



Patient Self-Determination Act of 1990

Implementation Strategies for Ethics Committees

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Implementation Strategies for Ethics Committees in the Development of Policies and Procedures to comply with U.S. Senate Bill 1766

PROLOGUE

The Kansas City Area Ethics Committee Consortium of Midwest Bioethics Center has attempted to develop implementation strategies that will benefit ethics committees as they work with their institutions/facilities to comply with U.S. Senate Bill 1766, i.e., the Patient Self-Determination Act of 1990. Although it is our hope to assist institutions/facilities to comply with the basic requirements set forth in the Patient Self-Determination Act, this document also reflects our commitment to the full spirit of this legislation. This legislation concerns both patient rights and advance directives, issues with which the Consortium is experienced. It is the belief of Consortium members that these strategies will prove helpful in the development of policies and procedures within organizations affected by this legislation. It is not the goal of the Consortium to in any way develop a model policy or a community standard.

PURPOSE

This legislation requires that adult patients be provided with information about their legal rights to make healthcare decisions, particularly the right to refuse treatment and the right to make advance directives. However, it is clearly the intent of this legislation to encourage healthcare providing institutions/facilities to enhance patient autonomy and self-determination through a wide variety of steps aimed at education of professionals, patients, and communities.

DEFINITIONS

- **Capacity:** A person has the functional ability to 1.) comprehend information relevant to the particular decision to be made; 2.) deliberate regarding the available choices, considering his/her own values and goals; and 3.) communicate, verbally or non-verbally, his/her decisions.
- **Durable Power of Attorney for Healthcare Decisions:** A signed, dated, and witnessed (or notarized) document which allows an individual to name an agent to make healthcare decisions in the event the person completing the document becomes incapacitated.
- **Healthcare Treatment Directive:** A signed, dated, and witnessed document, which allows individuals to state in advance their wishes regarding healthcare decisions. It is similar to a "living will"; however, it is far more comprehensive than most "living wills."

The Healthcare Treatment Directive is not necessarily restricted to use only when one is terminally ill.
- **"Living Will":** A signed, dated and witnessed declaration by which an individual may request that life sustaining procedures be withheld or withdrawn and that he/she be allowed to die. "Living will statutes" usually apply only when a patient is terminally ill.
- **Patients' Rights:** The concept of patients' rights can be understood to include a patient's legal rights within a particular jurisdiction; however, a patient's rights also include ethical rights based on duties, obligations and responsibilities of healthcare providers and institutions. Many healthcare institutions are required to maintain and to distribute a writ-

ten “Patients’ Rights Statement” which usually includes both legal and ethical rights.

SUMMARY OF LEGISLATION

Under the legislation, Medicare and Medicaid funded providers will:

- Maintain written policies and procedures regarding an individual’s rights under state law (whether statutory or recognized by the courts in the state) to make decisions concerning their care, including the right to accept or refuse medical or surgical treatment and the right to formulate advance directives;
- Ensure that this written information is provided to adult patients at the time of admission as a hospital inpatient or resident of a skilled nursing facility; in advance of coming under care with a home health agency or hospice; or upon enrollment in a health maintenance organization receiving federal funds.
- Note in patient records whether an advance directive has been made by the patient.
- Ensure compliance with advance directives, consistent with state law.
- Provide staff and community education on advance directives.

The Department of Health and Human Services will assist states in developing written information on state law, and will initiate a nationwide public education campaign to increase awareness of advance directives.

IMPLEMENTATION STEPS

I. Provide written information

A. To whom: information must be provided to all patients age 18 years or older

1. Consortium members believe that capacity should be assumed and that all patients should be provided with information. In situ-

ations in which a patient is unconscious, critically ill or otherwise incapacitated, it would be reasonable to provide this information to guardians, family, or other surrogate decision makers and temporarily defer giving information to the patient.

2. It should *not* be assumed that persons who have been adjudicated to be incompetent or diagnosed as mentally ill or mentally retarded are necessarily unable to complete advance directives.
3. Although persons who have permanently lost capacity cannot complete advance directives, Consortium members believe that information regarding patient rights and relevant hospital policies and procedures (e.g., do not resuscitate [DNR] policies, and policies and procedures regarding forgoing life sustaining treatment) should be provided to surrogate decision makers.
4. Members also concluded that legally emancipated minors should be provided with information required under this legislation.
5. This legislation requires that in the case of a hospital this information is to be provided at the time of admission as an “inpatient”; however, it is the opinion of Consortium members that hospitals should make reasonable efforts to make this information available to all patients including short-term stay, day surgery, emergency room and other outpatients.
6. Although not specifically covered by the legislation, Consortium members agreed that current residents of long-term care facilities should be provided this information and the opportunity to complete advance directives.

B. What is to be provided: Consortium members assumed that all written information should be available in at least both English and Spanish and written at no higher than an 8th grade reading level. Consideration should be given to making

easy to read, large type documents available particularly in nursing homes.

1. A statement of patient's rights, including
 - a. the right to refuse treatment — in accordance with state law,
 - b. the right to make an advance healthcare treatment directive (e.g., 'living will,' a healthcare treatment directive, a durable power of attorney for healthcare, do not resuscitate [DNR] request)

2. A written description of the state law regarding healthcare decision making. (Although responsibility for development of this written description has been delegated to the state Medicaid regulatory agencies, it may not be available by December 1991.)

3. Materials developed by the federal government regarding Senate Bill 1766. These have yet to be developed. (A preliminary draft is expected to be complete by October 1991.)

4. Written information regarding the institutional/facility policies regarding implementation of such rights.

5. Consortium members believe that information about how to obtain assistance in completing advance directives should also be provided. (Although it is not clear that the law requires providers to assist patients in the completion of advance directives, Consortium members feel strongly that there is an implied duty to do so.)

C. When is information to be provided: Consortium members agreed that ideally the provision of this information and completion of advance directives should take place when persons are well. One such time might be in the course of a routine visit with a person's primary physician. However, if this has not happened, this process should take place in a setting and at a time when patients can receive information, discuss their concerns, and complete advance directives if they desire. The initial point of contact between the patient and

the institution/facility [e.g., the admissions office or the emergency room] is probably not an ideal setting or time for educating patients.

1. *Hospitals and skilled nursing facilities* - the legislation calls for this information to be provided "at the time of admission" which is intended to be defined by institutional policy and may be defined as broadly as to include the admission process. (Consortium members assumed that the regulations supporting this legislation will include a specific time frame and that it is likely to be within 24 hours of admission.)

2. *Home healthcare agencies* - in advance of individuals coming under care of the agency.

3. *Health maintenance organization* - at the time of enrollment.

4. *Hospice* - at the time of initial receipt of hospice care.

D. By whom should information be provided?

1. Information as to whether or not a patient has previously completed an advance directive may be obtained and documented by any member of the staff.

2. Responsibility for providing information to patients as required by this law should be delegated to members of the professional staff who have received appropriate training.

Patients' rights include a patient's legal rights but also ethical rights based on duties, obligations, and responsibilities of healthcare providers and institutions.

3. More comprehensive education, discussion and assistance in completion of advance directives should also be provided by trained professionals. Social workers, patient representatives and pastoral counselors may play an important role in this process. Consortium members believe that it is essential for physicians and nurses also to be involved.

II. Elements for development of institutional policies regarding advance directives.

A. Legislatively mandated:

1. Compliance with state laws regarding advance directives
2. Patients' rights statement
3. Non-discrimination provision
 - a. Patient may not be denied care as a result of the implementation of an advance directive.
 - b. Care of the patient may not be compromised because the patient has enacted an advance directive.
4. Conscientious objection clause (Senate Bill 1766 - notes that it shall not be construed to negate a conscientious objection clause in any state law.)
5. Documentation of compliance with Self-Determination Act should include consideration of the following:
 - a. Which member(s) of staff will be responsible for documentation?
 - b. Where in the medical record will this information be included?
 - c. How will a patient's desire to complete an advance directive be noted and what procedures are needed to respond to such requests?

B. Important elements not legislatively mandated.

1. Members of the Consortium felt it especially important that the implementation policy include provision for physicians to review all advance directive documents with their patients.
2. Consideration should be given to the relationship between policies for implementing the Patient Self-Determination Act and the

institution's/facility's existing Do Not Resuscitate (DNR) policy, patients' rights statements, and forgoing treatment policies.

3. A procedure should be developed for situations in which the patient or patient's family/surrogate claims that a directive exists but is not produced in a reasonable period of time. A patient with decisional capacity might be asked to complete a new directive.
4. Consortium members felt that policies and procedures should include some provision for the resolution of conflicts regarding patient self-determination and the implementation of advance directives. Ethics committees are well suited for this purpose. Consortium members felt strongly that guardianship procedures and court determinations should be a matter of last resort.

C. Incorporation of advance directives into permanent medical records.

1. Mechanisms need to be developed for incorporation of advance directives furnished by patients/surrogates into the patient's permanent medical record.
2. Consideration needs to be given to where in the permanent medical record such documents should be placed, for flagging records that contain advance directives, and for ensuring that copies of advance directives are included in the patient's current chart.
3. Medical record procedures must be developed to allow for the revocation or amending of advance directives maintained in the permanent medical record.
4. Consideration should be given to including information about advance directives in computer databases.
5. Alternative mechanisms to alert healthcare professionals to the existence of advance directives (e.g., patient identification bracelets, wallet cards and Medic Alert bracelets) could

be considered as a means of prompting review of records for such information.

6. Procedures should be developed for transferring advance directive information from patients' charts when a patient is readmitted or transferred to another care unit, institution or facility
7. Consortium members recommend that procedures be developed for providing residents of long-term care facilities with the opportunity to periodically review their advance directives.

III. Education

A. Continuing education for staff: Although institutions may choose particular persons or specific departments or services to assume responsibility to act as educators about advance directives, virtually everyone in the institution who patients contact should be prepared to respond to requests for information about advance directives. In addition, it is important that quality assurance, utilization review, risk management and hospital attorneys understand both the letter and the spirit of this significant legislation. Therefore, the Consortium believes that it is necessary to provide in-service training throughout the institution.

1. All members of an institution's medical staff should be provided with education regarding both this law and relevant institutional policies developed to implement it.
2. Consideration should be given to the educational needs of hospital attorneys and risk managers regarding this legislation.
3. Board members should also be made aware of these important developments in recognition of patient self-determination.
4. After initial implementation, orientation programs for all new employees and staff should include this information.
5. Ethics committee members may be appropriate staff educators.

B. Specific training programs for professional staff delegated responsibility for educating patients about advance directives should reflect the following:

1. Education about advance directives is complicated by the psychological difficulty most people have in confronting and working through the possibility of their future incapacity and death. Training for professionals needs to include information and skill development necessary to prepare staff to communicate effectively about these sensitive issues.
 - a. Elements of such programs should include effective communication and listening skills, psychological and ethical issues related to death and dying, religious and cultural views.
 - b. Staff training should provide ample time for people to express their concerns and ask questions.
 - c. Role playing is an important part of training and should be provided.
2. Information about the various types of advance directives, i.e., living wills, healthcare treatment directives and durable powers of attorney.
3. Information about relevant state law (both statutory and case law.)
4. Information should be provided about the Patient Self-Determination Act itself.
5. Persons trained to educate patients should be knowledgeable about relevant institutional/facility policies.

C. Community education: Many institutions represented at the Consortium regularly provide advance directive workshops free of charge to the community. Based on this experience Consortium members recommend that:

1. Presentations should be short, concise, and made in laymen's terms. The focus of these presentations should be on what advance

directives are and what people need to know in order to complete a directive. People should be informed of their rights regarding healthcare decisions.

2. Experts from a variety of perspectives should participate in these workshops and respond to the diverse questions the public may have.
 - a. Professionals who may be helpful in these workshops are nurses, physicians, healthcare attorneys, members of the clergy, patient representatives, social workers and persons trained in clinical ethics.
 - b. It may also be helpful to have someone representing administration who can answer questions about the institution's/facility's policies.
3. There should be suitable advance directives provided to people who attend these presentations. (Some institutions have trained personnel available to assist participants to complete advance directives at the workshops.)
4. Relevant policies and procedures should be available. (it will also be helpful to have summaries of relevant state law when they are available.)
5. There should be sufficient time for questions and answers.
6. Community educational programs should provide for special communication needs (e.g., sign language, translators, etc.)

D. Volunteer speakers bureaus

1. The Ethics Committee Consortium of Midwest Bioethics Center, the local bar association and

the local medical society have formed a volunteer speakers bureau. Trained speakers are available, without charge, to churches, civic groups, and other organizations.

2. Institutions/facilities may wish to develop their own speakers bureaus utilizing ethics committee members or through the training of volunteers. (Midwest Bioethics Center will continue to offer training programs for such volunteer efforts.)

E. Special educational resources: Midwest Bioethics Center has produced a 17-minute video, *Living Choices*, for use by healthcare providers and facilities in the implementation of the Patient Self-Determination Act. This film is designed for inpatient education, staff education and/or community education and is already being used nationally. Further, Midwest Bioethics Center provides:

1. A combined Healthcare Treatment Directive/ Durable Power of Attorney for Healthcare Decisions form. (This document was developed by the Consortium in conjunction with local bar associations and medical societies.)
2. An educational brochure entitled "Making Healthcare Decisions for Your Future: Advance Directives" which provides necessary assistance for persons completing the aforementioned document.
3. In-service training for healthcare professionals.
4. Speakers for community education programs and forums.