as mechanical ventilation, CPR, dialysis, antibiotics, parenterally or enterally administered fluids or nutrition, and organ transplantation [64]. The MOLST or POLST form is typically divided into four sections: resuscitation status, preferred level of medical interventions (comfort measures, limited additional interventions, or full treatment), antibiotic therapy preferences, and preferences regarding administration of artificial nutrition [96]. The completion of orders for life-sustaining treatment increases conversations about patient goals and treatment preferences and is associated with a decrease in unwanted emergent resuscitations [97]. In the United States in 2016, a total of 47 states had adopted a POLST program, used predominantly in the care of adults [98]. However, orders for life-sustaining treatment are increasingly being implemented in the pediatric setting, in some cases by law, for hospitalized children [97]. The standardized use of forms describing orders for life-sustaining treatment in pediatrics normalizes the process, but requires broader clinician training and implementation of advance care planning discussions.

MOLST or POLST forms are transferrable between healthcare settings, allowing for use in the home by emergency medical services (EMS), in school, and in the emergency room. This allows patients and families the assurance that treatment preferences will be respected regardless of their environment. Use of a MOLST or POLST form is particularly effective when coupled with dissemination of a family's most recent treatment preferences to the healthcare team in a clear and simple manner [38, 99]. Within the school environment, the AAP recommends that both pediatricians and parents meet with school, EMS, and legal counsel to discuss goals of in-school care, with review of goals of care and the child's medical condition at least every 6 months [100]. In implementing a MOLST or POLST form, treatment preferences can be changed at any time based on the decision of a parent or surrogate alongside the patient and in accordance with the trajectory of illness and clinical situation.

Withholding and Withdrawing Medical Interventions

Ethical Approach to Withholding and Withdrawing Medical Interventions

Children and young adults with cancer for whom cure is no longer possible and goals of care have transitioned to comfort may decide, along with parents and the healthcare team, to limit or forgo life-sustaining medical treatment. In the United States, most pediatric deaths in hospitals occur after critical care interventions are forgone [70]. This decision, made in alignment with patient and familial values and medical recommendations, is nonetheless often emotionally, socially, and spiritually challenging for family and medical providers, rendering an

understanding of ethical guidelines, such as the seminal guidelines provided by the AAP for withholding and withdrawing life-sustaining medical treatment, essential for clinicians.

Importantly, there is no ethical or legal difference between discontinuing a medical intervention that has already begun and withholding an intervention not yet started, however, it is important to acknowledge with families that these actions may “feel” very different [64]. The omission of a life-sustaining medical intervention is considered an active decision, equivalent to the decision to discontinue a medical therapy. A medical treatment that is no longer beneficial should be discontinued to prevent associated harm to the patient [64], upholding the ethical tenets of beneficence and nonmaleficence. For a patient with advanced cancer, an intervention might be initiated as a part of a timed trial, for a defined period of time, in order to ascertain potential medical benefit. Clinicians’ fears surrounding withdrawal of therapy should neither preclude initiation of a potentially beneficial therapy nor should they prohibit discontinuation once the therapy has become nonbeneficial. The course of treatment throughout illness is determined by the goals of the patient and family, the best interests of the patient, and the potential benefits and burdens of available treatment options [64]. It is the clinician’s responsibility to inform the patient and family of potential therapeutic options and to advise families on the recommended choice for the individual child. A clinician who is unable to participate in limiting or withdrawing life-sustaining treatment, despite patient and family goals, is responsible for facilitating transfer of care to a more appropriate provider [64].

Parents provide consent for most medical treatment for children who are not legally considered either emancipated or mature minors, yet the expressed wishes of the child regarding life-sustaining medical treatment are given considerable weight. The child or young adult should be included in goals-of-care discussions pertaining to potential interventions, in accordance with the child’s development, capacity, desired level of involvement, and family values. Young adults who have been legally emancipated, or determined to be mature minors, can themselves decide to limit medical interventions [64].

Potentially Inappropriate Medical Interventions and Medical Futility

The definition of medical futility has evolved over decades and is now interpreted narrowly as being a medical intervention that *cannot* accomplish an intended physiologic goal [101]. It is accepted that clinicians should not offer or provide futile medical interventions in the rare circumstance that such an intervention is requested. Conversely, ethical conflict or controversy in critical care and end-of-life situations often centers on the continuation or initiation of a medical intervention considered by the clinician to be nonbeneficial or potentially harmful. In such a situation, the

term “potentially inappropriate” is used to define medical interventions that pose some chance of accomplishing the hoped for physiologic effect, but are not recommended or are refused by the clinician because of underlying ethical concerns. Ethical concerns may include an extremely low likelihood that the intervention will be successful, concern surrounding the likely outcome or intended goal or the high cost of the intervention [101]. Notably, potentially inappropriate medical interventions can be differentiated from those defined as medically futile, in that clinician recommendations depend on value-laden judgments regarding what is considered appropriate treatment in advanced illness [101] and on available prognostic information. Within the pediatric intensive care setting in the United States approximately 6.5% of pediatric patients receive broadly defined potentially inappropriate medical interventions [102]. In the United Kingdom, potentially inappropriate medical treatment occurs in an estimated 13% of pediatric critical care cases [103]. These situations are ethically and emotionally challenging for all involved, requiring a fine balance of patient and surrogate autonomy with a clinician’s obligation to uphold a patient’s best interest and to prevent harm within potentially time-limited clinical circumstances.

Often, an approach that focuses on collaborative, proactive communication, prognostic honesty, and shared decision-making is best equipped to prevent intractable conflict. The American Thoracic Society Policy on Responding to Requests for Potentially Inappropriate Treatment in Intensive Care Units advocates institutional strategies to improve communication, including end-of-life communication education, conflict-resolution, and emotional support skill-building, as well as the early involvement of expert consultants, namely ethics and palliative care consultation [101]. In the event that formal conflict-resolution measures are required, the recommended institutional approach is as follows: (1) consult mediation experts to continue collaborative communication and negotiation; (2) provide notice of the mediation process to surrogates and family; (3) provide a second medical opinion; (4) Provide a review of the case by an interdisciplinary hospital committee; (5) facilitate an opportunity for transfer to another medical facility, when clinically possible; (6) provide information on pursuing external judicial appeal to surrogates and family members; and (7) implement the resolved clinical decision [101].

Notably, two specific types of requests for treatment fall outside the accepted categorization of either futile or potentially inappropriate medical treatment. These include legally proscribed and legally discretionary treatments, which are interventions that may in fact result in the desired treatment goal, but are specifically prohibited by law, or for which judicial precedent or public policy permits limitation of use [101]. Examples include manipulating the process of organ allocation or administering medication for the purpose of physician-assisted death in a U.S. state in which such action is illegal [101]. Though such requests will occur exceedingly rarely, exploring the patient’s or surrogate’s hopes and goals in the request, clearly explaining the reason for refusal, exploring alternative options, and providing ongoing social and emotional support will prove beneficial.

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