

# Discussing Advance Care Planning With Elderly Patients

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**Advance care planning maximizes the patient's chances of receiving the care he or she wants and minimizes confusion. Frank discussion, time, and persistence are needed to optimize this shared decision-making process. This article discusses the important components of advance care planning and the recommended documentation.**

**T**he desire to live a long and healthy life has always been a part of human nature. In Greek mythology, human-born Tithonus was made immortal by Zeus so that he and his lover, Eos, could spend eternity together. Tragically for Tithonus, he continued to age and become frail despite his immortality. Ultimately, he became immobile and unable to speak clearly, and he was left alone in a room to spend eternity in a continuing state of physical decline [1].

Thanks in part to improvements in medical science, average life expectancy in the United States is nearly 79 years [2]. However, stories reminiscent of Tithonus' exist in today's health care system. The use of cutting-edge technologies and treatment modalities can prolong life, but it may come at a high cost to the patient and to society.

A well-publicized case that highlights the conflict between prolonging life and focusing on quality of life is that of Terri Schiavo. After suffering a cardiac arrest at her home in 1990, she received cardiopulmonary resuscitation and multiple life-prolonging measures, including artificial hydration and nutrition through a feeding tube. She was declared to be in a persistent vegetative state and never regained a significant level of awareness or interaction with the environment. Over the next 15 years, multiple court arguments were heard as her husband and her parents fought over whether or not to continue artificial nutrition. Finally, in 2005 a Florida court ordered that Schiavo's feeding tube be removed, and she died soon afterward [3]. Her story might have been very different if she had had an advance directive such as a living will that outlined what sort of care she would have wanted to receive under such circumstances. Her story illustrates the difficult choices made across the country thousands of times each day by family members and health care agents.

Advance care planning is a process that can help to avoid the confusion and conflicts that may result if a patient is unable to make known his or her health care wishes and desires at the time when decisions are required. A well-

prepared advance care plan has several key components, including identification of a proxy health care decision maker, clarification of the overall goals of care, and an outline of the specific treatment modalities desired or not desired. When carried out properly, advance care planning helps to ensure that the patient's medical care reflects his or her wishes; advance care planning also decreases depression, anxiety, and stress in family members, thereby improving the family's overall satisfaction with end-of-life care [4].

A study of Medicare claims for nursing home residents with advanced physical and cognitive impairment who died from 2000 through 2007 [5] found that the presence of an advance care plan was associated with a decrease in burdensome transitions. (A transition was defined as burdensome if it occurred within 3 days of death, if the patient was sent to a different nursing home after being hospitalized, or if there were multiple hospitalizations during the last 90 days of life.) Nursing home residents in regions that were in the highest quintile with regard to number of burdensome transitions were more likely than those in the lowest quintile to have a feeding tube, to spend time in an intensive care unit during the last month of life, to have a stage IV decubitus ulcer (pressure ulcer), or to be enrolled in hospice late [5].

Unfortunately, advance care planning is often not discussed with geriatric patients, and advance care plans are often not well documented in patient charts. The National Center for Health Statistics reported that, according to surveys conducted in 2004 and 2007, only 28% of home health care patients and 65% of nursing home patients had an advance care plan on record [6]. Medical providers should be aware that patients often do not bring up advance care planning in their health care encounters [7]. For example, studies published in 1997 [8] and in 1994 [9] found that, among patients who did have an advance directive, the patient's physician was aware of the directive in only about one-quarter to one-third of cases.

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Recent initiatives are trying to increase the frequency and documentation of advance care planning. For example, Medicare now covers discussion of advance care planning as part of a “welcome to Medicare” preventive visit (during the first 12 months of Medicare coverage) as well as during annual wellness visits [10]. Many electronic health record (EHR) systems send reminders to providers to discuss advance care planning; these are similar to EHR alerts regarding cancer screening and immunizations. To discuss advance care planning with patients, providers need to be knowledgeable about and comfortable with the topic, and they need to have enough time to discuss these complicated decisions. However, in today’s fast-paced medical settings, it is becoming more difficult for many providers to find that time, and advance care planning is often deferred until a major health care crisis occurs.

Being able to discuss advance care planning well in today’s environment is truly a key component of the art of medicine; there is no substitute for a frank conversation, eye contact, and patient-provider trust. Shared patient-centered decisions can only be made after fully exploring the patient’s understanding of his or her health care issues, the risks and benefits of various health care options, and personal goals of care. This takes time and may require multiple discussions over several visits. Persistent follow-up is essential to help patients fully explore the complicated and multifaceted aspects of advance care planning and to keep current with possible changes in the patient’s wishes. For example, a recent study of long-term nursing home residents found that 40% of those who requested full-code cardiopulmonary resuscitation when they entered the facility later changed their status to DNR (do not resuscitate) [11].

A point that must be emphasized regarding advance care planning is that it is a process. The conversations that the patient has with his or her family members, designated health care decision maker, and/or health care provider are far more important than the forms that are filled out as a result of these conversations. This point has become more obvious as medical treatments have become more advanced and technical, and it becomes increasingly impossible for the patient to consider and document his or her wishes for every medical option that might be available in every health situation. Also, the line that separates essential, lifesaving treatments from those that merely prolong life can be very unclear. If the overall goals and wishes of the patient in regard to health care are discussed in advanced with a proxy decision maker, choices can be made with less ambiguity and more confidence. After discussing an advance care plan with medical providers, patients need to share this information with their proxy health care decision maker and family members. This open line of communication is essential in order to avoid confusion. In the event that the patient is incapacitated and has not designated a specific proxy health care decision maker, North Carolina law specifies who can make decisions on the patient’s behalf [12]; these individu-

als are listed in Table 1.

Once these discussions have taken place and the patient has had enough time to decide on his or her health care goals and wishes, these choices can be documented in various forms to be made available when needed in the future. Advance directive forms that meet all of North Carolina’s statutory requirements, including living will and health care power of attorney forms, can be found on the Web site of the North Carolina Department of the Secretary of State [13]. It is important to note that these forms must be signed, witnessed by 2 people, and notarized in order to become official [12]. Other documentation methods—such as the popular Five Wishes living will template [14], a locally drafted living will, or a low-literacy living will—can also be used if the state’s witness and notarization requirements are met [12]. Currently, advance care planning documents can be uploaded to a national online registry [15], a North Carolina online registry [13], or both; advance directives stored in these databases can be easily accessed by health care providers [13, 15]. Health care providers can access these documents via the Internet using the patient’s registration number, or they can request the documents over the phone.

Medical providers can also choose to carry out patient preferences by using a DNR form or a MOST (Medical Order for Scope of Treatment) form. [Editor’s note: The MOST form is discussed in more detail in the sidebar by Caprio on pages 349-350.] These forms, which are available online [16], are portable and should travel with the patient to any health care setting to provide clear directives. Put simply, living wills provide guidance for health care decisions, and

**TABLE 1.**  
Persons Who Can Make Health Care Decisions Regarding the Withholding or Discontinuation of Life-Prolonging Treatment Under North Carolina Law [12], in Order of Priority

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|--|
| 1. The patient   |
| 2. The patient’s parent or guardian, if the patient is a minor   |
| 3. A guardian who has been appointed by a court because the patient is incompetent <sup>a</sup>  |
| 4. A health care agent with a valid health care power of attorney, to the extent of the authority granted  |
| 5. An attorney-in-fact appointed by the patient with powers to make health care decisions, to the extent of the authority granted                                    |
| 6. The patient’s spouse  |
| 7. A majority of the patient’s reasonably available parents and children who are at least 18 years of age  |
| 8. A majority of the patient’s reasonably available siblings who are at least 18 years of age  |
| 9. An individual with an established relationship with the patient who is acting in good faith on behalf of the patient and can reliably convey the patient’s wishes |

<sup>a</sup>However, if the patient has a health care agent with health care power of attorney, that agent—not the guardian—makes all decisions authorized by the power of attorney.

*Caprio sidebar*

medical orders provide instructions. The advantages of using the DNR form are that it is very simple and clear, and there is an option to make the form not expire. However, only the resuscitation status of the patient can be delineated by this form. The MOST form contains more choices regarding the overall goals of care, use of antibiotics, and use of artificial hydration and nutrition. In its current version, the MOST form needs to be reviewed and renewed at least once per year to remain valid. This may be a barrier to using the form effectively, and there is a proposal to remove this requirement in the future.

In summary, advance care planning is an essential part of an individual's health care decision making and should be discussed and documented for all geriatric patients. The

goal of such planning is to allow patients to receive the care they want and to minimize confusion and conflicts. Any discussion of advance care planning should include the patient, the proxy health care decision maker or a family member, and the medical provider. Finally, patients should be encouraged to register their advance directives with both the state and national online registries. **NCMJ**

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