
Advance Directives and Patient Rights: A Joint Commission Perspective

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Advance directives for health care are an inherent right from the perspective of the Joint Commission for the Accreditation of Healthcare's standards. Highlighting standards from the Comprehensive Accreditation Manual for Hospitals: The Official Handbook, the authors outline this right. They contrast barriers patients encounter to having their preferences respected.

The Patient Self-Determination Act passed by Congress in 1990 and implemented in December 1991, was intended to ensure that patients are informed of their rights to participate in treatment decisions and to execute state-sanctioned advance directives that protect their rights, particularly in the event of loss of decision-making capacity.

Hospitalization today can be a daunting, confusing experience. Understanding the course of care, as well as the rights of all hospitalized patients, can remove some of this confusion and potentially improve the outcomes of the hospital experience. Thought and preplanning by patients further insure involvement in decisions that guide their course of care. Recognizing the importance of patient rights relating to a course of care, the Joint Commission has identified *Patient Rights and Organizational Ethics (RI)* as an organization-wide function since 1995 in the Accreditation Manual for Hospitals.

The overview portion of the Patient Rights and Organizational Ethics chapter of the *Comprehensive Accreditation Manual for Hospitals* defines the goal of this function to be "to help to improve patient outcomes by respecting each patient's rights and by conducting business relationships with patients and the public in an ethical manner."

The standards in this chapter allow the patient's family or a significant other to make care decisions for the patient when he or she no longer has decision-making capacity. This is especially important when the patient has indicated advance planning specifics through an advanced directive. Such directives help resolve dilemmas regarding withholding resuscitative services and other means to sustain life. Decisions such as these relate directly to patients' values and thus only the patient can determine the content of an advance directive.

Patients have a fundamental right to considerate care that safeguards their personal dignity and respects their cultural, psychological, and spiritual values. An understanding and respect for these values guide the provider in meeting the patients' care needs and preferences. Standards described in the Patients Rights portion of this chapter are intended to create an organizational environment that promotes patient involvement in decision making regarding all aspects of their care.

Following are the standards as they appear in the Patient Rights and Organizational Ethics chapter of the Joint Commission's *Comprehensive Accreditation Manual for Hospitals*.

RI.1 The Hospital Addresses Ethical Issues in Providing Patient Care.

A mere listing of patient rights cannot guarantee that those rights are respected. Rather, a hospital demonstrates its support of patient rights through the processes by which staff members interact with and care for patients. These day-to-day interactions reflect fundamental concern with and respect for patients' rights. All staff members are aware of the ethical issues surrounding patient care, the hospital's policies governing these issues, and the structures available to support ethical decision making.

The hospital establishes and maintains structures to support patient rights, and does so in a collaborative manner that involves the hospital leaders and others. The structures are based on policies, procedures, and their philosophical basis, which make up the framework that addresses both patient care and organizational ethical issues, including the following:

- a. The patient's right to reasonable access to care;
- b. The patient's right to care that is considerate and respectful of his or her personal values and beliefs;
- c. The patient's right to be informed about and participate in decisions regarding his or her care;
- d. The patient's right to participate in ethical questions that arise in the course of his or her care, including issues of conflict resolution, withholding resuscitative services, forgoing or withdrawal of life-sustaining treatment, and participation in investigational studies or clinical trials;
- e. The patient's right to security and personal privacy and confidentiality of information;
- f. The issue of designating a decision maker in case the patient is incapable of understanding a proposed treatment or procedure or is unable to communicate his or her wishes regarding care;
- g. The hospital's method of informing the patient of these issues identified in this intent;

h. The hospital's method of educating staff about patient rights and their role in supporting those rights; and

i. The patient's right to access protective services.

RI.1.2 Patients are involved in all aspects of their care.

Hospitals promote patient and family involvement in all aspects of their care through implementation of policies and procedures that are compatible with the hospital's mission, have diverse input, and guarantee communication across the organization. Patients are involved in at least the following aspects of their care:

- Giving informed consent
- Making care decisions
- Resolving dilemmas about care decisions
- Formulating advance directives
- Withholding resuscitative services
- Forgoing or withdrawing life-sustaining treatment
- Care at the end of life

To this end, structures are developed, approved, and maintained through collaboration among the hospital's leaders and others.

Patients' psychosocial, spiritual, and cultural values affect how they respond to their care. The hospital allows patients and their families to express their spiritual beliefs and cultural practices, as long as these do not harm others or interfere with their treatment.

RI.1.2.1 Informed consent is obtained.

Staff members clearly explain any proposed treatments or procedures to the patient and, when appropriate, the family. The explanation includes:

- Potential benefits and drawbacks
- Potential problems related to recuperation
- The likelihood of success
- The possible results of nontreatment

- Any significant alternatives

Staff members also inform the patient of:

- The name of the physician or other practitioner who has primary responsibility for the patient's care;
- The identity and professional status of individuals responsible for authorizing and performing procedures or treatments;
- Any professional relationship to another health care provider or institution that might suggest a conflict of interest;
- Their relationship to educational institutions involved in the patient's care;
- Any business relationships between individuals treating the patient, or between the organization and any other health care, service, or educational institutions involved in the patient's care.

RI.1.2.2 The family participates in care decisions.

Care sometimes requires that people other than (or in addition to) the patient be involved in decisions about the patient's care. This is especially true when the patient does not have the mental or physical capacity to make care decisions, or when the patient is a child. When the patient cannot make decisions regarding his or her care, a surrogate decision maker is identified. In the case of an unemancipated minor, the family or guardian is legally responsible for approving the care prescribed. The patient has the right to exclude any or all family members from participating in his or her care decisions.

Decision-making capacity refers to the ability of an individual to demonstrate to the satisfaction of his health care provider that he understands and appreciates the nature and consequences of a health care decision. The expected results of decision-making capacity are decisions that reflect the patient's values and promote his judgment of personal well being. The elements of this capacity usually include possession of a set of values and goals, the

ability to communicate and understand information, and the capacity to reason and deliberate about one's health care choices. These directives provide for the designation of surrogate decision makers or written instructions regarding end-of-life treatment preferences, or both.¹

RI.1.2.3 Patients are involved in resolving dilemmas about care decisions.

Making decisions about care sometimes presents questions, conflicts, or other dilemmas for the hospital and the patient, family, or other decision makers. These dilemmas may arise around issues of admission, treatment, or discharge. They can be especially difficult to resolve when the issues involve, for example, withholding resuscitative services or forgoing or withdrawing life-sustaining treatment. The hospital has a way of resolving such dilemmas and identifies those who need to be involved in the resolution.

RI.1.2.4 The hospital addresses advance directives.

Further, the standards address situation in which patients can make their wishes known should they become incapacitated and unable to actively participate. Problems can arise, however, in determining when and if the patient has lost capacity to make such decisions. As long as a patient is capable of expressing treatment wishes directly, these expressions override whatever instructions the patient may have previously put in writing, since by law, advanced directives come into force only when the patient loses decision-making capacity. As outlined in RI.1.2.4, the hospital addresses advance directives, which are defined as written or verbal statements made by the patient indicating treatment wishes in the event the patient becomes incapacitated. Advance directives may include living wills, durable power of attorney, or similar documents or documentation conveying patients' preferences.

The intent of this standard is that the hospital determines whether a patient has or wishes to make an advance directive(s). The hospital also ensures

that health care professionals and designated representatives honor the directives within the limits of the law and the organization's mission, philosophy, and capabilities. For example, if a patient elects to donate organs at the end of life, the organization must have a process to honor that directive. In the absence of the actual advance directive, the person who is responsible for determining the existence of an advance directive as designated in hospital policy, for example, the admitting nurse or physician, should respond as follows:

First, arrangements could be made to immediately obtain a copy of the existing advance directive(s).

Second, the patient may be offered assistance in completing a new written advance directive(s).

Third, the hospital designee may inform such patients that they may verbalize treatment preferences. That is they may explain "content" of the original advance directive including treatment preferences, preferred surrogates, and statements regarding wishes concerning a minimum quality of life. If a patient chooses to verbalize treatment choices, the conversation is documented in the patient's medical record and the patient's physician is informed. The patient has the right to, and may at any point make clarifications, modifications, or revocations of the directive(s). Such conversation should be documented in the patient's medical record and the physician informed.

The Joint Commission is not suggesting that obtaining a verbal description of a written, existing advance directive is necessarily the same, under any applicable law, as that of actual possession by the hospital of the actual document. The lack of advance directives does not hamper access to care. The hospital, however, provides assistance to patients who do not have an advance directive but wish to formulate one. The hospital determines whether a patient has or wishes to make advance directives. The hospital also ensures that health care professionals and designated representatives honor the directives within the limits of the law and the

organization's mission, philosophy, and capabilities.

RI.1.2.5 The hospital addresses withholding resuscitative services.

RI.1.2.6 The hospital addresses forgoing or withdrawing life-sustaining treatment.

Decisions about withholding resuscitative services or forgoing or withdrawing life-sustaining treatment are among the most difficult choices facing patients, families, health care professionals, and hospitals. No single process can anticipate all of the situations in which such decisions must be made. All the more reason why it is important for the hospital to develop collaboratively a framework for making these difficult decisions.

The framework:

- Helps the hospital identify its position on initiating resuscitative services and using and removing life-sustaining treatment;
- Ensures that the hospital conforms to the legal requirements of its jurisdiction;
- Addresses situations in which these decisions are modified during the course of care;
- Offers guidance to health professionals on the ethical and legal issues involved in these decisions and decreases their uncertainty about the practices permitted by the hospital.

The decision-making process is applied consistently, and the lines of accountability are clear. To ensure this, a guiding process should be formally adopted by the hospital's medical staff and approved by the governing body.

RI.1.2.7 The hospital addresses care at the end of life.

Dying patients have unique needs for respectful, responsive care. All hospital staff is sensitized to the needs of patients at the end of life. Concern for the patient's comfort and dignity should guide all aspects of care during the final stages of life.

The hospital's framework for addressing issues related to care at the end of life provide for:

- Providing appropriate treatment for any primary and secondary symptoms, according to the wishes of the patient or the surrogate decision maker
- Managing pain aggressively and effectively
- Sensitively addressing issues such as autopsy and organ donation
- Respecting the patient's values, religion, and philosophy
- Involving the patient and, where appropriate, the family in every aspect of care
- Responding to the psychological, social, emotional, spiritual, and cultural concerns of the patient and the family

Effective pain management is appropriate for all patients, not just for dying patients.

Of the standards in the Patient Rights and Organizational Ethics chapter, RI. 1.2.4 (The hospital addresses advance directives), generated scores of 3, 4, or 5 in 3.2 % of all hospitals surveyed during 1996. A score 3 indicates partial compliance, a score of 4 indicates minimal compliance and 5 is a score given for non-

compliance. While the percentage of hospitals that need to improve the ways in which they handle advance directives is not high, it was the highest percentage of scores of 3, 4, or 5 for standards in the entire chapter. With the increasing acuity of patients admitted to hospitals, staff turnover, organizational redesign and decreased length of stay, hospitals need to continually examine their mechanism for respecting this important patient right. Organizations need to keep asking the questions, "How well is our process for respecting patient care preferences working?" A second related question would be, "How well does our staff understand the concepts surrounding patient rights and advance directives?"

With increasing staff turnover, care may be fragmented; therefore, ongoing education, training, and assessment of competency become imperative. Staff and physicians need to be aware of the content of advance directives for patients under their care and be sensitive to patient and family preferences should changes occur in the health of the patient. Further, staff should be comfortable discussing these issues with patient and family. Educational efforts need to target not only the concepts of advance directive(s), but also common barriers to their implementation. The stan-

dards provide guidance in developing a framework for hospitals to follow to remove some of these common barriers.

The complex decisions that often occur at the end of life make this period extremely difficult for patients and their families. Advanced directives are an essential safeguard to ensure that the patient's right to describe their care preferences, be they at the end of life or in preparation for receiving care that places them at risk, is protected and formalized. Patients' preferences regarding whether they wish life-extending measures to be withheld or whether measures to extend life should be exercised is a patient's inherent right, and all health care organizations have an ethical responsibility to honor.

Bibliography

- Comprehensive Accreditation Manual for Hospitals: The Official Handbook*. 1996. Oakbrook Terrace: Joint Commission on Accreditation of Healthcare Organizations, RI-13.
- Pearlmann, Robert A. 1996. "Challenges Facing Physicians and Healthcare Institutions Caring for Patients with Mental Incapacity." *Journal of the American Geriatrics Society* 44 (August): 994-996.

Health Care Decisions/Advance Directive

■ **Take a copy of this with you whenever you go to the hospital** ■

I, _____, SS# _____ want everyone who cares for
(please print)
me to know what health care I want when I cannot let others know what I want.

I always expect to be given care and treatment for pain or discomfort even when such care might shorten my life, make me feel like not eating, slow down my breathing, or be habit-forming.

I want my doctor to try treatments that may get me back to an acceptable quality of life. By acceptable quality of life, I mean living in a way which lets me do the things that are important and necessary to me. Those things are:

- Examples: the ability to
- recognize family or friends
 - make decisions
 - communicate
- feed myself
 - take care of myself

If there is no reasonable hope that I will be able to understand or communicate, I want these directions followed.

I direct that no treatment be given just to keep me alive when I have

- a condition that will cause me to die soon, or
- a condition so bad (including substantial brain damage or brain disease) that it is not expected that I will regain a quality of life acceptable to me (as described above)

When I have one of the above conditions, the treatments I **DO NOT** want include:

- surgery
- doing things to start my heart or breathing, if either stops (CPR)
- medicine to treat infections (antibiotics)
- artificial kidney machine (dialysis)
- breathing machine (respirator, ventilator)
- food or water given through a tube in the vein, nose, or stomach (tube feedings)
- chemotherapy (cancer treatment)
- blood transfusions
- other treatment _____

■ **If you DO want one or more of the above treatments, circle it and initial at the end of the line** ■

I want to donate my organs or tissues and realize it may be necessary to maintain my body artificially until my organs can be removed. yes no undecided

My other directions include: _____

- Examples: • hospice care • death at home, if possible • specific directions regarding organ donation

Talk about this form and your ideas about your health care with the person you have chosen to make decisions for you, your doctor(s), family, friends, and clergy, and give each of them a completed copy. You may cancel or change this form at any time. You should review it every so often. Each time you review it, put your initials and the date here _____

■ **Be sure to sign this form on the reverse side of this page** ■

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e-mail – midbio@qni.com • web site – www.midbio.com

Durable Power of Attorney for Health Care Decisions

It is important to choose someone to make health care decisions for you when you cannot. **Tell the person you choose what you would want.** The person you choose has the same right as you do to make decisions and to make sure your wishes are honored. If you **DO NOT** choose someone to make decisions for you, write **NONE** on the line for the agent's name.

I appoint the person named below to be my agent to make health care decisions for me when and only when I cannot make decisions or communicate what I want done. This is a Durable Power of Attorney for Health Care Decisions and the power of my agent shall not end if I become incapacitated. I grant to my agent full power to make all decisions for me about my health care, including the power to direct the withholding or withdrawal of life-prolonging treatment. In exercising this power, I expect my agent to be guided by my directions as stated in my Health Care Decisions (*see reverse side*). Any costs should be paid from my own resources. I and my estate hold my agent and my caregivers harmless and protect them against any claim based upon following this Durable Power of Attorney for Health Care or my Health Care Decisions. My agent may not appoint anyone else to make decisions for me. My agent is also authorized to:

- Consent, refuse or withdraw consent to any care, treatment, service or procedure (including artificially supplied nutrition and/or hydration/tube feeding) used to maintain, diagnose or treat a physical or mental condition;
- Make all necessary arrangements for any hospital, psychiatric treatment facility, hospice, nursing home, or other health care organization; to employ or discharge health care personnel (any person who is authorized or permitted by the laws of the state to provide health care services) as my agent shall deem necessary for my physical, mental, or emotional well being;
- Request, receive and review any information regarding my personal affairs or physical or mental health, including medical and hospital records; and to execute any releases of other documents that may be required to obtain such information;
- Move me into or out of any state or institution for the purpose of complying with my Health Care Decisions or the decisions of my agent;
- Take legal action, if needed, to do what I have directed;
- Make decisions about autopsy and organ donation, and the disposition of my body;
- Become my guardian if one is needed.

If you **DO NOT** want the person (agent) you name to be able to do any of the above things, draw a line through it, and put your initials at the end of the line.

Agent's name _____ Phone _____

Address _____

If you do **not** want to name an alternate, write "none."

First Alternate Name _____

Second Alternate Name _____

Address _____

Address _____

Phone _____

Phone _____

SIGN HERE for the *Durable Power of Attorney* and/or *Health Care Decisions* forms. Many states require notarization. Please ask two (2) persons not related to you to witness your signature.

Signature _____ Date _____

Witness _____ Date _____ Witness _____ Date _____

Notarization:

On this ___ day of _____, in the year of _____, personally appeared before me the person signing, known by me to be the person who completed this document of his/her free act and deed. IN WITNESS WHEREOF, I have set my hand and affixed my official seal in the County of _____, State of _____, on the date written above.

Notary Public _____ Commission Expires _____