

State Initiatives in End-of-Life Care

Issue 23, March 2005

Focus: Advance Care Planning—III

New Directions in Policy and Practice



Dave Eulitt

John Bruner, left, chats with his mother, Violet Bruner, in the social room of Trinity Lutheran Manor in Merriam, Kansas. Luther, the dog that stays at Trinity, visits Violet every day in her room.

Talking with loved ones about their preferences for care at the end of life, designating a proxy in a durable power of attorney for health care, and documenting conversations in a living will are important activities of advance care planning in which too few Americans engage. Even when such advance directives exist, too often they cannot be found, or health care workers misunderstand or disregard them. One result is that the care outlined in the directive may not be consistent with the care delivered. For more about the strengths and weaknesses of advance directives, see page 4.

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The “Critical” Process That Too Few of Us Carry Out

Most Americans, by far, spend their last days in the hospital. And a minority of those patients—as little as 5 percent, according to a 1990 study by Smedira et al. of withholding and withdrawal of treatment in the critically ill—have the capacity to make decisions about their treatment. In cases where patients cannot make decisions, it is not only customary but legally sanctioned in many states to have family members serve as “surrogate” or “proxy” decisionmakers. Ethicists and health care professionals consider family members and intimate others best able to know how long the patient might want to continue aggressive treatment.

But making such decisions is emotionally taxing for the proxies. A 2001 study published in *Nursing Research* found that the stress level of family members authorizing clinicians to withdraw life-sustaining treatment was greater than that reported by those who survive house fires, construction disasters, or ferry disasters. And six months after the patients’ deaths, the bereaved family members’ stress *still* exceeded the levels reported in those other traumatic situations. The study also found that those who make such decisions with a living will report much less stress than those whose dying loved ones have not provided a written advance directive (see chart).

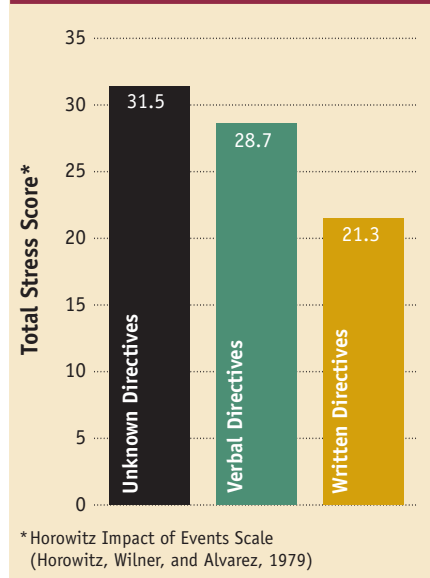
“Advance directive” is a generic term that describes several different kinds of actions that express preferences about end-of-life treatments, including living wills, health care treatment directives, and durable powers of attorney for health care. Advance care planning (ACP) is the process of creating an advance directive. In the best of situations, it involves a patient’s documenting conversations with family, physicians, and others in a living

will and designating a surrogate in a durable power of attorney for health care, and clinicians’ ensuring the advance directive is honored.

Despite ACP’s clear and compelling benefits for patients and families, evidence differs widely about how successful the 25-year-old ACP movement has been. “It all depends on what you count as successful,” says Joan Teno, MD, MS, associate professor of community health, Brown University Center for Gerontology and Health Care Research, and a prominent expert in end-of-life care. A study Teno published in the *Journal of the American Medical Association* in January 2004 suggests that in at least 70 percent of American deaths (excluding traumatic deaths, e.g., homicide or car crashes), an advance directive exists. And in some communities, such as Kansas City or LaCrosse, Wisconsin, this may be a result of broad community education and outreach about advance care planning.

But other studies have turned up far lower numbers. “We found that 1.6 percent of Montefiore patients 65 and older have ADs,” says Nancy Neveloff Dubler, LLB, director of the Division of Bioethics at Montefiore Hospital and professor in the Department of Epidemiology and Population Health at the Albert Einstein College of Medicine. The single greatest indicator of an individual’s having completed an advance directive, Dubler has found, is a connection with an estate and trusts attorney. “We are in the Bronx and not many people in the Bronx have estate and trust attorneys. And advance directives are perceived by people as limiting access to care, and people of color are not interested in *limiting* care; they’re interested in *access* to care.”

Family Stress Levels during Decisionmaking to Withdraw Treatments



For family members authorizing the withdrawal of life support for dying loved ones, family stress was higher in the absence of advance directives, was lower when verbal advance directives guided the family, and was lowest when written advance directives guided the family.

Source: V. P. Tilden et al., “Family Decision-Making to Withdraw Life-Sustaining Treatments from Hospitalized Patients,” *Nursing Research* 50, no. 2, (2001): 112.

The issues explored in this edition of *State Initiatives* include:

- the strengths and weaknesses of the living will and durable power of attorney
- ethical principles that guide advance directives’ implementation
- tools available to guide patients and families in advance care planning
- policy barriers to effective advance care planning and key suggestions for policymakers about how to overcome them. ■

Advance Directives: History and Ethical Principles

Forms versus Conversations

In 1990 the U.S. Supreme Court, in the case of Nancy Cruzan (an incapacitated Missouri woman in her twenties whose parents sought to withdraw life support), ruled in a landmark decision that families could decide to forgo life-sustaining treatment for their incapacitated loved ones as long as such a decision was based on an understanding of the patient's own wishes—in effect, as long as the decision was based on sound advance care planning. Capable adults can choose or refuse medical treatment, even if those decisions “hasten death.” Congress passed the Patient Self-Determination Act (PSDA) requiring all hospitals to ask patients at admission if they have advance directives, to chart the patient's response, and to offer information about advance directives and the right to refuse treatment.

The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO) enforces standards based on the PSDA by fining institutions that fail to inquire about advance directives. While well-intentioned, this creates an incentive mainly focused on getting more documents completed rather than on getting the more important part of the process going—that of initiating ongoing conversations between patients and their loved ones about how decisions will get made at the end of life. Because of JCAHO's focus on documents rather than process, “You hear all the time, ‘How can we increase the number of advance directive documents?’” says Charles P. Sabatino, JD, assistant director of the ABA Commission on Law and Aging. “You can increase the number of people signing advance directives, but that doesn't mean they're talking about the right stuff,” such as the patients' understanding of the decisions they

may have to make in the future; their reflection on these decisions within the context of their beliefs and values; and how to promote good communication between patients, those closest to them, and health care practitioners.

“The document should be a memorandum of the process of reflection and communication; instead, the focus has become the document itself,” Sabatino concludes.

Protecting Patient Autonomy: The Living Will

“It is critical to have explicit advance care planning—it means that there is no question about families having to reconstruct some conversation that may or may not have taken place,” says Linda Farber Post, JD, BSN, MA, clinical ethics consultant at Montefiore Medical Center. When there is no living will or designated surrogate, Post says, “We have to ask families, ‘Did mama ever say anything about ventilators?’ Then they have to think back and say, ‘Yes, absolutely, it was last Thanksgiving dinner and we all heard her say . . .’ That works, but it can be very excruciating for the families. They shouldn't have to go through that.”

The living will was conceived in 1967 as a method to protect patient autonomy, to let patients refuse life-sustaining treatment that they did not want, even if they were too ill to speak on their own. The living will permits individuals to request whatever level of care they want—even aggressive treatment: it's not just about limiting care.

Back then, doctors found it difficult to accept that patients might prefer death to treatment when they had lost their capacity to speak independently. Living wills seemed to solve this problem. The document usually voiced a patient's preferences in a series of hypothetical “If I am ever . . .” statements, anticipating particular medical crises. Living wills have evolved over time to state more positively a patient's wishes for particular treatment: “Here is how I wish to be treated,” or, “Here is how I want my quality of life to be.” In the best of circumstances, living wills have eliminated much of the uncertainty families perennially feel about refusing or withdrawing treatment near death.

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“Public policy should focus on the reality of how decisions are actually made. The reality is, decisions are made by a grieving family member or members without specific authority. . . . We need robust notions of family decisionmaking. We need to empower families.”

Nancy Neveloff Dubler, LLB, director,
Division of Bioethics, Montefiore Hospital

Advance Directives: History and Ethical Principles

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Divining What’s Right for Patients: The Health Care Proxy

As medical technology has progressed, however, the limitations of the living will have become clear. Accordingly, advance care planning is shifting away from reliance on static, legalistic forms and toward reliance on the flexibility of a human being, in the form of an advance directive called a durable power of attorney for health care. Ideally, the proxy can protect the patient’s autonomy as well as act in the patient’s best interests:

- The proxy can try to establish with as much accuracy as possible the decision the patient would make if he or she were capable, thus adhering to the ethical test of substituted judgment. This standard seeks above all to preserve the patient’s autonomy by placing the patient’s own preferences at the center of decisionmaking, while recognizing that the patient will probably not have clearly articulated his or her exact preferences in advance.
- The agent can, in responding to real-time challenges, try to make decisions that are best for the patient. Working according to the principle of beneficence, this test asks families to make decisions based upon a reasonable person’s judgment of the patient’s best interests.

Proxy as Covenant, Not Contract

The durable power of attorney for health care was conceived as a way to augment the living will’s static, impersonal qualities with a person who would not simply carry out the patient’s wishes as expressed in the living will but also would respond to changing circumstances in real time. But far from just augmenting the living will, the health care proxy has—in the opinion of those working in end-of-life care policy and practice—

evolved into the best mechanism extant to make treatment decisions when the patient is incapacitated. This is perhaps because the proxy is informed by his or her *relationship* with the patient—a dynamic, freely given *covenant* that cuts deeply into personal identity—not the static quid pro quo contract of a living will, according to Joseph J. Fins, MD, FACP, chief of the Division of Medical Ethics in the Departments of Medicine and Public Health at the Joan and Stanford I. Weill Medical College of Cornell University.

In states where the law privileges the proxy over the living will, physicians are required to involve the proxy in all

treatment deliberations and permit the proxy to make decisions just as the patient would. But even in such states, physicians may fail to involve the proxy fully in decisionmaking. Also, some state laws restrict the withholding or withdrawal of life support under a “best interest” test and require a higher “clear and convincing” level of proof of the patient’s wishes to make such decisions. Progressive policy would permit decisions to be made to the extent possible by family surrogates under the substituted judgment test and to the extent not possible—i.e., where the patient’s wishes are not fully known—under the best interest test. ■

Strengths and Weaknesses of Advance Directives

Living Will

Strengths

- Provides a record of the patient’s treatment preferences to which families and health care professionals may refer when decisions need to be made
- Works to eliminate uncertainty families may feel about reconstructing some conversation that may or may not have taken place

Weaknesses

- Most patients put off creating them
- Most institutions do not treat the completion of living wills as an ongoing process; documents become outdated and no longer express patients’ wishes
- Often vague and poorly understood by clinicians as well as patients and families
- Too static to offer direction in complex and/or changing medical circumstances
- Often misplaced and not honored by health care professionals
- Often disappear during transfer of patients from one facility to another
- Many state laws specify onerous, discouraging requirements, such as notarization and multiple, unrelated witnesses
- Formats and legal language vary widely from state to state, so they cannot be transported easily over state lines

Proxy/Surrogate

Strengths

- The proxy has authority to make any and all health care decisions, even decisions the patient never anticipated
- Provides a flexible, intelligent alternative to the static document of the living will
- Patients can also include instructions or guidelines for decisionmaking, just as they could do in a living will
- Patients can actually restrict decisions proxies can make

Weaknesses

- Few proxies receive training in how to fulfill their responsibilities
- May be useful in a hospital or nursing home environment, but often not effective during an emergency—such as an accident—when the health care agent cannot be reached
- Hypothetically gives proxy the opportunity to take advantage of the patient (though experts agree this infrequently happens in practice)
- Physicians too often ignore their obligation to fully engage the proxy in decisionmaking. Thus, the proxy often needs to be assertive in advocating for the patient, which may be difficult in an uncertain clinical situation

Guiding the Advance Care Planning Process: A Sampling of Tools

Many tools exist to guide patients and families in their conversations about end-of-life care preferences. A sampling of a half-dozen highly respected tools appears below, each with

diverse characteristics and designed to reach audiences in different ways. For more in-depth information about each tool, visit the Web sites listed under “Contact Info.”

Tool	Five Wishes	Respecting Choices	Caring Conversations
Owner	Aging with Dignity	Gundersen Lutheran Medical Foundation (LaCrosse, Wis.)	Center for Practical Bioethics
Contact Info	www.agingwithdignity.org/5wishes.html	www.gundluth.org/eolprograms	www.midbio.org/mbc-cc.htm
Format	Five-page lay language document offering five questions for patients and families to discuss	Training program for facilitators who become resident experts in ACP at health facilities—strong focus on organizational policy	Includes 16-page workbook; directive documents; speakers’ training program; 2 videos; facilitator’s notebook for four-hour workshop
Costs	\$5 individual copies, \$1 each for 25 or more	Varies with length of service contract and number of trainees	Entire toolkit, \$250; workbook \$2.50 or free for individuals online
Living Will	Included	Included	Included
Durable Power of Attorney	Included	Included	Included
Incentives for Honoring Wishes	None	Goal is to build respect for choices into each organization’s policies	None
Extent of Utilization (according to owner)	More than 3 million copies circulating in the U.S.; more than 5,000 organizations distributing	In use in 45 communities/health systems in the U.S.; partnership with Australia under development	More than 2 million documents have been distributed
Tool	Critical Conditions	Hard Choices for Loving People	Fidelity, Wisdom & Love
Owner	Georgia Healthcare Decisions	A&A Publishing	Joan and Sanford I. Weill Medical College of Cornell University
Contact Info	www.critical-conditions.org	www.hardchoices.com	http://fidelitywisdomandlove.org
Format	40-page booklet uses real-life health-crisis scenarios to help patients talk about their final health care choices with family members and record their wishes	80-page booklet covering most common medical decisions and emotional and spiritual issues, written by hospice chaplain in easy-to-read style	Based on empirical research. Workbook leads patient through choosing proxy; companion video provides additional support in preparing for decisionmaking
Costs	From \$8,500 to \$22,500 depending on size of health system enrolling in service contract	\$1 to \$4 apiece depending on quantity ordered, plus shipping; free to individuals on Web site	Workbook \$13, video \$19; quantity discounts available
Living Will	Included in customized document: “Directive for Final Health Care”	Not included	Discussed, but not included
Durable Power of Attorney	Included in “Directive for Final Health Care”	Not included	Included
Incentives for Honoring Wishes	Goal is to build this into each enrolled health system’s policies	None	None
Extent of Utilization (according to owner)	More than 100 Georgia health systems and many area agencies on aging and public health districts	More than 1 million copies sold to hospitals, nursing homes, hospice programs and faith communities since first printing (1990)	More than 1,000 Internet orders received from all 50 states; nearly 30,000 sold to institutions

Improving Advance Care Planning Policy and Practice

A Failed Policy?

Though many people were optimistic about the living will's capacity to improve end-of-life decisionmaking, unfortunately it has been fraught with limitations (see chart on p. 4).

Recently, experts have begun to express long-standing reservations or concerns that the living will, as a public policy instrument, has failed to carry out its expectations for transforming end-of-life decisionmaking. For example, a scathing March 2004 editorial in the *Hastings Report*, a prominent bioethics journal, called for the rejection of living wills as public policy: "Resources have been lavished to make living wills routine and even universal. This policy has not produced results that recompense its costs, and it should therefore be renounced."

As just one example of such "lavish" resources, the Center for Practical Bioethics (CPB), formerly Midwest Bioethics Center, has distributed more than 2 million health care treatment directives and educational brochures for free. "There's been a lot of money involved in this social policy," Myra Christopher, CPB, executive director, says ruefully. "And it is a social policy that has not worked on its own."

Christopher and others, while not advocating for the total renunciation of the living will, believe it should be used in conjunction with the durable power of attorney and that the latter should be given priority over the former. "Public policy should focus on the reality of how decisions are actually made," says Montefiore's Dubler. "The reality is that decisions are made by a grieving family member, or members, without specific authority. . . . We need to empower families."

For as helpful as the process of advance care planning can be to families, there are many barriers that prevent patients, families, and health care professionals from engaging in the process. Major barriers are created by state laws that privilege the standard of substituted judgment over the standard of best interests as represented by a proxy. Important ways to empower families through policy are described in the box to the right.

Best Interests versus Substituted Judgment

"When a person is unable to participate in a decision, we doctors should involve their agent just as if they were that person," says Brown's Teno. "But some states put limits on the durable power of attorney." In many states, the proxy's discretion to make end-of-life decisions is limited by the choices stated in the living will, if one exists, or to substituted judgment if there is no living will.

Many studies have defined the limitations of substituted judgment as a principle for end-of-life decision making for incapacitated patients. Daniel P. Sulmasy, MD, PhD, director of the Bioethics Institute at New York Medical College, says his work in progress is showing that, at diagnosis, most patients prefer a mixture of substituted judgment and best interests—and that this preference changes as illnesses progress. "During the illness, as they lose capacity, patients come to look for more input from the family," Sulmasy says. "When they can speak for themselves, patients put more weight on what the doctor says; as they lose capacity, they put more weight on their families" and their ability to decide what is best for them, he notes.

Five Tips for State Policymakers

- 1. Prioritize Use of the Health Care Proxy**
 Experts suggest states prioritize the use of the health care proxy over the living will, and broaden the task of the proxy to permit use of the best interests standard in addition to substituted judgment.
- 2. Simplify and Integrate Disparate Laws**
 Streamlining laws and combining numerous little laws into one comprehensive health care decisions law is one way to support effective decisionmaking.
- 3. Learn from the Uniform Act**
 The Uniform Health Care Decisions Act (UHCDA) places a high premium on simplicity. For more about the UHCDA, see the box on page 7.
- 4. Use a Regulatory, Not Just a Legislative, Approach**
 Maryland's regulatory agency, the Health Department's Office of Health Care Quality, for example, is conducting chart reviews in all nursing homes in the state to check whether the care specified in advance directives is consistent with care actually delivered.
- 5. Adopt Default Surrogacy Laws Where They Are Now Absent**
 Default surrogacy laws spell out specific procedures for determining surrogates when no advance directive exists. Having such laws on the books helps to ensure quality care at the end of life.

Accordingly, Sulmasy suggests state laws be revised “to privilege the use of the health care proxy over the living will, which would allow people who wanted to have substituted judgment to enact that, but also allow people who want best interests to enact that—or to permit a combination of the two,” he says. “A living will is based solely on the substituted judgment model, and not everybody fits into that model.”

Simplifying and Integrating State Laws

Another way to support patients and proxies is to streamline the law and combine separate laws into one. For example, West Virginia in 2000 integrated and simplified three disparate advance care planning laws into one comprehensive health care decisions act. Proxies in West Virginia now have the same authority as the patient in all medical decisionmaking, says Sabatino. And—underscoring Sulmasy’s findings—patients like it this way: a study of dialysis patients and their proxies from three states

showed that 85 percent of those from West Virginia felt comfortable with their state law, while only 26 percent of those from New York and 18 percent of those from Pennsylvania felt comfortable with their states’ laws. In the latter two states, Sabatino notes, the authority of the proxy is limited, with New York’s law prohibiting proxies from making any decisions on their own: they may only communicate the patient’s previously articulated preferences, “at least in theory,” he adds. “In practice, it is impossible for people to express their preferences about every possible decision, so proxies by necessity have to exercise their own judgment on behalf of patients for whom they are acting.”

In addition, Sabatino notes, “There is a sizeable handful of states, including New York, that have no law on family decisionmaking in absence of advance directives.” Such laws are called “default surrogacy laws,” and because the reality is that so many individuals never appoint a proxy, states that do

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Charles P. Sabatino, JD, assistant director of the ABA Commission on Law and Aging

More about the Uniform Act (UHCDA)

In considering ways to change their laws to make advance care planning more effective, the Uniform Health Care Decisions Act (UHCDA) is one source of ideas to which states have looked. This model legislation was drafted in the wake of the Cruzan case by the National Conference of Commissioners on Uniform State Laws, which recognized a need for more uniformity in state advance care planning laws that were developing in fits and starts across the country.

“The Uniform Act places a high premium on simplicity,” says the ABA’s Sabatino. It eliminates some requirements that states place on advance directives, including

notarization and witnesses (some states require multiple witnesses, and some specify they must be unrelated or disinterested in the patient’s case). Many state laws require patients to complete their advance directives on prescribed forms that can be difficult to obtain and understand; the UHCDA permits patients to express advance directives orally.

Modeling its amended law on the UHCDA, Maryland now permits residents to designate a proxy and express their advance directives orally if they wish. “In the real world, patients are in the hospital or nursing home, in a place where what they really want to do is talk to their doctor,” says

Schwartz. “States should have a provision allowing the advance care planning process to be done in a conversation between the doctor and patient, so that the patient doesn’t have to wade through four pages of a legal document—they can just talk.”

Alabama, Delaware, Hawaii, Maine, Mississippi, and New Mexico have also enacted revisions to their advance directives legislation based on the UHCDA. “The goal is to make portability of advance directives across state lines easier and more consistent,” Sabatino says.

not have them should consider them, Sabatino suggests. Most default surrogacy laws include a hierarchical list of potential proxies, giving next of kin top priority, and moving down the ranks of nearness of relation. If there is more than one person at the operational level—for example, a number of adult children—then usually the majority rules. “This works well in the Senate but not in the hospital corridor,” Sabatino says. He and others suggest that state default surrogacy laws encourage family and providers to achieve consensus and provide supports, such as ethics committees, to help work through disputes when they arise.

Regulatory Approaches to Honoring Advance Directives

Some end-of-life care experts believe that it may be better to depend on regulatory agencies than on laws to ensure that advance directives are honored. For example, in Maryland, the Health Department’s Office of Health Care Quality has initiated a routine practice for surveyors to check whether nursing home residents have advance directives, and if so, whether the care delivered was consistent with the plans in the record.

The most prominent sanction the agency has delivered came in 2002, when the regulatory agency fined a Baltimore nursing home \$10,000 for violating the living will of one of its residents. The living will had made it clear that, at an end-stage condition, the resident wanted no artificial nutrition and hydration. “It was as clear as any instrument could be,” says Schwartz. Yet at that moment, the patient’s agent—her adult son—insisted that she receive nutrition and hydration despite the directive. “Although the nursing home knew it should follow the directive, the son threatened to sue, and the facility caved in,” Schwartz says. Later, during the chart review, the regulatory agency found that the violation of the resident’s wishes was a major deficiency of care and enacted the penalty. There have been other lesser cases, Schwartz says.

“The lawsuit was an empty threat,” says Schwartz. “In any case, threats or no threats, there was an overriding ethical and legal obligation to honor the expressed, unambiguous wishes of the patient.” ■

New!

Series Addressing the Nursing Shortage Announced

The Robert Wood Johnson Foundation (RWJF) has just launched a series of policy briefs offering practical guidance to policy leaders, policy influencers, nursing educators, and employers working to address the growing nationwide shortage of registered nurses. Titled *Charting Nursing’s Future: Reports on Policies That Can Transform Patient Care*, the series will examine a wide range of problems contributing to the shortage and showcase policy-related solutions that are getting promising results.

Issue #1 of *Charting Nursing’s Future* features ten model partnerships among governments, nursing schools, and nurse employers that are improving nursing work environments and increasing the number of nursing faculty as well as nursing school students and graduates. The eight-page brief offers national and state-by-state data illustrating the scope of the shortage (2005–2020), as well as perspectives by policy leaders and nurse educators and employers.

Information about the Series

“Advance Care Planning—Part III: New Directions in Policy and Practice” is the 23rd in a series of briefs profiling promising policies and practices in end-of-life care, and the third in a miniseries about improving advance care planning.

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Editorial guidance for the *State Initiatives* series is provided jointly by the Center for Practical Bioethics (CPB) and The Robert Wood Johnson Foundation. The Foundation supplies series funding.

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