

Controlling Death: The False Promise of Advance Directives

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Advance directives promise patients a say in their future care but actually have had little effect. Many experts blame problems with completion and implementation, but the advance directive concept itself may be fundamentally flawed. Advance directives simply presuppose more control over future care than is realistic. Medical crises cannot be predicted in detail, making most prior instructions difficult to adapt, irrelevant, or even misleading. Furthermore, many proxies either do not know patients' wishes or do not pursue those wishes effectively. Thus, unexpected problems arise often to defeat advance directives, as the case in this paper illustrates. Because advance directives offer only limited benefit, advance care planning

should emphasize not the completion of directives but the emotional preparation of patients and families for future crises. The existentialist Albert Camus might suggest that physicians should warn patients and families that momentous, unforeseeable decisions lie ahead. Then, when the crisis hits, physicians should provide guidance; should help make decisions despite the inevitable uncertainties; should share responsibility for those decisions; and, above all, should courageously see patients and families through the fearsome experience of dying.

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Most patients want a say in their future care (1–6). Yet severe incapacity prevents many patients from expressing their wishes during a crisis. In advance care planning, a competent patient expresses wishes about medical care, placement, or related financial and legal issues to cover times of future incapacity. Advance directives, a kind of advance care planning, specifically address medical care. Instructional advance directives, or “living wills,” issue treatment instructions; proxy advance directives, or durable powers of attorney, name proxies to make medical decisions on a patient's behalf.

Medical advances in the 1960s prompted the creation of advance directives. The emergence of life-support technology saved patients who would have died before, but some of those patients survived with brain damage. Advance directives promised patients a say in their care even after severe brain damage (7). Legal events soon spurred widespread interest in advance directives. High-profile court cases involving long-term treatment for persistently vegetative patients (7–14) convinced many people, hoping to avoid similar fates, to sign advance directives. Meanwhile, Congress passed legislation requiring health care institutions to inform patients about advance directives on admission (15).

Despite an admirable purpose, advance directives now face increasing criticism. Prompted by that criticism, I reevaluate advance directives in this paper. I describe their use, benefits, and problems and conclude that serious problems afflict advance directives—whether instructional or proxy—and that attempts at solutions have proven inadequate. Other experts attribute the problems to flawed execution of a sound concept, but I attribute them to a fundamentally flawed concept: Advance directives simply promise more control over future care than is possible. Unexpected problems arise repeatedly to defeat advance directives. I present a dramatic case showing how just 1 of many possible problems derailed an especially well-prepared advance directive. I conclude that, while drawing lessons from advance directives, advance care planning must evolve

beyond them (16). Advance care planning must refocus from completing advance directives to preparing patients and families for the uncertainties and difficult decisions of future medical crises.

AN APPROACH TO ADVANCE CARE PLANNING

While physicians may approach advance care planning differently, the following case illustrates how I have typically approached such planning in the past.

A stroke has permanently damaged Mr. Jones's gag reflex, causing aspiration pneumonias. He requires frequent hospitalizations and occasional mechanical ventilation. At his first clinic visit after an especially turbulent hospital stay, Mr. Jones's primary care physician suggests advance care planning.

Patients expect their physicians to initiate advance care planning (17–19), and that responsibility falls naturally to primary care physicians. Their training uniquely emphasizes a holistic perspective, coordination of care, and excellent communication—all necessary for effective advance care planning. Furthermore, primary care physicians are used to navigating the typical obstacles to the process, such as impersonal hospital bureaucracies or overenthusiasm for curative technologies. Thus, primary care physicians seem the best prepared of all physicians to hear and implement patients' wishes regarding care (20).

In fulfilling that responsibility, primary care physicians might target their sickest patients first. Some patients undertake advance care planning willingly, although others resist it and need encouragement. The best planning has physicians and patients thinking about options beforehand, making decisions jointly, and reviewing those deci-

See also:

Web-Only
Appendix Table

sions whenever circumstances change. Unfortunately, lack of insurance reimbursement remains a major impediment to the process (7).

USING AN ADVANCE DIRECTIVE IN ADVANCE CARE PLANNING

I advocate using a sample advance directive to help guide the advance care planning process. The ideal sample is easily accessible, concise, accurate, conversational in style, and available in languages that are commonly spoken by the physician's patients. Many advance directives suitable for use as samples also contain the following elements: 1) a requirement that the signer meet basic decision-making standards—specifically, knowing the purpose of the advance directive, grasping the choices presented and their implications, and being able to decide on the basis of the signer's own values; 2) choices covering diagnostic procedures, treatments, proxies, and organ donation; 3) a commitment to providing comfort care always; 4) an option to withhold artificial sustenance (if consistent with patient interests); 5) a recommendation that the signer inform all personal physicians and medical proxies about his or her choices; 6) a requirement that the advance directive be placed in the signer's medical record; and 7) revocation procedures.

Despite these commonalities, no 2 advance directive forms are exactly alike. Differences arise from state laws and authors' perspectives (21) and affect patient eligibility, document layout, medical conditions and choices covered, witnessing and notary requirements, implementation procedures, and locations of strict legal validity. Physicians seeking a sample advance directive might consult the **Appendix Table** (available at www.annals.org), which compares some prominent directives (22–30). When adopting any sample advance directive, the physician must ensure that it complies with state law.

In introducing advance care planning, the physician assures Mr. Jones that he is not imminently dying. She then hands him the sample advance directive and says, "Your wishes about future care are important. We want to follow those wishes even if illness prevents you from expressing them. This form may help. Take it home. Talk about it with those closest to you, and choose someone to make medical decisions if you cannot. Then bring that person and the form to the next visit. We will discuss your wishes at that time."

CONDUCTING THE ADVANCE CARE PLANNING VISIT

Advance care planning typically requires at least 30 minutes for the physician to explain life-support procedures and to help the patient make choices. For me, scheduling such a visit before normal office hours works best for meaningful, unhurried discussions. I recommend that the physician first complete any pressing medical tasks and then move quickly on to advance care planning. The pro-

cess itself involves asking the patient sequentially about choice of medical proxy, functional states that make the patient's life worthwhile (19, 31, 32), and wishes concerning specific medical interventions.

Mr. Jones brings his wife to the next appointment. To focus the advance care planning discussion, his physician redistributes the sample advance directive. The physician asks Mr. Jones's choice for medical proxy. He names Mrs. Jones, who confirms her willingness to fulfill that role. The physician then asks Mr. Jones, "What makes life worth living for you?" (33). When Mr. Jones has difficulty answering, his physician asks alternative questions, such as "What do you enjoy doing?" and "How do you like spending time?" She offers examples, such as visiting grandchildren, watching television, or taking walks. Mr. Jones says he wants only to be home with his wife. Next the physician asks, "Which past hospital treatments have you liked or disliked and why?" and "Do you want resuscitation attempts if your heart or lungs stop?" Mr. Jones says the pneumonias exhaust him, draining his will to live. He declines any more "life-saver" treatments (including antibiotics for pneumonia) and requests only comfort care. He completes his advance directive accordingly. The physician also asks who else will likely witness a future medical crisis. Mr. and Mrs. Jones cite their daughter and assure the physician that their daughter knows Mr. Jones's care choices and agrees to them even in case of another pneumonia. Finally, the physician summarizes the discussion in a progress note, photocopies the advance directive and her note for the family, places the originals in the medical record, and urges the Joneses to give copies to their daughter.

BENEFITS OF ADVANCE DIRECTIVES

Advance directives have at least 2 notable benefits. Most important, advance directives symbolize medicine's recent commitment to patient empowerment. Medicine has historically empowered only physicians but, increasingly sensitized to the illness experience, now empowers patients, too. Advance directives remind physicians to value patients as partners in planning care. Obviously, advance directives also encourage planning for death. Many people do not "deny" death so much as ignore it. As Henig states: Despite death's inevitability, "the hardest thing . . . is to really, deeply believe that we or our loved ones will die" (34). For that reason, people often resist thinking about death. However, as the case suggests, advance directives act as concrete aids in prodding people to overcome their aversions and to face the hard decisions about dying (28).

PROBLEMS WITH COMPLETION OF ADVANCE DIRECTIVES

Despite the benefits of advance directives, completing them raises many problems. One is that so few patients sign advance directives. Completion rates among most patient groups run only 4% to 25% (31, 35–44), and intensive education (45–47) and promotion (48) do little to

improve those rates (42), except in special populations (38, 48–53). Possible explanations for the low signing rates among North Americans include resistance to thinking about death (18, 28, 54), unawareness of advance directives (35, 36, 39, 44, 54), incompatibility of advance directives with some ethnic cultures (3, 54–56), daunting technical language and legal requirements, perceived inconvenience or irrelevance of advance directive discussions at legally mandated times (such as hospital admission) (18), and poor preparation or motivation of personnel who must initiate those discussions (7).

Another common completion problem is documenting wishes of questionable validity. Because patients may poorly understand medical care (21, 57, 58), many unwittingly misrepresent their wishes in advance directives. For example, patients who request cardiopulmonary resuscitation (CPR) on the basis of the widespread misperception of its long-term survival rate as 70% (57) might decline CPR if they knew that the actual survival rates are only 0% to 22% depending on medical circumstances. Similarly, patients who request do-not-resuscitate (DNR) status might not do so if they knew that some surgeons refuse to operate under it. Patients' preferences may also change with time. A healthy patient's rigid refusal of chemotherapy may change when that patient faces life-threatening cancer. Likewise, a patient's preferences for proxies may change as relationships change. Health professionals can rightfully wonder whether past wishes written into advance directives remain valid in present crises.

The advance care planning process helps Mr. Jones avoid many common completion problems. As a result, he formulates clear end-of-life care wishes and writes them into an advance directive. Surely, Mr. Jones's wishes are more reliable than most other patients': He declines treatments for pneumonia and other life-threatening conditions that he has experienced, and he chooses Mrs. Jones as his proxy—the person who knows him best, has seen him through such treatments before, and promises to implement his wishes.

PROBLEMS WITH IMPLEMENTATION OF ADVANCE DIRECTIVES

Even when advance directives are completed perfectly, implementation may raise problems. One is inaccessibility. Too few signers routinely carry their advance directives on them, distribute their directives to all possible decision-makers in a crisis, or store their directives in places that do not hinder access (as safe deposit boxes and locked filing cabinets may). When unable to access advance directives in an emergency, health personnel face life-or-death decisions with at best bystanders' immediate recollections of patient wishes. (Because those recollections may be mistaken, the out-of-hospital DNR law in Texas permits withholding CPR in the field only on the basis of a direct reading of an advance directive or other physical proof of the patient's refusal.)

Another implementation problem is poor proxy representation. Many proxies lack the knowledge, insight, or courage to fulfill their role (28, 59, 60). They may not know that they have been chosen as proxies or what patients want for care (7). When inadequately informed, even spouses or partners cannot accurately intuit patients' care wishes. Furthermore, because advance directives often issue ambiguous (61) or conflicting instructions (7), crises usually require proxies to make uncomfortable decisions based on interpretation. Wrangling with other parties over such decisions magnifies the distress (12). Proxies may eventually confuse their own or others' interests with the patient's interests or may begin to doubt their adequacy as advocates. Increasingly overwhelmed as stakes rise and uncertainties loom (7), many proxies wilt under the strain.

A third implementation problem is physician non-adherence (28, 43, 62). Of course, some circumstances justify not honoring advance directives. Physicians may not have copies and may rightfully hesitate to rely on hearsay from others. But even advance directives in hand may have questionable validity. Patients may lack decision-making capacity when they sign advance directives, may create interceding advance directives, or may fail to update instructions as conditions change. Moreover, physicians may question whether the stated circumstances for invoking an advance directive, such as a "hopeless" illness, have materialized (59). Physicians may also feel obliged to disregard advance directives that conflict with hospital policy, family preference, or ingrained practice habits. Still, most physician nonadherence to advance directives probably stems from physicians' miscommunication or misunderstanding about patients' wishes (62).

When the crisis hits, Mr. Jones's case avoids these common implementation problems. Mr. Jones has acute, severe dyspnea while his primary care physician is unavailable on vacation. Mrs. Jones panics and calls an ambulance to rush Mr. Jones to the hospital. There he is admitted, unresponsive with another pneumonia. Mrs. Jones shows her husband's advance directive to the hospitalist on duty. The hospitalist reads it, Mrs. Jones confirms her husband's treatment choices, and the hospitalist orders comfort care accordingly.

FUNDAMENTAL FLAWS IN ADVANCE DIRECTIVES

By avoiding many common problems with completion and implementation, Mr. Jones's directive surely is among the strongest advance directives possible. Yet even his directive eventually runs aground on unforeseen problems.

Mr. and Mrs. Jones's daughter storms into the hospital, objecting vehemently to comfort care only. She accuses her mother and the hospitalist of "murdering Daddy." The daughter threatens to notify "hospital authorities," contact the press, and sue the hospitalist unless he administers antibiotics immediately. When the hospitalist balks, she calls the chief of staff on the patient abuse hotline. Notified that Mr. Jones's primary care physician is unavailable, the chief of staff demands anti-

biotics and full life support. Intimidated and emotionally spent, Mrs. Jones and the hospitalist capitulate. The hospital's risk management committee meets in emergency session the next day and endorses fully aggressive care. Despite the antibiotics, Mr. Jones slips into respiratory failure. Mechanical ventilation sustains him briefly until he has a cardiac arrest, does not respond to CPR, and finally dies.

When first created, advance directives seemed the perfect way to tailor future care to patients' wishes, but outcomes have consistently frustrated expectations. Even Mr. Jones's well-executed directive could not save him from the aggressive treatment he did not want. Such a devastating failure raises doubts that advance directives can ever succeed. We must ask: Can they possibly be fixed?

The answer depends on the root problem. If the root problem is simply flawed use (19, 31), then advance directives can work if they are properly understood, signed, and executed. Yet 30 years of Herculean efforts to clarify, advertise, and distribute advance directives; to educate people about them; to encourage patients to sign them; and to teach faithful implementation by health professionals have yielded few successes but many disappointments.

Thus, I suspect a different root problem—flawed underlying assumptions (42, 55, 63, 64). One flawed assumption is that people already think about their end-of-life care (65, 66). Most people surely want “dignified” care that is tailored to their wishes. However, the necessary detailed prior planning is emotionally draining, and most people lack the courage for it (54). They prefer to avoid signing advance directives and to leave end-of-life care decisions to their physicians, proxies (30), or even fate.

Of course, some highly motivated people do make end-of-life care plans (1). One author, for example, wants to “choreograph” her death because she “can't imagine the final splat” (34). Still, these people fall victim to another flawed assumption—that advance directives can control future medical care. In reality, critical illness thwarts the very purpose of advance directives (64) through the many on-the-spot decisions necessitated by unpredictable, uncertain, and complex circumstances (7). Thus, advance directives simply promise more control than they can deliver (7, 42, 59, 60). They provide an unrealistic but comforting “illusion of certainty” (67).

A third flawed assumption is that, even if advance directives do not facilitate critical care, they do not complicate it (12). Experience suggests otherwise. Disagreements over vague advance directive instructions require careful adjudication (68), and ineptness of designated proxies may create confusion in the decision-making process. Advance directives also seem to set too exacting a standard for care (31), implying that a good death fulfills a patient's every instruction, however impractical. (For example, a patient may ask to die at home but may lack sufficient care-giving resources there.) Families and health professionals may blame themselves for any unfulfilled patient instructions.

A PERSPECTIVE FROM ALBERT CAMUS

Although advance directives are seriously flawed (7, 42, 59, 69), no alternative yet exists. Should we still use them (6, 7, 14, 19, 28, 37, 44, 70) or not (60, 71)? Commentators answer on both sides, but I favor a middle option: Search conscientiously for alternatives but, until a better one emerges, use advance directives with a realistic perspective on critical illness and dying.

What might that realistic perspective be? Albert Camus, the 20th-century existentialist, describes one that helps me (72, 73). Rejecting overly idealized or rational views, Camus sees life as largely unpredictable, illogical, or “absurd.” People lack control over it and should acknowledge that. Still, Camus believes that people are precious and that their lives have meaning. Events may alienate people from each other, but authentic communication overcomes alienation and sustains people amid the chaos (73). Camus also believes that trying circumstances shape and reveal character. He urges facing those circumstances with courage, integrity, and responsible decision making. Such wholehearted engagement, Camus thinks, ennobles people.

This perspective helps one understand Mr. Jones's case in a new way.

That last pneumonia precipitates a cascade of “absurdities.” Despite Mr. Jones's wish to stay home, Mrs. Jones panics at his dyspnea and calls an ambulance. At the hospital, Mr. Jones's daughter creates even more problems that eventually nullify the advance directive. Although previously informed of Mr. Jones's advance directive, his daughter objects to the plan for comfort care only. She bullies Mrs. Jones and the hospitalist until they capitulate and institute full life support. A technological juggernaut follows, leading to a death that Mr. Jones did not want.

The perspective based on Camus also suggests management changes. First, the primary care physician should have ensured that Mr. and Mrs. Jones accurately grasped the advance directive's purposes and limitations. It was a means, not the end, in the advance care planning process. The advance directive could not anticipate in any detail Mr. Jones's future medical problems (66), could not issue treatment instructions for all possible situations, could not spare others some difficult discretionary decisions in the crisis (33), and could not guarantee fulfillment of Mr. Jones's wishes (31, 47). However, the advance directive could cement the commitment of Mrs. Jones and the physician to doing their best for Mr. Jones. Thus, his advance care planning could have started, but should not have ended, with the advance directive.

The primary care physician should have also prepared Mr. and Mrs. Jones emotionally for the coming crisis (66). She should have warned about common decision-making problems (including self-doubt, conflicting interests, family recriminations, and bureaucratic insensitivity), mentioned the inevitable emotional traumas, and pledged to stand by Mrs. Jones and share responsibility for decisions.

Such support would have reassured Mrs. Jones, built trust, and alleviated feelings of isolation and inadequacy (1).

Furthermore, when Mr. Jones's daughter objected to comfort care only, the hospitalist should have begun antibiotics immediately to buy adequate time to hear her out (12, 74). The hospitalist should have simultaneously explained that he was committed to honoring Mr. Jones's wishes; that, until convinced otherwise, he had to assume Mrs. Jones—as the designated proxy—was the best authority on Mr. Jones's wishes; and that he was instituting antibiotics only to be able to weigh carefully the conflicting opinions about Mr. Jones's true wishes.

Finally, if the daughter could not argue convincingly that she represented those wishes best, the hospitalist should have politely but firmly overruled her. He should have then stopped the antibiotics; reinstated comfort care only; and documented meticulously his discussions, decision, and rationale and the daughter's dissent. If further objections arose, the hospitalist should have publicly accepted responsibility for the treatment plan (6) and defended it courageously even to the chief of staff and the risk management committee. The hospitalist should have also anticipated the daughter's future recriminations, prepared Mrs. Jones for them, and protected her steadfastly against them (even if the hospitalist himself suffered recriminations as a result).

Whenever family cannot reach consensus, hospitals typically adopt the treatment plan perceived as safest—maximally aggressive care. Unfortunately, the hospital did so here. Powerful institutional forces wrested control of Mr. Jones's end-of-life care. Because of the absurdity of the situation and the unavailability of the primary care physician, the hospitalist should have actively supported Mrs. Jones throughout the hospitalization. Even after Mr. Jones was transferred to the intensive care unit, the hospitalist should have called (repeatedly if necessary) to remind Mrs. Jones that together they had done their best for Mr. Jones, that events had spun out of their control, and that she must not blame herself for a death Mr. Jones did not want.

CONCLUSION

Flawed in concept and not just use, advance directives provide little control over future care (6, 7, 64). The last-minute objections to comfort care by Mr. Jones's daughter illustrate the many unexpected problems that can defeat advance directives. Thus, I urge deemphasizing advance directives while searching for better approaches to advance care planning. Camus's ideas suggest one approach that stresses honest communication (33, 57, 75); preparation of patients and families for death's harsh and unpredictable reality (7, 66); mutual support; nonformulaic, individualized care; and courageous decision making despite uncertainties.

At the end of Camus' *The Plague*, the main character—a physician named Rieux—reflects on his role

throughout the plague epidemic. He realizes that, along with providing care that had to be given “by all who . . . strive . . . to be healers,” he bore witness to patients' suffering (76). Physicians surely have the duty to fight disease in most circumstances, but physicians always have the still greater duty to see patients and survivors through their suffering and thereby to bear witness to it. Perhaps that greater duty lifts medicine from a mere occupation to a true profession.

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Appendix Table. A Comparison of Selected Advance Directives*

Variable	A Living Will (22)	The Medical Directive (23)	Your Life, Your Choices (24)	Texas Advance Directive Act (25)	Five Wishes (26)
Publication date	1978	1990	1996 and 2001	1999 and 2004	2000
Author or publisher	Concern for Dying Unspecified	Ezekiel LE, Emanuel EJ Discussed but unclear	Peafman et al., VHA, U.S. Department of Veterans Affairs Discussed but unclear	Office of the Attorney General, State of Texas Texas	Aging with Dignity 36 states and District of Columbia
Area of legal validity	Probably no longer accessible	JAMA (1989;261:3288-93)	www.hsrd.research.va.gov/publications/internal/ylyc.htm (accessed 6 March 2007)	www.oag.state.tx.us/elder/elder.shtml#illegal (accessed 6 March 2007)	www.agingwithdignity.org (accessed 24 November 2006); also available at 888-5WISHES
Where accessible?					
Additional information	<i>Questions and Answers about the Living Will</i> , other bibliography, articles, case studies, and films—likely outdated and unavailable	Professional journal article	52-page workbook	5-page <i>Senior Texans: Advance Care Planning</i> supplement at www.oag.state.tx.us/AG_publications/facts/Advance_Care.shtml (accessed 20 November 2006)	<i>Five Wishes</i> video
Eligible signers	Unspecified	Adults of sound mind	Any nonpregnant person capable of willful, voluntary decisions	Nonpregnant adults may sign all 3 documents; proxies or 2 physicians of incompetents may also sign out-of-hospital DNR† order	Anyone older than age 17 years
Length and format	2 pages and wallet card (for a contribution)	4 pages, no wallet card	4 pages and wallet card	8 pages for all 3 documents, no wallet card	12 pages and wallet card
Conditions for effecting	No recovery expected from "extreme physical or mental disability"	4 "representative" states of mental incompetence (such as coma, vegetative state, and other brain damage) with varied survivals and disabilities	Coma or vegetative state, stroke, dementia, and terminal illness	Condition likely to kill patient within 6 months or irreversible condition such that patient "cannot care for (him)self or make decisions and (would die) without life support"	Imminent death, severe brain damage (such as permanent coma), or other conditions the signer describes
Treatment choices†	Decline "artificial means" or "heroic (life-support) measures"	Choose or decline life-support and other measures	Choose or refuse life-support measures and hospice care	Choose or refuse life-support measures individually or as a package	Choose or refuse life support as a package or allow a physician to decide
Choices about cadaver	Tissue donation	Organ or body donation for transplantation, education, or research	Organ donation, autopsy, other research on body, and burial or cremation	None	Organ donation, burial, and cremation
Special features	The most familiar early directive; now outdated Very brief Allows request for home care if it would "not jeopardize . . . recovery to a meaningful and serene life or impose an undue burden" on family	Brief Lists many life-support and other treatments Poses questions to help patient define medical conditions too "hard" to justify prolonging life Acknowledges need for proxy judgment when patient's wishes are unclear, patient is undecided, or situations are different from the 4 representative states States priority between patient instructions and proxy decisions and among proxies if conflicts arise Emphasizes physician's ongoing duties to diagnosis, assess prognosis, educate, and recommend	Easy-to-read layout with excellent graphics Comprehensive Workbook defines key concepts simply and uses case examples Emphasizes the patient's understanding of concepts conditions and their treatments Keys patient preferences to explanations in grid format Helps patient define relevant spiritual beliefs, hope for recovery, and acceptance of risk Workbook includes directives; Web site gives parallel references to VHA, directives Gives tips for end-of-life care discussions with family and physicians Cautions about ambiguities of common terms, such as "pulling the plug" Allows instructions about how strictly to follow patient's wishes Includes funeral wishes Uses divider tabs, sidebar summaries, and prompts for easy reference Gives completion checklist Gives contact information for relevant organizations	Combines laws about instructional directives, proxy directives, and out-of-hospital DNR orders Emphasizes that spouses cannot inhibit patient wishes Differentiates powers of attorney for medical care and property management Directives come in English and Spanish language; out-of-hospital DNR only in English Requires physician to transfer patient if physician cannot fulfill patient's wishes Allows expiration date Authorizes out-of-hospital DNR identification band Explains hospice care	Uses simple language Addresses personal, emotional, and spiritual needs, as well as medical needs; claims to be "The Living Will with a Heart and Soul" Gives instructions about revoking previous directives Lists traits of good proxy Lists decision-making powers of proxy Allows patient to write additional instructions Includes funeral wishes
Drawbacks	Does not define key concepts Gives vague instructions that are difficult to interpret clinically	Uses word-dense layout Explains treatments too simplistically Allows mutually exclusive treatment choices	Workbook length is daunting States some hopes as facts, such as directives "prevent confusion and . . . ease the burden on families" 1996 workbook directives use legal language and key to Washington state law	Gives sketchy definitions of life-support measures Makes unrealistic promises to "prevent arguments and bad feelings at the end of life," to achieve a "gentle" or "good end of life," and to help give survivors "a more peaceful bereavement"	Copyrighted Costs \$1–\$5 each Makes unrealistic promise to give "control (over) . . . how you are treated if you get seriously ill" Lists but does not define specific life-support measures Offers some unrealistic options, such as to "be kept fresh and clean at all times" and to protect family from guessing "what you want" and making "hard choices"

Appendix Table—Continued

Advance Health Care Directive (27)	VHA Long-Term Care Advance Care Proxy Planning (28)	VHA Advance Directives (29)	Medical Orders for Life-Sustaining Treatment (30)
2000–2006 California Medical Association California www.amanet.org/publicdoc.cfm/7 (accessed 6 March 2007)	2002 Volkert et al.; VHA National Ethics Committee Unclear: not an “official” form but a model for local facilities to use in developing their own forms J Am Geriatr Soc (2002;50:761-7)	1998 and 2003 VHA National Center for Ethics in Health Care Veterans Health System www1.va.gov/vhapublications/viewPublication.asp?pub_ID=1450 (accessed 6 March 2007)	2005 Rochester Health Commission New York www.health.state.ny.us/professionals/patients/patient_rights/molst (accessed 24 November 2006)
6-page Advance Health Care Directive Kit and Deciding To Forgo Treatment: Advance Directives Legal adult California residents	Professional journal article Proxy and professional caregivers of incapacitated veteran patients	7-page VHA handbook defining staff duties Veteran patients	20-page Guidebook to MOLST Health professional completes, and physician signs for patient or proxy
8 pages and wallet cards Kit claims “any situation (when) you are unable to make your own decisions,” but directive specifies only death within months or permanent life-support dependence with inability to make decisions	2 pages, no wallet card Conditions that normally require hospitalization and life support	6 pages, no wallet card Irreversible unconsciousness or terminal condition	4 pages, no wallet card Patient’s current condition specified, but other conditions not specified
Choose or refuse proxy, physician, care facility, life-support measures, and release of information	Choose or refuse acute care hospitalization, “advanced interventions,” other life-support measures, artificial hydration and nutrition, and comfort care	Refuse life-sustaining measures as a package	Choose or refuse CPR, intubation and mechanical ventilation, nutrition and hydration, antibiotics, and comfort care only; may also choose trial of treatment
Organ donation, autopsy (for education, research, or transplantation purposes), and body disposal	None	None	None
Offers DNR form for patients and preferred intensity of treatment form for physicians to complete on behalf of patients in long-term care facilities Kit and DNR form in English or Spanish language Uses simple language Kit answers common questions succinctly Kit gives space to list people with copies Allows personal statement about treatment wishes Reminds proxies to make sure patient wishes guide decision making Gives option allowing proxy to make decisions before patient loses decision-making capacity Requires signatures of 2 witnesses, notary public, or nursing home ombudsman Allows an expiration date Encourages use of prehospital DNR form Replaces Natural Death Act Declaration and Durable Power of Attorney for Health Care	Commits to respecting patient wishes Emphasizes advance care planning in outpatient clinic “Tools” to aid discussion Emphasizes patient education and collaborative decision making Defines key concepts simply (including decision-making capacity) Allows verbal instructions when patient cannot sign Reminds to communicate wishes and distribute directive properly Assigns to each facility’s staff the responsibility for conducting this process Gives specific instructions for filing and implementing Requires review annually and at each hospitalization Allows health professional to transfer patient if directive violates professional’s conscience Outlines dispute resolution procedures	Adopted from a model document used in Oregon’s orders* “Translates current treatment preferences into Physician Summaries but does not replace New York Living Will or New York Health Care Proxy directives Supplemental documentation form for special patients, including those lacking capacity to consent Requires review at hospitalizations and transfers, at changes of medical condition or wishes, and at least every 60 days for nursing home residents or every 90 days for other patients Physician may complete sections about non-CPR treatments on the basis of “clear and convincing evidence” of patient’s wishes Default for uncompleted sections is full treatment Uses bright-pink paper for ready identification	
Gives sketchy definitions of life-support treatments Kit is copyrighted Kit and forms cost \$1–\$5 each	Makes exaggerated claim that patients “can continue to direct their medical care” when no longer competent Specific for VHA; may have limited validity elsewhere	Specific for VHA; may have limited validity elsewhere Does not implement features of state directives conflicting with VHA policy Prevents care team from overruling any proxy decision	Copyrighted Conditions for effecting other than patient’s current condition are unspecified Burdensomely frequent review

* CPR = cardiopulmonary resuscitation; DNR = do not resuscitate; MOLST = Medical Orders for Life-Sustaining Treatment; VHA = Veterans Health Administration.
 † “Life support,” as used in these documents, typically includes CPR, intensive care, and mechanical ventilation but may also include antibiotics, chemotherapy, fluids and nutrition, and other treatments.
 ‡ Includes Texas’ Directive to Physicians and Family or Surrogates (revised 1999), Medical Power of Attorney (revised 1999), and Out-of-Hospital DNR order (revised 2004).
 § Physicians’ Orders for Life-Sustaining Treatment: Information about this prototype document is available at www.polst.org; at the Center for Ethics in Health Care, Oregon Health Sciences University, 3181 Sam Jackson Park Road, UHN-86, Portland, OR 97239-3098; or at 503-494-3965.