

*Advance Proxy Planning for Residents
of Long Term Care Facilities Who Lack
Decision-Making Capacity*

*A Report by the National Ethics Committee
of the Veterans Health Administration*

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Founded in 1986, the National Ethics Committee (NEC) of the Veterans Health Administration (VHA) is an interdisciplinary group authorized by the Under Secretary for Health through the National Center for Ethics. The NEC produces reports on timely topics that are of significant concern to practicing health care professionals. Each report describes an ethical issue, summarizes its historical context, discusses its relevance to VHA, reviews current controversies, and outlines practical recommendations. Previous reports have been useful to VHA professionals as resources for educational programs, guides for patient care practices, and catalysts for health policy reform. Scholarly yet practical, these reports are intended to heighten awareness of ethical issues and to improve the quality of health care, both within and beyond VHA.

Executive Summary

The National Ethics Committee of the Veterans Health Administration (VHA) issues periodic reports that are intended to heighten awareness of ethical issues and to improve patient care, both within VHA and beyond. These reports also provide insight into the development of ethics standards by the largest integrated health care delivery system in the country.

This report examines whether long term care facilities should implement policies and procedures to support advance care planning by proxy for residents who lack decision-making capacity. The report reviews clinical, legal, and ethical perspectives, concluding that advance proxy planning is ethically sound and can improve patient care. Because experience with advance proxy planning is still fairly limited, however, the Committee does not recommend that a particular standardized approach be mandated at the national level. Instead, local facilities are advised to develop their own policies, then evaluate their impact. The report contains specific recommendations for the advance proxy planning process.

Introduction

Advance directives enable competent patients to express their wishes and to provide instructions about their future medical care in the event that they lose decision-making capacity at some later time.^{1,2} In this way, patients can continue to direct their medical care even when they are no longer able to make their own health care decisions. But the usual types of advance directives apply only to patients who have decision-making capacity at the time the directive is completed. No analogous mechanism is routinely available to families of patients who have already lost decision-making capacity. As a result, many families never seriously consider their loved one's preferences for life-sustaining treatment until they are called upon to make a critical decision in the midst of a medical emergency. The stress of these situations can be significantly mitigated when families have the opportunity to discuss and document health care plans in advance.

To apply the concept of advance care planning to patients who lack decision-making capacity, several Veterans Affairs Medical Centers (VAMCs) have successfully pioneered and implemented what they call "proxy plans" – a type of advance care planning in which a surrogate decision-maker or proxy represents the patient's interests in specifying treatment preferences on behalf of a decisionally incapacitated patient. This type of planning is particularly suited to long term care settings such as nursing homes, where it is common for patients and families to choose to forgo life-sustaining treatments, and where undue suffering can often be avoided by anticipating medical decisions before they occur.

The national policy of the Department of Veterans Affairs (VA) provides no specific guidance on advance care planning for long term care residents who lack decision-making capacity.^{3,4} This report by the VHA National Ethics Committee examines the issue of advance care planning for residents of long term care facilities who lack decision-making capacity. It analyzes the ethical and legal issues involved, discusses experience within VHA, and concludes with recommendations that may be useful to policymakers both within VHA and beyond. The Committee chose to focus this report on long term care facilities because most of the experience with advance proxy planning within VHA and in the literature has occurred in this setting. Although many of the concepts of advance proxy planning described in this report are equally applicable outside of long term care facilities, the details of the recommended process would need to be modified for use in other settings.

Background

A fundamental value expressed in advance health care planning is that, to the extent possible, patients should have a right to choose their own medical care. Competent patients have the right to specify in advance how they would like health care decisions to be made if they were to become unable to make decisions themselves. The right to execute advance directives is affirmed by the Patient Self-Determination Act (PSDA), a Federal law that requires all health care institutions that receive Medicare or Medicaid funding to inform patients about their legal rights to execute an advance directive.⁵ Since the passage of the PSDA, the frequency of advance directives in nursing homes has risen significantly, though there has been no demonstrable increase in physicians' orders to withhold or withdraw specific life-sustaining interventions.^{6,7}

The use of advance directives is now commonplace. Even so, a majority of individuals still never formally express their preferences or name a proxy in a written document. There are several possible explanations of why more people do not complete advance directives. For example, some people may fail to consider the possibility that they would ever lose cognitive capacity. Others may be reluctant to discuss their own deaths or trust their loved ones to make decisions for them. Surveys suggest that most patients do want to discuss these issues, but many believe that physicians (who tend to raise the topic infrequently) should be the ones to initiate advance directive

conversations.^{8,9,10} In some cases, individuals who intend to sign an advance directive may lose decision-making capacity before they have the chance to do so.

Patients who become unable to make decisions do not lose the right to have their previously expressed wishes followed or to have a proxy decision-maker act on their behalf.¹¹ For the purposes of this paper, we will define “proxy” as the person who is best qualified to speak for the patient. The term proxy is often used interchangeably with the word surrogate. Most often the proxy is the patient’s next of kin or other close family member or friend who knows the patient well and is in a position to represent the patient’s interests. The proxy may also be an individual designated by the patient (power of attorney for health care) or by a court (guardian) to make health care decisions for the patient. The proxy should base decisions on the “substituted judgment” standard where the proxy follows the preferences expressed by the patient prior to losing capacity to make decisions. If the patient’s preferences are not known, the proxy should use a “best interests” approach, where decisions are based on an assessment of the best interests of the patient.¹²

Current VHA national policy allows proxies of decisionally incapacitated patients to consent to medical treatments, including decisions to limit care.^{13,14} For example, a proxy may authorize a do-not-resuscitate (DNR) order even in the absence of any advance directive.¹⁵ Although proxies are empowered to make health care decisions for incapacitated veterans, there is no uniform standardized process for discussing and documenting specific treatment decisions in advance. Proxies who are confronted with such decisions in the face of an acute change in the patient’s clinical condition may feel unprepared, confused, or overwhelmed. Anticipating and discussing such decisions in advance can help protect and recognize the interests of vulnerable individuals.

The Role of Families in Advance Care Planning

Families play a critical role in helping to determine the care received by patients who lack the capacity to make their own health care decisions. In long term care facilities, where residents commonly have dementia or other illnesses that prevent them from participating in medical decision-making, families often serve as advocates and decision-makers for their loved ones.^{16,17} Historically, physicians and others have routinely relied on family members to serve as proxy decision-makers in such settings.¹⁸

From a philosophical perspective, the moral authority of families to serve as proxy decision-makers is complex and multifaceted.^{19,20} From an evidence-based perspective, most people seem to want their family members to determine what is best for them when they are no longer able to do so. For example, in an interview study of residents of Kentucky, 90% of participants who were asked “If you were too sick to make an important decision about your health care, who would you want to make the final decision for you?” responded that they would prefer a family member as surrogate.²¹ Seriously ill and elderly patients appear to be especially likely to want their family and physician to make decisions for them.^{22,23} At least one study suggests that a possible explanation for the low rates of advance directives use by the elderly is that they trust their families to make decisions for them.²²

Survey of State Statutes and Case Law

In writing this report, the Committee surveyed state statutes and recent case law to determine how legislatures and courts have dealt with the issue of advance care planning by proxy decision-makers. The Committee found broad support for the right of competent adults to plan for their future health care through advance directives. Also widely accepted is the authority of proxies to make health care decisions on behalf incompetent patients, including decisions to forgo life-sustaining treatment. A majority of states have statutes that specifically authorize family members or other proxies to make health care decisions on behalf of patients who lack decision-making

capacity and have no advance directive.²⁴ Most states and courts have never directly addressed the question of whether proxies can authorize the withholding or withdrawal of treatment in advance.

A handful of states do, however, specifically authorize the documentation of proxies' treatment decisions in advance. Under the Arkansas Rights of the Terminally Ill or Permanently Unconscious Act, a parent, spouse, adult child, adult sibling, or legal guardian may sign a declaration on behalf of a patient who lacks decision-making capacity regarding the use of life-sustaining treatment.²⁵ Louisiana law also allows certain individuals to sign a declaration to withhold or withdraw life-sustaining treatment on behalf of patients with terminal and irreversible conditions who are incapable of communication.²⁶ Proxy decision-makers are similarly authorized to complete advance directives on behalf of terminally ill minor children in Louisiana,²⁷ Texas,²⁸ and New Mexico.²⁹

The Oregon Experience

Oregon has been progressive in its efforts to support the rights of patients to direct their health care near the end of life. One recent effort involved the development and implementation in long term care settings of the POLST (Physician Orders for Life-Sustaining Treatment) form. The first portion of the POLST form details the preferences of either the patient or surrogate with respect to resuscitation, transfer to an acute care facility, antibiotics, artificial fluid and nutrition, and overall treatment approach. The remainder of the document describes how to use the form and how to revise it. Use of the POLST form is voluntary, but periodic review and updating of active forms is required. The POLST form is designed to complement, not replace, advance directives. It centralizes information, facilitates record keeping, and ensures the communication of appropriate information between health care providers and settings. A survey of eight geographically diverse long term adult-care facilities in Oregon where the form was employed showed that the preferences documented on the forms were universally followed.³⁰ Consistent with the form's instructions, study subjects received high levels of comfort care and low rates of transfer for aggressive life-extending treatments.

Survey of Current Practice in Several VHA Facilities

Three focus groups involving 20 health care providers from 10 VA health care facilities were convened to collect information regarding current proxy planning practices in VHA. Although participants were familiar with national and local policies regarding DNR orders for terminally ill patients who lack decision-making capacity, they reported no uniform method for recording DNR decisions. Decisions were variously documented in progress notes, on state forms designed for individuals who lack decision-making capacity, on advance directive forms designed for competent patients, or on VHA forms designed for a specific institution. The signature of the proxy decision-maker was rarely required, although several participants thought that requiring a signature might encourage more detailed discussions.

None of the focus group participants knew of any specific VAMC policies that support documentation of advance proxy plans apart from DNR orders. Participants noted that in the absence of such plans, on-call physicians with little knowledge of patient and family preferences often initiate discussions with proxies in the midst of a medical emergency, causing undue stress. The participants also felt that it was difficult if not impossible to build a mutually trusting relationship under such unfavorable circumstances. They additionally believed that patients without advance care plans often suffer needlessly, in that unwanted or unhelpful interventions may be provided unless there are specific orders to the contrary. None of the focus group members thought that communication between proxies and health care teams would decrease due to excessive reliance on proxy planning documents. Rather, they thought that the documents would serve as a stimulus for further discussion.

Although no one in the focus group knew of any specific VAMC policy supporting advance proxy planning for residents of long term care who lack decision-making capacity, there are in fact at least two such policies. At the Leestown Division of the VAMC in Lexington, Ky, the health care team uses a Family Treatment Preference form to help family members articulate a patient's previously expressed wishes and best interests. The form also prompts the health care team and the proxy to develop an explicit plan of care, which can later be changed. These plans often relieve clinicians of the need to ask proxies to make new decisions during a medical crisis. The institution's policy also encourages conferences for the purpose of sharing information between families and treatment teams. The policy and form have been successfully tested at several long term care sites and were well received by family members.³

A similar process has been used for the past 14 years at the Dementia Special Care Unit at the E.N. Rogers Memorial Veterans Hospital in Bedford, Mass, where all residents have advanced dementia and lack decision-making capacity. Once the nursing staff has had time to fully evaluate a new long term care patient, a meeting is scheduled between family members and members of the interdisciplinary team. At family meetings, consensus is reached regarding various therapeutic options, and proxy plans are recorded using a form designed by the Bedford Ethics Advisory Committee. Issues discussed with proxies include transfer to an acute care setting and use of respirators, renal dialysis, antibiotics, and tube feeding. Also discussed are any previous verbal statements or written directives made by the patient that could be used to guide end-of-life decision-making.³¹ Proxies are informed that proxy plans can be changed at any time. One copy of the plan is placed in the patient's record, and another is given to the family. The physician writes specific treatment orders as appropriate. Whenever there is a change in the patient's condition, the proxy is notified. Proxies do occasionally change proxy plans in times of crisis, and they have reported comfort in being able to do so.

Recommendations

Based on its review of ethical, legal, and clinical perspectives, the NEC concludes that advance care planning for residents of long term care facilities who lack decision-making capacity is ethically sound. The process encourages clinicians and proxies to discuss and plan for end-of-life scenarios prior to the onset of crises, carefully considering the patient's expressed or inferred wishes. Advance proxy planning also helps to build trust and shared understanding, and reduces undue burdens on the patient, family, and health care team. Several published studies from the private sector as well as the experience and focus groups within VA confirm that advance proxy planning, when done properly, can help to improve the quality of patient care.

Current VA national policy does not specifically address the issue of advance proxy planning in long term care. Because the experience with advance proxy planning is still fairly limited, the NEC does not at this time recommend mandating a particular standardized approach at the national level. Instead, the Committee recommends that local facilities develop and implement their own policies and procedures, and that the impact of these policies and procedures be evaluated before a VHA directive is issued on the topic. The NEC recommends the following as minimum criteria for a process of advance care planning for residents of long term care who lack capacity:

- 1) The process of proxy planning should include at least one meeting (face-to-face if possible) between the patient's proxy and members of the interdisciplinary team. This meeting should be held soon after admission, but after the staff has completed a full assessment of the resident.

- 2) During the meeting the proxy and others who know the patient should carefully consider and articulate the patient's previously expressed goals, values and preferences to the extent that they are known.
- 3) If the patient had executed a formal advance directive while competent, the directive should be examined and used to help establish the patient's wishes. The proxy plan should be consistent with any specific instructions expressed in an advance directive document. In the absence of specific instructions, plans should be based on the patient's goals and values, and on the best interests of the patient as determined by the proxy with the help of the health care team.
- 4) The attending physician should document the proxy plan both in an explanatory progress note and on a standardized proxy planning form. An example of one such form (Long Term Care Advance Proxy Planning Form) is reproduced in the Appendix. An appropriate physician order should be entered based on decisions contained in the proxy plan.
- 5) Proxy planning forms are intended to help guide discussion, clarify decisions, and document plans. They are not to be used as a substitute for ongoing discussions between the proxy and members of the health care team. Even after a proxy planning form is completed, clinicians still need to be in regular communication with the proxy to provide information about changes in patient's status, seek guidance, and obtain informed consent as appropriate.
- 6) Proxy planning documents should be prominently and consistently filed in the patient's medical record. The documents should accompany patients when they are transferred to other settings.
- 7) The patient's proxy should sign the proxy planning document and receive a copy.
- 8) The proxy may choose to change or revoke the plan at any time. In addition, the form should be reviewed with the proxy and updated on an annual basis or sooner when any of the following occurs: patient transfer to another setting; significant change in the patient's health; or availability of new treatments. Any changes to the proxy plan need to be documented in the patient's chart as well as on the proxy planning form itself.
- 9) If an existing proxy dies, loses decision making capacity or becomes unavailable, a new proxy plan should be instituted with a substitute proxy. The new proxy should take into consideration decisions made by the previous proxy.
- 10) Conflicts between the proxy, other family members, and/or the clinical staff concerning the type or level of treatment that cannot be resolved at a meeting of family members with interdisciplinary staff should be referred to a local Ethics Advisory Committee for consultation.
- 11) To ensure quality, the proxy planning process should be regularly evaluated from the perspective of its various participants. Interviews with family members after the patient's death should be conducted with appropriate sensitivity to their loss.

Conclusion

Providing care for patients who have lost the capacity to make decisions about their medical treatment raises difficult challenges for proxies and clinicians who must work together to determine the appropriate care of such patients. Advance care planning provides an opportunity for open

dialogue between proxies and the health care team at a time when patients are relatively stable. The proxy planning form is appropriately used to clarify, communicate, and update patient care plans as they change over time.

(This is Not an Official VHA Form)

LONG TERM CARE ADVANCE PROXY PLANNING

This template is not an official VA form, but is provided as an example to assist local facilities in developing their own form, which must be reviewed and approved by the local medical records committee. VA Form 10-0137, "VA Advance Directive" should still be used for advance care planning by patients who have the ability to make their own health care decisions (see VHA Handbook 1004.2). Forms like this one may be used to facilitate advance care planning on behalf of patients who lack decision-making capacity. The form is intended to promote: a) in-depth discussion between health care teams and proxies of patients who lack decision-making capacity; and b) documentation of treatment preferences and goals of care. The "proxy" is the patient's legal guardian or health care proxy, if available, or the person designated by the patient and/or family to make health care decisions on the patient's behalf. The involved parties should discuss the patient's personal values, treatment preferences, and best interests. The overall goals for care, including providing or not providing life-sustaining treatments, should be clarified. In addition, health care teams should explain to proxies how available levels of care vary across different health care settings. This form should not be used as a checklist in the absence of discussion. After completion, the original of the approved form should be placed in the patient's medical record, and a copy given to the proxy.

PATIENT/RESIDENT INFORMATION:

(Last Name, First Name Middle Initial)	(Social Security Number)	(Date of Birth)
(Attending Physician)	(Service of Specialty)	(Office Phone or Pager)
(Proxy)	(Daytime Phone)	(Evening/Weekend Phone)
(Alternate if proxy listed above is not available)	(Daytime Phone)	(Evening/Weekend Phone)
Advance Directive on File? <input type="checkbox"/> Yes <input type="checkbox"/> No		

MEDICAL INTERVENTIONS (check one option from each pair):

Attempt Resuscitation <input type="checkbox"/>	or	Do Not Attempt Resuscitation <input type="checkbox"/>
Transfer to Acute Care Facility <input type="checkbox"/>	or	No Transfer to Acute Care Unless Required for Comfort (This will restrict certain interventions) <input type="checkbox"/>
Advanced Interventions (Consider oral/nasal airway, bag-mask/demand valve, monitor cardiac rhythm, IV medication and fluids) <input type="checkbox"/>	or	Comfort Measures Only (Oral and body hygiene, food and fluids orally, oral medications, positioning, wound care, warmth, appropriate lighting, other measures to relieve pain and suffering and assure privacy and respect for the dignity of the patient/resident) <input type="checkbox"/>
Administer Antibiotics <input type="checkbox"/>	or	No Antibiotics Except if Needed for Comfort <input type="checkbox"/>
Initiate Artificial Nutrition/Hydration <input type="checkbox"/>	or	No Feeding Tube/IV fluids (Provide other measures to assure comfort) <input type="checkbox"/>
Other Instructions: _____ _____		

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