



## Defining Features of Advance Directives in Law and Clinical Practice

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In the > 30 years since the New Jersey Supreme Court's seminal opinion in the case of Karen Ann Quinlan, all 50 states and the District of Columbia have enacted legislation to recognize the legal right of competent adults to write advance directives. The purpose of advance directives is to provide direction for health-care decisions near the end of life, when the ravages of illness, disease, or injury have taken the ability to decide for one's self. This article reviews the defining features of advance directives and the governing law, discusses some common practical concerns regarding the use and effectiveness of advance directives, and identifies several significant ethical-legal challenges for honoring advance directives at the bedside. With a primary focus on the health-care proxy, the anatomy of advance directives is analyzed under four general rubrics: formal requirements, decisional capacity and when the directive takes effect, rights and responsibilities of proxies and health-care providers, and the scope and limitations of decisions to forego life-sustaining treatment. There is much common ground among state laws, but particular legal provisions may vary from state to state. Physicians, nurses, social workers, and other health-care professionals should be familiar with the law of their home state. *CHEST* 2012; 141(1):232–238

**Abbreviations:** POLST = Physician Orders for Life-Sustaining Treatment; PVS = persistent vegetative state

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All 50 states and the District of Columbia recognize the legal right of competent adults to write advance directives to provide direction for health-care decisions near the end of life, when the ravages of illness, disease, or injury have taken the ability to decide for one's self. Advance directives may designate someone to make health-care decisions on the

patient's behalf (a "proxy directive" or "durable power of attorney for health care"), state with some specificity the person's wishes and instructions for care (a "living will" or "instruction directive"), or both (a "combined directive"). Most state statutes recognize both proxies and living wills and allow for combined directives; New York, Massachusetts, and Michigan recognize by statute only the health-care proxy.<sup>1</sup> This article reviews the defining features of advance directives and the governing law. I discuss some common

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### For editorial comment see page 8

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practical concerns regarding the use and effectiveness of advance directives and identify several significant ethical-legal challenges for honoring advance directives at the bedside. Though the living will was the first approach to advance directives, developed in 1967 by the Euthanasia Society of America,<sup>2</sup> health-care proxies have become the preferred and most widely used directive. Among the reasons are that they are simple to use, permit the designated proxies to respond prudently to the patient's current circumstances, and avoid many (but not all) of the well-documented problems that arise with the

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interpretation of living wills that were sometimes written ten years ago and that may not anticipate the patient's current condition and treatment options.<sup>3</sup> Hence, this review focuses primarily on the role of health-care proxies. While there is much common ground among state laws, particular legal provisions may vary from state to state. Physicians, nurses, social workers, and other health-care professionals should be familiar with the law of their home state.

## BACKGROUND

As discussed elsewhere in this series, the right to refuse life-sustaining treatment was first established in case law.<sup>4</sup> In the seminal case of *Karen Ann Quinlan* (1976),<sup>5</sup> the New Jersey Supreme Court recognized a constitutional right to refuse unwanted bodily interventions, including life-sustaining treatment, and held that when patients are unable to exercise that right, family members may forego life support on behalf of incompetent loved ones based on the patient's wishes and best interests (often referred to as "substituted judgment"). In the ensuing two decades, states across the country had their own much-publicized cases that required judicial resolution, patient-care dilemmas that played out before the very public scrutiny of the courtroom and the media. Although *Quinlan* was not binding beyond the Garden State, courts consistently found the *Quinlan* opinion's reasoning persuasive. In the next 15 years, a judicial consensus emerged supporting patients' rights and the authority of family members to make end-of-life decisions. Some courts ground these rights in the Constitution, others look to the common-law right of self-determination. The US Supreme Court's decision in the case of *Nancy Beth Cruzan* (1990)<sup>6</sup> solidified the legal-ethical consensus while allowing states freedom to craft rules for decisions near the end of life that do not unduly infringe on patients' constitutionally protected rights to control their own health care.

Daily experience in hospitals across the country evidences the very same challenges presented to the courts. When making end-of-life decisions for loved ones unable to make their own informed decisions, how are family members and health-care providers to reconstruct and present a reliable account of the patient's wishes based on the patient's prior statements, values, and beliefs? In response to this problem, high-profile court cases, the growing complexities of end-of-life care, the ascent of patient autonomy in medical ethics, and the clarion call for expansion of patient and family rights, state legislatures began to enact advance-directive laws. These laws establish the right to put one's wishes for future care in writing

and impose obligations on physicians, hospitals, families, and others to honor the patient's wishes. In this way, the law extends to incompetent patients the same rights of self-determination that we have as competent patients. Most often, advance directives are used to appoint a health-care proxy and to direct the withholding or withdrawal of life-sustaining interventions. Many states also allow the use of directives to request continued life support. Advance directives are grounded in the principle of prospective autonomy, the idea that it is an expression of our moral agency to make plans and take actions now that are intended to control our health care in the future.<sup>7</sup> A prospectively autonomous directive commits to writing a personal plan for control of the dying process to guide the course of care and treatment when a person is no longer able to make contemporaneous decisions and perhaps no longer able to appreciate whether his or her wishes and values are honored or disregarded.<sup>8</sup>

In the aftermath of the *Cruzan* case, the US Congress made a rare foray into the end-of-life arena with the enactment of the Patient Self-Determination Act. This procedural law imposes obligations on hospitals and other health-care facilities nationwide to ask patients and families if there is an advance directive, document patients' "advance directive status," and provide information about patients' rights and advance-care planning.<sup>9</sup> The Patient Self-Determination Act bolsters state law, but defers to the states as the source of substantive rights and rules for end-of-life decisions.

## THE ANATOMY OF ADVANCE DIRECTIVES

Advance-directive laws nationally share a familiar anatomy. It is useful to group state legal provisions under four general rubrics: formal requirements, decisional capacity and when the directive takes effect; rights and responsibilities of proxies and health-care providers, and the scope and limitations of decisions to forego life-sustaining treatment. The role of ethics consultation in resolving disagreements, typically not required by law, is a further important feature of the landscape.

### *Formal Requirements*

Modeled after time-honored statutes governing testamentary wills that provide for family and distribute one's property after death, advance directives must comply with prescribed formalities for valid execution of the document. Directives must be signed and dated and must usually be witnessed by two people.<sup>10</sup> States impose various restrictions on who may serve as witnesses. Most often the appointed

proxy, a spouse or relative, and the health-care provider are not permitted to witness. A few states also require a notary public (eg, North Carolina)<sup>11</sup>; others allow this as an alternative to witnessing (eg, California).<sup>12</sup> Generally, the individual can choose a spouse, adult child, sibling, close friend, or religious advisor as his or her proxy, but most states prohibit the patient's physician or long-term care provider from serving in both roles out of concern for possible conflict of interest. Individuals are encouraged to also choose an alternate proxy, anticipating the possibility that the first choice may be unavailable, unwilling, or not able (competent) to serve when the time comes. Directives remain valid unless and until revoked by the author, such as by destruction of the document, stating the intent to revoke it, completing a new directive, or divorce. Most states provide that use of a standard form is optional, but incorporation of the "suggested" form itself into the law (eg, Minnesota)<sup>13</sup> makes the statutory form the most recognizable and creates the impression that it is the preferred document. Adoption of a standard form by state agencies sends the same message. At the same time, the option to use other approaches so long as they comply with the requisite formalities has allowed various consumer and advocacy organizations to develop more user-friendly forms and educational materials that are widely available.<sup>14</sup> Laws uniformly state that no one can be required to have an advance directive as a condition of receiving health care, nor can insurance companies make having or not having advance directives a condition of coverage.

Nearly all states recognize directives from other states (termed "reciprocity"), so long as the formalities comply with the law of the home or neighboring state. Out-of-state documents are to be respected on the same basis as in-state documents. But an important limitation is that physicians and hospitals have no obligation to comply with instructions in out-of-state directives that contravene the law of their own state. Strictly speaking, a hospital in Wisconsin, where express authority to refuse a feeding tube is required,<sup>15</sup> need not comply with this refusal by a proxy appointed in neighboring Iowa, where there is no such requirement, when the proxy cannot identify a statement from the patient authorizing forgoing artificial feeding. (This and other limitations on the right to refuse treatment are discussed in the following sections.)

In a recent review of advance-directive laws nationally, Castillo and colleagues<sup>16</sup> identify several common "legal and content-related barriers" to effective use of advance directives. The authors found that standard-form documents are typically phrased in legalese and use complex or ambiguous terms (poor readability), a possibly significant problem for those with limited health literacy. Restrictions on who may serve

as a health-care proxy may disenfranchise some patients; so too, the requirement that two witnesses attest the patient's signature. These legal mandates may be impediments, for example, for the unbefriended elderly in nursing homes whose closest relationship is with a care provider. Only some states expressly include domestic partners as eligible proxies. Though domestic partners should qualify as "close friends" for this purpose, this may be unclear in some states. The standard range of options in legally sanctioned forms may also fail to accommodate the diversity of religious, cultural, and social values by discouraging expression of personal values and directions. And forms are frequently not available in languages other than English (Spanish-language documents are sometimes available).<sup>17</sup>

Castillo et al<sup>16</sup> argue that these "unintended consequences" should be addressed through law reform to enhance the use and effectiveness of advance directives. Others have identified these same problems with similar calls to change the law.<sup>18</sup> Practical challenges with advance-care planning are likely to persist. A few states have successfully amended their laws to relax some of these requirements and make the law more patient friendly,<sup>19</sup> but these efforts have been unsuccessful elsewhere.<sup>20</sup> Law-reform advocates should be mindful that they may thereby invite legislative reconsideration of the scope of rights to refuse treatment that so many have worked so hard to establish for patients and their families.

Recent complementary developments in law and practice address some of these shortcomings of advance directives by offering an alternative mechanism to document patient and family wishes. Many states have adopted some version of the Physician Orders for Life-Sustaining Treatment (POLST) document, originally developed in Oregon.<sup>21</sup> This document (MOLST in New York,<sup>22</sup> LaPOST in Louisiana<sup>23</sup>) allows physicians to document the patient's choice of a preferred surrogate and his or her treatment preferences, such as for a do-not-resuscitate order. It is important to note that POLST and its variations are not advance directives, as the two are sometimes confused. Usually completed in the hospital, POLST brings together in one place all physician orders for end-of-life care based on patient and surrogate decisions about the patient's current condition and treatment options now and in the near-term. The easily recognized form (often brightly colored) is a contemporaneous vehicle for making patient wishes count when there is no advance directive, and it is also used to enter orders implementing directives. Though supported by law, POLST and its variations generally do not create substantive rights. They complement surrogate consent laws in place in most states that authorize families to decide for incompetent

loved ones in the absence of a written directive.<sup>24</sup> (An article on this topic will be forthcoming from Thaddeus Pope, JD, PhD, in a future issue of *CHEST*).

### *Decisional Capacity: When the Directive Takes Effect*

Advance directives take effect and become the primary basis for decisions only when the patient lacks decisional capacity. Adults are presumed competent (to have capacity) until determined otherwise. The attending physician is responsible for determining capacity and incapacity; the nature, extent, cause, and probable duration of the patient's incapacity is to be documented in the medical record. Often, a second physician must confirm this judgment. Some states require that the confirming physician have specialized expertise if the patient has a history of mental retardation or developmental disability (eg, New York)<sup>25</sup>; some waive the second physician requirement if the patient's incapacity is clearly apparent, for example, a patient in a persistent vegetative state (PVS) (eg, New Jersey).<sup>26</sup>

In practice, two sorts of capacity-related questions frequently arise. First, the patient may be unable to understand and reason about his or her medical condition and the risks and benefits of treatment alternatives, but still be able to choose a spouse or adult child as a health-care proxy. Here, a decision-specific approach to capacity may allow the patient to select a proxy despite cognitive impairments that prevent the patient from giving informed consent or refusal for the more complex treatment decision. Second, patients may have fluctuating capacity, able to make certain decisions one day but not the next. Respect for autonomy includes maximizing opportunities for patients to make their own decisions. When a patient has the capacity to decide, the patient's wishes trump prior directives and the urgings of a health-care proxy. In effect, the locus of decisional authority shifts back to the patient, but when the patient's condition deteriorates and capacity is lost again, the directive would again spring into effect. A decision-specific approach to capacity assessment is widely accepted in medical ethics and clinical practice but is expressly found in only some advance-directive laws (eg, New Jersey).<sup>27</sup>

### *Rights and Responsibilities of Proxies and Health-Care Providers*

The heart of the law addresses rights and responsibilities when patients without decisional capacity have advance directives. First, the designated proxy is to make decisions based on the patient's own wishes and values. Second, the proxy is to act in the patient's best interests. A proxy's fiduciary duty is recited both in law and in advance-directive forms themselves. It is

often stated that proxies may make any and all decisions the patient could if competent. While the focus is on whether to provide or forego life support, proxies may also give consent for discharge to home hospice care or a nursing facility, control access to otherwise confidential patient information, carry out the patient's intent to donate organs, and make other choices the patient could if able to do so. Sometimes, directives seek to anticipate decisions about psychotropic drugs, restraints, hospital admission, and other mental-health issues. A number of states have separate legislation for "psychiatric advance directives" (not included in this review).<sup>28</sup> Proxies may also consent to nonhospital do-not-resuscitate orders, but proxy refusal of CPR is not likely to be honored by emergency medical technicians in the field absent a physician's order (usually on a specific form).<sup>29</sup>

Physicians and other health-care providers are obligated to respect patients' directives, in particular, to accept the rights and authority of proxies. To encourage compliance, statutes uniformly grant immunity from civil or criminal liability and from professional discipline to physicians, hospitals, and others who act in good faith to forego life support, consonant with accepted medical standards and in accord with the patient's wishes (and the proxy's direction). Historically, these immunities were intended to address concerns that removal of life support could lead to lawsuits from grieving family members, or even criminal charges. In fact, few lawsuits and fewer criminal charges have claimed wrongful withdrawal of life support when done in compliance with the patient's or family's wishes. Conversely, suits alleging wrongful disregard for the now-incompetent patient's treatment refusal (loosely, a claim for "wrongful life") have also been few and have been nearly always unsuccessful.<sup>30</sup> As a vehicle for shaping professional behavior, statutory immunities themselves have likely had modest impact, but they are an important piece of the evolution to a medical-ethical-legal consensus that it is the standard of care to abate aggressive interventions when the patient or appropriate surrogate refuses prolongation of the dying process.

Physicians sometimes believe that the law commands adherence to the proxy's decision whatever it is. Others resist ceding authority over treatment decisions or are simply ambivalent about the proxy's role.<sup>31</sup> Though proxies are entrusted to know the patient's wishes, their accounts are sometimes inaccurate.<sup>32</sup> In practice, other family members provide important information about the patient's wishes and may disagree about what their loved one would want. On occasion, families contest the circumstances and propriety of the proxy appointment itself. Legally, the proxy's authority takes precedence (unless the patient

has directed that decisions be made jointly). But where the ethical imperative to honor the patient's wishes and/or best interests conflicts with the legal mandate of the proxy—there is reason to believe the proxy is emotionally unable to bear the burdens of decision making or the proxy has ill motive—overriding the proxy may be considered. Removing a “rebel proxy” for failure to meet his or her fiduciary duty to the patient or overriding his or her decision about life support may require going to court.<sup>33</sup>

Building on long-standing ethical and legal commitments to respect for professional conscience, statutes typically allow physicians and other health-care professionals to refuse to participate in decisions to forego life support if doing so would violate sincerely held personal, religious, or professional values and commitments. Withdrawal of feeding tubes (discussed in the “Scope of Decisions to Forego Life-Sustaining Treatment” section) is the paradigm example, but increasingly physicians object to proxy (or family) insistence on interventions considered inappropriate or “medically futile.” Notwithstanding the overwhelming ethical-legal consensus that from the standpoint of patients' rights there is no difference between withholding and withdrawing treatment, some physicians may find it psychologically or emotionally difficult to withdraw, but not to withhold, treatment.<sup>34</sup> When conscientious objection is asserted, physicians and hospitals bear the responsibility for notifying the patient and family and arranging a transfer of care. Pending appropriate transfer to another provider who will comply with the patient or proxy directions, care must be provided and the patient cannot be abandoned. Parallel rights of institutional conscience for private, religiously affiliated facilities (eg, a Catholic hospital) are also common, with conditions that there must be written policies, notice to patients and families prior to or upon admission, and an obligation to transfer care in the event of conflict.<sup>35</sup>

#### *Scope of Decisions to Forego Life-Sustaining Treatment*

Most advance-directive laws permit the forgoing of life support when the patient is either terminally ill or permanently unconscious. This approach is heavily influenced by precedent court cases that most often involved patients who were either terminally ill or in a PVS. Statutory limitations also represent a political and value compromise between patients' rights and the societal interest in preserving life. By statute or under related law and practice, a “terminal condition” may be defined as “death within a short time” or within approximately 1 year<sup>10</sup>; clinical practice often follows hospice guidelines that call for a prognosis

of  $\leq 6$  months. Physicians caring for dying patients know well that making a definitive prognosis can be an uncertain task. Literal legal definitions are often ignored in practice, and “terminal” is interpreted flexibly with the goal of honoring the patient's refusal of treatment and desire to be comfortable throughout the dying process. A second concurring opinion from a “qualified physician” that the patient's condition is terminal or of permanent unconsciousness is often required. Though not specified by law, the diagnosis of PVS typically follows established clinical guidelines that require an observation period of months to  $\leq 1$  year to rule out any chance of meaningful recovery, depending on the nature of the brain injury.<sup>36</sup>

Judicial consensus firmly establishes the right to refuse any and all unwanted bodily interventions and draws no distinctions among respirators, feeding tubes, dialysis, antibiotics, and other medical modalities. By contrast, a number of state legislatures have given limited voice to the minority view that artificial fluids and nutrition are akin to the provision of food and water, are symbolically and culturally expressive of basic human caring, and should be considered obligatory care. (The mistaken belief that patients in a PVS experience death by starvation and dehydration also achieved some political traction.) The compromise of this highly charged debate<sup>37</sup> has been that some state laws impose special rules for the withholding and withdrawal of artificially-provided fluids and nutrition,<sup>1</sup> such as a requirement that the patient's directive give specific authorization or direction to forego artificial fluids and nutrition (eg, Pennsylvania).<sup>38</sup>

These limitations with respect to medical conditions and the modalities of artificial fluids and nutrition place boundaries on patient rights and restrict proxy authority. (So, too, do restrictions on forgoing treatment during pregnancy.) They can pose major substantive concerns at the bedside, presenting a conflict between what is ethical and what is legal. Consider the patient with progressive, irreversible Alzheimer dementia not yet at a terminal stage, for whom the proxy refuses antibiotics that would cure an otherwise life-threatening pneumonia. Or consider the patient who has suffered a devastating stroke and is relatively stable with a minimal level of consciousness, for whom the proxy refuses a ventilator, knowing there is a chance the patient could be weaned and breath on his or her own, but with no meaningful prospect of recovering mental function. Many of us would find being sustained in such conditions with their inevitable downward path to be a life with no meaningful quality an undignified existence that imposes unwanted burdens on self and family. Some states authorize and recognize directives that refuse treatment when the patient has a progressive, irreversible condition and the burdens of aggressive

intervention outweigh the benefits, designating such a condition as an “end-stage condition” (Florida)<sup>39</sup> or “progressive illness that will be fatal and is in an advanced stage” (Oregon).<sup>40</sup> But in most states, where forgoing life-sustaining treatment is expressly authorized only for terminal conditions and permanent unconsciousness and not in these latter circumstances as well, health-care providers must ask, If the law does not permit forgoing treatment, does it, therefore, prohibit it?<sup>41</sup> Phrased differently, there may be a strong ethical argument to comply with the patient’s (and proxy’s) refusal, but is this legal?

When dilemmas arise about the compatibility of ethical principles and legal rules, proxy authority, professional conscience, or other issues, ethics consultants and ethics committees can be valuable resources to help resolve disagreements and avoid legal entanglements. There is very little law that directly addresses the role of ethics committees, and less still regarding consultants. Importantly, ethics consultants give advice and make recommendations, but do not make patient-care decisions. Ultimately, decisional authority remains within the confines of the physician-patient-proxy relationship.

#### CONCLUSION

The first advance-directive law, California’s “Natural Death Act,” was enacted in 1976, shortly after the *Quinlan* decision. More than 30 years later, legislation nationally has established the right to plan ahead to control treatment decisions in anticipation of future loss of decisional capacity and has figured prominently in the paradigm shift in medical practice and culture that puts the patient’s voice at the center of end-of-life decisions. Yet only about 20% of us have written advance directives, a number that has remained relatively stable over time,<sup>42</sup> with greater frequency of use reported among the elderly,<sup>43</sup> nursing home patients,<sup>44</sup> and people living with HIV/AIDS.<sup>45</sup> Continuing efforts to ease legal restrictions, promote advance-care planning, and even reimburse physicians for end-of-life discussions<sup>46</sup> should increase the use of advance directives, but these likely will be modest gains. More than 1 million people die in US hospitals each year after a decision to withhold or withdraw life support.<sup>47</sup> It will no doubt continue to be true that more often than not we will look to family, friends, and others to decide for incompetent loved ones without written evidence of the patient’s wishes. An article in a forthcoming issue of *CHEST* from this series will discuss the ethical-legal framework governing surrogate decision making for patients who have lost their decisional capacity and have not put their wishes in writing.

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