# Advance Directives: Navigating Conflicts Between Expressed Wishes and Best Interests

Commentary by SHAIDA TALEBREZA, MD, HMDC, *University of Utah School of Medicine, Salt Lake City, Utah*
ERIC WIDERA, MD, *University of California, San Francisco, California*

Case scenarios are written to express typical situations that family physicians may encounter; authors remain anonymous. Send scenarios to afpjournal@aafp.org. Materials are edited to retain confidentiality.

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## Case Scenario

L.S. is a 70-year-old man with advanced chronic obstructive pulmonary disease. He is intubated and unconscious in the intensive care unit with pneumonia complicated further by acute renal failure. His advance directive, completed seven years ago when he was highly functional, indicates that he wants life-sustaining treatments. He has not updated his advance directive since that time. Members of the medical team are concerned that he has little chance of surviving this hospital stay, and if he were to survive, he is at high risk of significant cognitive deficits that would require long-term skilled nursing care. The patient's wife is listed as his health care agent in his advance directive. She asks how she should proceed with decision making as she struggles to balance what she thinks would be in her husband's best interest and what he has indicated in his advance directive.

## Commentary

Clinicians and surrogates can be faced with challenging decisions when a patient loses the capacity to participate in medical decision making. A significant number of hospitalized and critically ill adults lose decision-making capacity during hospital stays and cannot make treatment decisions.[1-4] A systematic review of the effect of decision making on surrogates found that at least one-third of surrogates experienced significant emotional burden when making medical decisions.[5] The most common negative effects cited were stress when making decisions, guilt over the decisions made, and doubt regarding whether they had made the right decisions.[5] For some surrogates, the burden of decision making persisted for months or even years.[5]

In many cases, advance directives can help guide decision making, yet in some cases, directives may be vague or conflict with what clinicians or surrogates view is in the patient's best interest.[6] For clinicians, it can be challenging to guide surrogates through the decision-making process while attempting to balance the best interest of the patient and avoiding significant negative emotional impact on the surrogate. Clinicians can strike this balance by (1) knowing the key elements of advance care planning that can be conducted with patients before they lose decision-making capacity and (2) having an approach to medical decision making in place for when patients lose decision-making capacity and their previously expressed wishes appear to conflict with best interest. Key terms for navigating decision making at the end of life are defined in *Table 1*.[7-9]

### ADVANCE CARE PLANNING

Advance care planning involves meeting with patients and their surrogates to ensure a shared understanding of diagnosis, prognosis, treatment options, and relevant values and goals, and to establish plans for future treatment that work toward a patient's goals.[7] Although the focus of advance care planning is a high-quality conversation rather than just the creation of a static document, the discussion needs to be accurately documented.[8] A written advance directive or Physician Orders for Life-Sustaining Treatment (POLST) form can be prepared to document aspects of the advance care planning discussions. Because advance care planning is a dynamic process, these documents should be reviewed and updated accordingly. ▶

**Table 1. Key Terms for End-of-Life Decision Making**

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| Advance care planning involves meeting with patients and their surrogates to ensure a shared understanding of diagnosis, prognosis, treatment options, and relevant values and goals, and to establish plans for future treatment that work toward a patient's goals.[7] |
| Advance directives are the written expression, recorded on any type of document, of a patient's preferences for medical care at the end of life. There are two general categories of directives:<br>1. Substantive directives, such as living wills, communicate patients' stated values and treatment preferences should they become incapacitated.[8]<br>2. Process directives, such as health care proxies (also known as health care power of attorney, durable power of attorney for health care, etc.), are used by patients to state whom they choose to make their decisions should they become incapacitated.[8] |
| POLST paradigm is an approach to end-of-life planning emphasizing conversations and shared decision making about the care a patient would like to receive at the end of his or her life. A POLST form then translates the shared decisions into actionable medical orders. Only patients with serious illness or frailty who are unlikely to live longer than one year should have one. An advance directive is more appropriate to make future end-of-life care wishes known.[9] |
| Surrogate decision maker is an advocate for a patient who lacks decision-making capacity. This can be someone the patient has appointed in a durable power of attorney for health care document or, if the patient has not appointed someone, a default person according to a hierarchy usually specified by state law. |

*POLST = Physician Orders for Life-Sustaining Treatment.*

*Information from references 7 through 9.*

One of the most important functions of a written advance directive is designation of a surrogate decision maker. Clinicians can guide patients in choosing an appropriate surrogate who knows the patient well, can make decisions in stressful situations and crises, and makes decisions according to the patient's preferences or best interest rather than his or her own desires.[10] Studies have shown that surrogates' predictions of patient preference often mirror their own preferences[11]; therefore, clinicians can encourage patients to select a surrogate with similar values and preferences.

Once a surrogate has been chosen, it is important for patients to communicate their goals, values, and treatment preferences to this individual. Clinicians can refer patients to a number of decision aids to guide them in this process.[12] Encouraging patients to discuss goals, values, and treatment preferences with their surrogate is important to guide decision making in clinical situations that have not been anticipated, previously discussed, or documented in an advance directive form. If the patient chooses to complete a living will outlining specific treatment preferences, the clinician should discuss and document how strictly the patient would like written choices to be followed and how much leeway he or she would like the surrogate to have in decision making.[6,11] Knowing how much leeway patients have given their surrogate can help determine what should be done in situations when an advance directive contradicts what appears to be in the best interest of the patient.

### WHEN PREVIOUSLY EXPRESSED WISHES CONFLICT WITH BEST INTERESTS

A five-question framework has been proposed to help clinicians determine whether to focus on the patient's previously expressed wishes or on the current best interest of the patient.[6]

*1. Does the urgency of the clinical situation require a time-sensitive decision, are the patient's previously expressed wishes clear, and are POLST documents completed and available?*[6] In emergency situations when clear orders are present (e.g., POLST form), the clinician should follow the expressed wishes of the patient. In nonemergency or emergency situations without clear orders, the clinician should determine with the surrogate what would be in the best interest of the patient. In the case of L.S., the clinical situation is urgent yet not emergent and clear orders are not present. This favors a discussion with the patient's wife about the values and experiences that led her husband to choose life-sustaining treatment, which will help determine what would be in his best interest.

*2. Considering the patient's preferences and goals of care, are the burdens of the intervention likely to overshadow the benefits?*[6] When benefits of an intervention are weak or unlikely, and/or burdens are strong or likely, given the patient's values and goals, the framework recommends against the intervention. When benefits of an intervention are strong and likely, and/or burdens are weak and unlikely, given the patient's values and goals, the framework recommends in favor of the intervention. Discussing L.S.' goals and values with his wife can help determine whether to follow his advance directive or whether his wife should override the document to act in his best interest. If L.S. valued functional independence and had strong preferences about remaining at home rather than in long-term skilled nursing care, the benefits of continued hospitalization would be unlikely and the burdens would be strong. In light of these goals and values, it would be appropriate for L.S.' wife to override ▶

her husband's advance directive and make treatment decisions that would honor his preferences.

*3. Is the advance directive appropriate in the current situation?*[6] In situations where the advance directive fits well, the framework recommends favoring previously expressed orders. In situations where the advance directive fits poorly, the framework recommends favoring the best interest of the patient. L.S.' advance directive may not fit the situation at hand because it was written seven years ago when he was fully functional. This situation favors a discussion with L.S.' wife about what would represent his best interest. Investigating and respecting L.S.' values and goals may be better for approximating what he would choose than previously stated preferences that may have been meant for different circumstances.[6]

*4. How much leeway does the surrogate have to interpret the patient's advance directive?*[6] If the patient has not granted the surrogate leeway in decision making, the framework recommends favoring previously expressed orders. If the patient has granted the surrogate leeway in decision making, the framework recommends favoring the best interest of the patient. Some advance directive forms allow patients to specify if they would like their directive to be followed strictly or to serve as a general guide for their surrogate. When leeway is not indicated, what is known about the patient's previous values and goals needs to provide a compelling reason to modify directives.[6] In L.S.' case, there was no indication of his leeway preferences, and his advance directive is vague; therefore, it would be appropriate for the clinician to investigate L.S.' goals and values with his wife to determine appropriate recommendations.

*5. Is the surrogate acting in the patient's best interests?*[6] When the surrogate represents the patient's best interest poorly or represents his or her own interest, the framework recommends favoring previously expressed orders. When the surrogate represents the patient's best interest, the framework recommends favoring the best interest of the patient. In some cases, surrogates' emotional attachment may be so strong that they are unable to place the patient's best interest above their own.[6] If L.S.' wife stated that she could not let her husband go, the clinician would first need to address her emotions and anticipatory grief before talking with her to determine what would be in her husband's best interest.[6] The authors of this framework also encourage clinicians to recognize possible conflicts of interest, such as the surrogate's expressed desire to receive a pension or inheritance. To mitigate bias that may stem from these situations, they advise the clinician to consult with an ethics expert or contact adult protective services.[6]

*Address correspondence to Shaida Talebreza, MD, HMDC, at shaida.talebreza@hsc.utah.edu. Reprints are not available from the authors.*

Author disclosure: No relevant financial affiliations.

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