

# Respecting End-of-Life Treatment Preferences

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Most patients eventually must face the process of planning for their future medical care. However, few Americans have a living will or a durable power of attorney for health care. Although advance directives provide a legal basis for physicians to carry out treatment using a health care proxy or a living will, they also should reflect the patient's values and preferences. Family physicians are in a position to integrate medical knowledge, individual values, and cultural influences into end-of-life care. Family physicians can best respect the autonomy of patients by allowing the patient and family to prospectively identify relevant health care preferences, by sustaining an ongoing discussion about end-of-life preferences, and by abiding by the decisions their patients have made. (*Am Fam Physician* 2005;72:1263-8,1270. Copyright © 2005 American Academy of Family Physicians.)

► **Patient information:** A handout on advance directives, written by the authors of this article, is provided on page 1270.

Improvements in medical and life-sustaining technologies have contributed to extending human life expectancy. However, predicting treatment preferences at the end of life is complicated by the emotions of the patients and their families, especially given the complex nature of illness and the medical capability to sustain life.<sup>1</sup> Formal discussions about end-of-life care often do not occur before severe illness or impairment.<sup>2,3</sup> Even with end-of-life planning, the inaccessibility of transferring advance directives from ambulatory to acute care settings is an ongoing problem.<sup>4</sup>

In one case study,<sup>5</sup> a patient with advanced malignancy had indicated to her outpatient physician that she did not want cardiopulmonary resuscitation for cardiac arrest. While hospitalized, the patient developed a life-threatening pulmonary embolism, which was not specifically mentioned in the medical directive. Because the patient was not in cardiac arrest, the hospital physician felt obligated to begin mechanical ventilation and vasopressors. The patient was unable to explain her wishes because of her cardiopulmonary compromise. Although clear medical directives were given regarding the patient's care, there was little documentation about the patient's values and how they would influence the medical care she would want.

A recent review<sup>6</sup> noted several common pitfalls in establishing plans of care for patients

who are no longer able to make decisions. Steps for working with families to make appropriate and ethically informed choices were provided. There are steps that family physicians can take that may help establish patients' values and preferences while patients still have decision-making capacity.

## Patient Self-Determination Act

A 1990 U.S. Supreme Court decision<sup>7</sup> drew attention to the issue of life-sustaining treatments for patients who are unable to make their own decisions. This case affirmed a state's right to require "clear and convincing evidence" for wishes concerning life-sustaining medical care.<sup>8</sup> The Patient Self-Determination Act (PSDA)<sup>9</sup> was written in response to the case. The PSDA requires hospitals, nursing homes, and health care programs to ask patients about advance directives and then incorporate the information into medical records.<sup>9</sup> *Table 1* is a list of terms and definitions associated with advance directives.<sup>8,10,11</sup> The living will, a written advance directive, allows a competent person to indicate his or her health care preferences while cognitively and physically healthy. A living will may list medical interventions the patient would like withheld or withdrawn when he or she becomes unable to communicate.<sup>10,11</sup> Another type of advance directive, the durable power of attorney for health care, allows persons to designate a proxy (or

## SORT: KEY RECOMMENDATIONS FOR PRACTICE

<i>Clinical recommendation</i>	<i>Evidence rating</i>	<i>References</i>
Patients should be given the chance to review decisions and have interim discussions with their physicians to improve the stability of their end-of-life choices.	B	26
Patients should be offered a family-based decision-making plan because some cultures prefer family decision making over the individualist approach inherent in conventional written directives.	B	32, 34
Patients with chronic and terminal disease, such as acquired immunodeficiency syndrome, cancer, and end-stage lung disease, should be offered advance directives that are specific to their disease.	C	35

*A = consistent, good-quality patient-oriented evidence; B = inconsistent or limited-quality patient-oriented evidence; C = consensus, disease-oriented evidence, usual practice, expert opinion, or case series. For more information about the SORT evidence rating system, see page 1154 or <http://www.aafp.org/afpsort.xml>.*

surrogate) to make decisions for them if they become incapacitated.

Although the PSDA mandates that patients be asked about their advance directive status upon admission to the hospital, it does not require hospitals or individual physicians to offer patients an opportunity to complete an advance directive. Since the PSDA became effective in 1990, fewer than one in four patients have completed an advance directive.<sup>12</sup> Several studies<sup>1,3</sup> have shown that physicians often do not discuss end-of-life issues or do-not-resuscitate (DNR) orders with their patients, even when patients have serious medical illnesses. Although surveys have shown that patients strongly endorse advance care planning, the execution of these documents remains limited.<sup>13</sup> This may be attributable in part to the minimal institutional change that has resulted from the PSDA.<sup>14</sup> Also, hospitals and physicians have struggled with translating advance directive preferences into orders in hospital records,<sup>3</sup> and the acceptance and precision of verbal preferences varies from state to state. Although verbal discussions are binding in many states, five states require “clear and convincing evidence of patient preferences.” In California, Delaware, Michigan, Missouri, and New York, advance directives must include such evidence regarding a specific condition and/or treatment even if a durable power of attorney states prior general verbal preferences. Therefore, lack of an advance

directive may result in continued medical interventions to preserve life even if the patient may not want such treatment.<sup>15</sup>

### **Patient Autonomy**

Respecting patient autonomy is a primary tenet of Western medical ethics. Advance directives are legally sanctioned instruments that allow competent persons to exercise autonomous control over medical care in anticipation of future incapacity. Similar to informed consent, an advance directive is not the event of signing the written form but an ongoing physician-patient communication based on understanding and voluntary decision making.<sup>16</sup> Just as patients have a right to informed consent or to refuse medical therapy, they also have a right to choose or decline potentially life-sustaining medical therapies.<sup>15,17</sup> The challenge for family physicians is to maintain an understanding of their patients’ values and preferences.

### **Limitations and Challenges**

Examples of barriers that prevent advance directive completion and implementation in the office setting are summarized in *Table 2*. Although most dying patients are cared for in a community setting, nearly all studies evaluate patients in academic hospital settings.<sup>18</sup> A large multicenter study<sup>19</sup> demonstrated shortcomings in end-of-life care for patients in large teaching hospitals. The trial, which used nonphysician interviewers to assess patient preferences in more than 9,000 hospitalized patients, had no impact on physician-patient communication or use of advance directive preferences. Although

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**TABLE 1**  
**Advance Care Planning Terms and Definitions**

Advance directive	Written or verbal documentation in which a person indicates health care preferences while he or she is cognitively and physically able to make decisions. Each state has different regulations for the use of advance directives.
Combination document	An advanced directive that combines elements of a living will and durable power of attorney for health care into one document.
Do-not-resuscitate order	An order that prohibits the use of cardiopulmonary resuscitation in the event of cardiac arrest. Advanced directives do not need to include a do-not-resuscitate (DNR) order, and the patient does not need an advanced directive to have a DNR order. In some states, the DNR order also may be used in outpatient settings.
Durable power of attorney for health care	A written advance directive that assigns one person as a decision-making proxy should the user become incapacitated. The goal is for the designated decision maker to act as the patient's agent in carrying out his or her health care choices in a situation of severe medical impairment.
Living will	A written advance directive in which a competent person indicates health care preferences while cognitively and physically intact. A living will may specify instructions for care (e.g., feeding tubes, mechanical ventilation, surgery) in life-prolonging situations. Living wills take effect when the patient becomes physically or mentally unable to make his or her own decisions and is terminally ill or irreversibly comatose.
Medical directive	A detailed written directive that describes in questionnaire format what type of treatment a person would or would not want in various medical situations. A medical directive can be generic or disease-specific, but it is most useful when it contains specifics that apply to the patient's actual circumstance. Situations often arise that were not anticipated or addressed in the directive. A medical directive cannot document value-based decisions.
Values history	A written directive that offers a series of questions about values related to health care that are to be answered in an open-ended narrative format. A history identifies explicit values and articulates health care preferences based on these values. A history directly addresses patient values by asking questions related to quality of life. It has a section for specific medical care preferences and health care proxy indication. The structure facilitates discussion among the family physician, family, and patient to reflect and review end-of-life planning. The history requires greater introspection by the patient into his or her own values.

*Information from references 8, 10, and 11.*

nearly one third of the patients preferred that cardiopulmonary resuscitation be withheld, 49 percent of these patients did not have a DNR order in their charts, and their physicians were not aware of their preferences. Several other hospital-based studies<sup>20-23</sup> have shown that educational programs and nonphysician interventions do not increase advance directive completion rates.

A separate community-based study<sup>24</sup> showed that primary care physicians used few life-sustaining treatments for dying patients, and treatment decisions were influenced by

living wills and long-term relationships. It is unknown whether physician or nonphysician intervention impacts the outcome of advance directive implementation. Another community-based retrospective study<sup>25</sup> reported an increase in prevalence and adherence after a large community-based advance directive program. Unlike physicians in in-hospital and acute care settings, primary care physicians have an important role in documenting and implementing advance directives.

Predicting future health care choices is difficult in end-of-life planning. When

TABLE 2

**Common Barriers to Assessing Patient Preferences and Suggested Solutions**

<i>Health-disease continuum</i>	<i>Barriers to assessing preferences</i>	<i>Suggested solutions</i>
Young, healthy patient in office for wellness visit	Patient is unable or uninterested in thinking about end-of-life issues or values because it seems too remote, and patient has no experience with decision making. Physician does not feel there is enough time to discuss this at a wellness visit.	Discuss what end-of-life care means and why it is important when assessing general health. Provide patient with information about advance directives to read and discuss at next visit. Readdress end-of-life care briefly at subsequent visits.
Onset of new chronic disease	Patient is overwhelmed with implications of disease and is upset by physician's desire to discuss end-of-life issues. Physician is worried about overburdening the patient by talking about death.	Assess the patient's values about end-of-life care instead of discussing specific treatment preferences. Include family members in discussions about implications of the disease and integrate end-of-life choices into discussion.
Progression of disease	Health care decisions made when the patient was healthy may not be sustained with changes in health or other circumstances.	Revisit discussion about preferences on multiple occasions, especially after major life events or changes in health status.
Implementation of advance directive	End-of-life preferences in living will may be ambiguous.	Reconvene with the patient, durable power of attorney proxy, and the patient's family to address specific questions and goals of care.

compared with actual patient ratings of their quality of life, healthy persons tend to underestimate the quality of life associated with various health conditions.<sup>26</sup>

Declining health has been shown to modify patient health care decisions; however, cancer patients who choose *less* end-of-life treatment are less likely to change their mind over time than patients who initially choose *more* treatment.<sup>27</sup> This finding raises the possibility that patients may not be able to predict

what decisions they would make if diagnosed with a terminal or debilitating illness, causing misconstrued preferences for end-of-life treatment.<sup>28</sup> In one study,<sup>26</sup> stability of end-of-life choices improved if patients were given the chance to review decisions and if they had interim discussions with their physicians. Research also has evaluated the accuracy of surrogate decision making and has revealed discrepancies between the patient's wishes and the surrogate's wishes.<sup>29,30</sup> Again, much of the data use hypothetical scenarios highlighting the difficulty of determining future health care decisions.

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## Diversity and Advance Directives

The influence of culture on advance directives is not fully understood. Some cultures prefer family decision making to the individualistic approach inherent in written directives. The role of culture requires further evaluation, especially in the multicultural environment of Western society. Complicating end-of-life choices are reports that racial and ethnic minorities experience a lower quality of service and are less likely to receive routine medical procedures than are white Americans.<sup>31</sup> Several studies<sup>32,33</sup> report that black patients are more likely than white patients to continue futile therapies, possibly from the fear that refusing aggressive care may lead to compromised care. Patients should be informed that providers will not

abandon them or provide substandard care if they elect to formulate an advance directive.<sup>34</sup> The concept of patient autonomy and informed consent varies among cultures. Certain cultures believe that family members should spare patients the suffering of making their own end-of-life decisions.<sup>32</sup>

Patients with chronic and terminal diseases (e.g., acquired immunodeficiency syndrome, cancer, end-stage lung disease) may consider disease-focused advance directives or conceptual models specific to the disease.<sup>35</sup> In the event of mental illness, a patient would need to write an advance directive while competent to specify decisions he or she would want if mentally incapacitated. Again, the effectiveness of such documents is unclear.<sup>33</sup>

### Advance Directive Planning: A Process Model

Family physicians already integrate the emotional, social, spiritual, and medical aspects into a patient's end-of-life care.<sup>36</sup> The physician-patient-family model of advance care planning is less understood, however.

To promote end-of-life discussions, physicians should initiate communication between patients and families while patients are still relatively well. Patients can then identify their preferences while they are mentally and physically capable. These preferences can be documented in a living will or in a durable power of attorney for health care (as allowed by the jurisdiction of the patient). A collaborative process involving the patient, family members, and the physician can document an advance care plan (*Table 3*<sup>8,10,11</sup>). End-of-life discussions should be continued over time, especially when patients experience changes in health, function, or life events. Implementation would occur when circumstances arrive that are articulated in the advance directive. Any ambiguity would be addressed by reconvening the patient, family members, and physician to review past stated values and preferences to ensure accurate use of the directive.

Research suggests that families are the best sources of patients' values and preferences, and that patients will more likely

choose a loved one to make future decisions for them than someone who might best articulate their wishes.<sup>37,38</sup> The family covenant is one model of applying the physician-patient-family triad to advance directives.<sup>36</sup> The family covenant model is an open-ended, process-based approach to reaching an agreement for future decision making. In the medical lexicon since the early 1990s, this model has been described in end-of-life care and medical genetics settings.<sup>39-41</sup> The initial patient-physician interaction is followed by the involvement of the designated health care proxy and other family members as allowed by the patient, who can further validate the process of advance directive discussions and implementation.<sup>36</sup> This allows the physician and family to be involved in their respective process-based roles for advance care planning.

### Final Comments

The current advance care process has many limitations. A sustained partnership with patients and their families may allow for united rather than divided decision making. This approach, however, has not been tested with a randomized controlled trial.<sup>36</sup>

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TABLE 3

#### Steps for Setting up and Implementing Shared Advance Care Goals

1. Document the patient's values and cultural beliefs within the context of end-of-life planning.
2. Discuss the patient's health care preferences in advance (ideally, as an outpatient) while the patient is mentally and physically capable, and document them in a living will, if possible.
3. Have the patient select someone to serve as a durable power of attorney for health care proxy.
4. Facilitate a shared decision-making process between yourself, the patient, and the family, as permitted by the patient, and document an advance care plan with the group.
5. Repeat step 4 over time, particularly when the patient has major life or health changes.
6. When appropriate, per the preferences of the group, implement the advance directive(s).

Information from references 8, 10, and 11.

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