
Hope for the Future: *Achieving the Original Intent of Advance Directives*

by SUSAN E. HICKMAN, BERNARD J. HAMMES, ALVIN H. MOSS, AND
SUSAN W. TOLLE

The development of new, life-prolonging medical technologies in the 1970s aroused concern among Americans about the indiscriminant use of aggressive, life-prolonging treatments. Highly public cases such as those of Karen Ann Quinlan and Nancy Cruzan drew attention to the importance of end of life care planning for healthy adults. Advance directives were developed as a way for people to retain control over their medical care by specifying their treatment values and choices and by naming someone to make medical decisions once they were no longer able to do so. Over the past several decades, it has become clear that statutory advance directives alone have not been as successful as originally hoped in giving patients control over their end of life care. However, the initial goal of advance directives was laudable and is worth preserving. Promising new models have evolved from practice and research that move us closer to achieving the original intent of advance directives.

Most traditional advance directives, such as statutory living wills and surrogate appointments, were created by legislative processes that set specific requirements about content and established rules regarding their use to define the rights of adults to forgo medical treatment, to protect providers who honor these decisions, and to appoint an authorized surrogate decision-maker. Statutory living wills are a tool for patients to express preferences about medical treatments that can be used if a person is no longer able to make his or her own decisions. These

documents typically focus on potentially life-prolonging treatments in a very limited set of circumstances, such as when a person is faced with “imminent death regardless of treatment” or is in a “persistent vegetative state.” In most states, a person can also designate a surrogate to make decisions in the event the patient loses decisional capacity. Depending on state law, a surrogate may be called a health care proxy or agent, medical power of attorney, or durable power of attorney for health care.

Limitations of Traditional Advance Directives

Despite the hope that traditional advance directives would ensure that patient preferences are honored, numerous studies have found that only a minority (20 to 30 percent) of American adults have an advance directive and that these documents have limited effects on treatment decisions near the end of life, though more recent research suggests use may be higher at the end of life. In addition to a low completion rate, there are many reasons why traditional advance directives are less successful than originally hoped. These reasons include the following:

- (1) The focus is often on a patient’s legal right to refuse unwanted medical treatments, reflecting the legislative origins of traditional advance directives. Those who complete such documents generally do not receive assistance in understanding or discussing their underlying goals and values.
- (2) The instructions given in these documents and the scenarios provided for discussion are generally either too vague to be clear (for example, “If I am close to death”) or too medically specific to be helpful in com-

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mon clinical situations (for example, “If I am in a persistent vegetative state”).

(3) Vague instructions result in conversations that produce equally vague expressions of wishes such as “Do not keep me alive with machines” or “Let me die if I am a vegetable.”

(4) Once advance directives are completed, planning is typically considered finished. A systematic effort to reopen the conversation as a person’s health declines is rarely made. The only repeated question that a patient might hear is, “Do you have an advance directive?” as required by the Patient Self-Determination Act.

(5) Traditional advance directives are seen as a right of the patient, with little attention given to routinely integrate planning into the clinical care of patients.

(6) Traditional advance directives are based on the assumption that autonomy is the primary mode of decision-making for most people. However, many people in the United States, particularly those from non-Western cultures, conceptualize the broader social network as the basis of treatment decisions, not the wishes and needs of the individual. Patients may also choose to delegate their autonomy to a family member, religious leader, or others, and defer discussions about prognosis and treatments for cultural or other reasons.

(7) In selecting a surrogate, a patient authorizes someone to speak on his or her behalf; however, advance directives typically do not include directions for the surrogate or health care professionals about treatment preferences unless special instructions are also provided. Additional information about values and goals is important to assist surrogates in decision-making during stressful times.

(8) Some patients may wish for their surrogates’ or families’ interests to be taken into account in decision-making rather than expecting the surrogate to base decisions solely on the wishes of the patient using a substituted judgment standard. Research suggests that many patients do not expect surrogates to rigidly follow their traditional advance directives, but rather intend for surrogates to exercise judgment to determine the course of care when there is insufficient information available or for extenuating circumstances.

In response to the difficulties with traditional legalistic advance directives, clinicians and researchers have developed new models that preserve the original goal of advance directives while addressing their shortcomings. One

well-known example is “Five Wishes,” a document that incorporates a surrogate appointment with a range of wishes about medical, personal, spiritual, and emotional needs (www.agingwithdignity.org). Five Wishes offers advantages over traditional advance directives because it covers a range of issues typically not found in statutory living wills or health care power of attorney documents, such as how comfortable a person wants to be or how he or she wishes to be treated if unable to speak for him or herself. Five Wishes meets the legal requirements for advance directives in thirty-seven states and the District of Columbia. Unfortunately, there are no published research studies to support the efficacy of Five Wishes in guiding surrogates and health care professionals or in ensuring that wishes are honored.

“Let Me Decide” is a recently developed Canadian program with empirical data to support its effectiveness (www.newgrangepress.com). The program was studied in a randomized, controlled trial of 1,292 residents at a group of regional nursing homes and hospitals in Ontario. Residents and their family members had an opportunity to document a range of health care choices regarding levels of care, nutritional support, and cardiopulmonary resuscitation. The program was implemented systematically and nursing home staff received training in how to integrate the advance directive into clinical care. Results indicate that the intervention group had a higher prevalence of planning. Additionally, plans were more specific, residents were less likely to die in the hospital, fewer resources were used, and families were more satisfied with the process than were family members in the control facilities using more traditional advance care planning.¹

In La Crosse, Wisconsin, “Respecting Choices” began in 1991 as part of a community-wide care planning system (www.gundersenlutheran.com/eolprograms). Local health care systems developed institutional policies to ensure that written advance directives were always available in their medical records when needed. Components of the program include staff education about the program and advance care planning; clearly defined roles and expectations of physicians; training for advanced care planning facilitators; routine public and patient engagement in advanced care planning; clinically relevant advance directives incorporated into clinical care; and written protocols so that emergency personnel can follow physician orders that reflect patient preferences. Quality improvement projects were undertaken to measure outcomes and to improve parts of the system when they did not perform in the way intended.²

A study of the Respecting Choices program evaluated La Crosse County deaths over an eleven-month period (524 in all). Eighty-five percent of all decedents had some type of a written advance directive at the time of death; 96

percent of written plans were found in the medical record where the person died; and treatment decisions made in the last weeks of life were consistent with written instructions in 98 percent of the deaths where an advance directive existed. Decedents with written advance directives were also significantly less likely to die in the hospital (31 percent versus 68 percent, $p=0.001$). Respecting Choices is now being implemented by more than fifty-five communities and organizations in the United States and Canada and is being piloted nationwide in Australia.

One of the most studied systems of advance care planning and documentation is the “Physician Orders for Life-Sustaining Treatment” paradigm, originally developed in Oregon (www.polst.org) and complementary to Respecting Choices (in fact, the Respecting Choices program strongly advocates use of the POLST paradigm to document physician orders in the out-of-hospital setting). The POLST form is designed for patients with serious illness and advanced frailty. The centerpiece of the program is the POLST document, a brightly colored medical order form that converts patient treatment preferences into written medical orders based on a conversation among health care professionals, the patient, and/or surrogates about treatment goals (see figure 1). The form transfers with patients across care settings to ensure that wishes are honored throughout the health care system. The POLST form is an example of an actionable advance directive that is specific and effective immediately. In a prospective study at eight nursing homes, residents whose POLST forms included a do not resuscitate (DNR) order and an order for comfort measures only were followed for one year. None received unwanted intensive care, ventilator support, or cardiopulmonary resuscitation.³

In contrast to the varied out-of-hospital DNR orders used around the country, the POLST paradigm provides patients the opportunity to document treatment goals and preferences for interventions across a range of treatment options, permitting greater individualization.⁴ Research suggests that the POLST form accurately represents patient treatment preferences the majority of the time⁵ and that treatments at the end of life tend to match orders.⁶ A majority of nursing homes and hospices in Oregon use the voluntary POLST Program, and POLST is widely recognized by emergency medical services.⁷ At least thirteen states have adapted versions of the POLST program, including Oregon, Washington, West Virginia, Utah, and parts of Wisconsin, New York, Pennsylvania, North Carolina, New Hampshire, Tennessee, and Michigan, reflecting a high degree of acceptance by health care professionals. Each state has made minor alterations to the document to accommodate local regulations and statutes. A National POLST Paradigm Task Force formed in 2004 to support national growth of the program.

Elements of Successful Advance Directive Programs

The newer, more successful, clinically based advance directive programs share key elements: a facilitated process, documentation, proactive but appropriately staged timing, and the development of systems and processes that ensure planning occurs.

First, successful advance directive programs are not limited to the content or rules relating to legal documents. Instead, an individualized plan is developed through a process of interaction with the patient that is specific not only to the patient’s values and goals, but also to his or her relationships, culture, and medical condition. Advance care planning should focus on defining “good” care for each patient, rather than on simply listing the right to refuse treatment or promoting individual autonomy. A skilled facilitator can enhance advance care planning by engaging those who are close to the patient so that they understand, support, and follow the plans that are made. The process permits shared or delegated decision-making depending on the beliefs and preferences of the patient. Facilitators should encourage patients and surrogates to discuss how much leeway a surrogate has in decision-making.

Second, for advance directive programs to be implemented successfully as a patient moves between different treatment settings, documentation of wishes, goals, and plans is essential. This documentation should include the identity of a designated surrogate. Ideally, this documentation would be in the form of actionable advance directives that direct treatment with specific medical orders reflecting a patient’s current treatment preferences—in contrast to traditional advance directives that address preferences in hypothetical future scenarios. To be truly effective, the actionable advance directive form must be standardized and recognized throughout the broader health care system, and it must provide clear, specific language that is actionable in all settings to which a patient might be transferred. The power of actionable advance directives is most completely realized in a system in which all institutional entities that interact with the patient (health care personnel in emergency medical services, emergency departments, hospitals, nursing homes, hospices, home health care, and others) recognize the actionable advance directive form and are authorized to follow its written orders.

Third, successful advance directive programs also require proactive but appropriately staged timing: some discussion should anticipate health care decisions, but much of it must be revisited as the patient’s prognosis becomes known. For an otherwise healthy patient, the presumption is that the treatment goal is to return to his or her prior state of health. Individuals who fit this description do not need an advance directive to guide initial treat-

ment. However, healthy adults can benefit from the process of advance care planning to prepare for sudden, severe illness or injury. Healthy adults should appoint a trusted family member or friend to serve as a health care surrogate who can act as a strong advocate in the event

that they are unable to speak for themselves. Healthy adults should also discuss with their surrogates whether and when a permanent loss of neurological function would be so bad that the goals of medical care would change from prolonging life to providing comfort, and

Actual size is 8.5 x 11 inches. Reverse of form not shown.

The form is always a bright color.

The POLST form converts patient treatment wishes into medical orders.

In any section left unmarked, the highest level of treatment must be provided.

Decisions about the use or limitation of antibiotics may be decided in advance or on a case-by-case basis.

A brief summary of the patient's health status gives other providers a context for these orders.

A discussion about treatment preferences is required when completing the POLST form.

A physician must sign the POLST form, but the form may be completed by a nurse, social worker or other health care team member. In Washington it may also be signed by a nurse practitioner or physician assistant. The person who prepares the form is encouraged to sign the back of the POLST (not shown).

Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid

A patient or surrogate signature is mandatory in some, but not all, states using the forms based on the POLST paradigm.

The original form should accompany the patient on transfer and remain with the patient where they reside.

HIPAA PERMITS DISCLOSURE OF POLST TO OTHER HEALTH CARE PROVIDERS AS NECESSARY

**Physician Orders
for Life-Sustaining Treatment (POLST)**

FIRST follow these orders, **THEN** contact physician, nurse practitioner or PA-C. This is a Physician Order Sheet based on the person's medical condition and wishes. Any section not completed implies full treatment for that section. Everyone shall be treated with dignity and respect.

	Last Name
	First/Middle Initial
	Date of Birth

A CARDIOPULMONARY RESUSCITATION (CPR): Person has **no pulse and is not breathing.**
 CPR/Attempt Resuscitation DNR/Do Not Attempt Resuscitation (Allow Natural Death)
 When not in cardiopulmonary arrest, follow orders in B, C and D.

B MEDICAL INTERVENTIONS: Person has pulse and/or is breathing.
 COMFORT MEASURES ONLY Use medication by any route, positioning, wound care and other measures to relieve pain and suffering. Use oxygen, oral suction and manual treatment of airway obstruction as needed for comfort. **Patient prefers no transfer: EMS contact medical control to determine if transport indicated.**
 LIMITED ADDITIONAL INTERVENTIONS Includes care described above. Use medical treatment, IV fluids and cardiac monitor as indicated. Do not use intubation, advanced airway interventions, or mechanical ventilation. **Transfer to hospital if indicated. Avoid intensive care if possible.**
 FULL TREATMENT Includes care described above. Use intubation, advanced airway interventions, mechanical ventilation, and cardioversion as indicated. **Transfer to hospital if indicated. Includes intensive care.**
 Additional Orders: (e.g. dialysis, etc.) _____

C ANTIBIOTICS
 No antibiotics. Use other measures to relieve symptoms.
 Determine use or limitation of antibiotics when infection occurs, with comfort as goal.
 Use antibiotics if life can be prolonged.
 Additional Orders: _____

D ARTIFICIALLY ADMINISTERED NUTRITION: Always offer food and liquids by mouth if feasible.
 No artificial nutrition by tube.
 Trial period of artificial nutrition by tube. (Goal: _____)
 Long-term artificial nutrition by tube.
 Additional Orders: _____

E SUMMARY OF GOALS

Discussed with: <input type="checkbox"/> Patient <input type="checkbox"/> Parent of Minor <input type="checkbox"/> Health Care Representative <input type="checkbox"/> Durable Power of Attorney for Health Care <input type="checkbox"/> Court-Appointed Guardian <input type="checkbox"/> Other: _____	The basis for these orders is: (check all that apply) <input type="checkbox"/> Patient's request <input type="checkbox"/> Patient's known preference <input type="checkbox"/> Patient's best interest <input type="checkbox"/> Medical futility
Print Physician/ARNP/PA-C Name _____	Physician/ARNP/PA-C Signature (mandatory) _____ Phone Number _____
Patient/Resident or Legal Surrogate for Health Care Signature (mandatory) _____ Date _____	

SEND FORM WITH PERSON WHENEVER TRANSFERRED OR DISCHARGED

Use of original form is strongly encouraged. Photocopies and FAXes of signed POLST forms are legal and valid

Figure 1. Sample POLST Form from Washington State

they should address the degree of leeway that they grant to the surrogate.

In people with advanced chronic disease and frailty, planning should expand to include discussion of changing treatment goals. Success rates for interventions decline as disease and frailty progress, and patients' evaluations of the desirability of interventions often change in the face of this new reality. Patients and families look to health care professionals to initiate conversations about end of life care planning, and it seems most relevant to broach the topic in the context of a limited prognosis. Once the prognosis has been discussed, health care professionals (but not necessarily physicians) trained to facilitate advance care planning discussions can help guide patients so that plans are specific not only to the patient's experiences, values, and goals, but also to the patient's health condition, culture, and personal relationships. This planning should focus on treatment goals in scenarios likely to occur in the course of that person's chronic disease. Completion of an actionable advance directive may be particularly helpful at this time.

Finally, perhaps the most crucial elements of more successful advance directive programs are policies, procedures, and teamwork within each part of the health care system that ensures advance care planning and implementation occurs. Plans need to be clear and should reflect the individual's values and goals. Plans should be updated over time and available when needed; whenever possible, plans should be honored. A successful model requires the establishment of systems at many levels to achieve these goals. Health care organizations can create policies and procedures to assure that any written plan is available when needed. The roles and responsibilities of different health professionals must be clearly defined so that each person knows his or her part and can perform it. Furthermore, optimal performance of each player's role benefits from periodic assessment, which requires that health organizations conduct quality improvement initiatives to ensure that the implemented system achieves the desired outcomes. Organizations should be prepared to gather the necessary information to improve the system when and where it falls short.

For advance directives to be effective, they need to be integrated into each part of the system of care, including emergency medical service protocols and regulations. State statutes vary regarding traditional advance directives, surrogate appointment, and other relevant factors, such as emergency medical technicians' scope of practice. Therefore, state end of life coalitions consisting of key stakeholders (emergency medicine, long-term care, hospice, nurses, physicians, and health lawyers, among others) may need to identify and overcome state-specific regulatory, legal, and cultural barriers to the implementation of optimal advance care planning.

The original intent of advance directives to enable patients to retain control over their terminal care once they lose decision-making capacity was not fully achieved through the use of the traditional advance directives. New, more successful models address the limitations of the traditional models yet remain true to the concept's original intent. The key elements of these new models are advance care planning in a system with specially trained personnel; highly visible, standardized order forms that are immediately actionable; proactive, appropriately staged timing; ongoing evaluation and quality improvement.

For these new models to be used more broadly, systems to implement them will need to be established in each state and within every health organization. These systems need to ensure that traditional and actionable advance directives are written at the appropriate time, that they are recognized, and that they are honored. Given the initial success of these models, it is reasonable to believe that the original goal of advance directives—to ensure respect for patients' treatment wishes at the end of life—can and will be more completely realized in the future.

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4. S.E. Hickman et al., "Use of the POLST (Physician Orders for Life-Sustaining Treatment) Program in Oregon: Beyond Resuscitation Status," *Journal of the American Geriatrics Society* 52 (2004): 1424-29.

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