Living Wills and Durable Power of Attorney: Advance Directive Legislation and Issues

Pat Milmoe McCarrick
April, 1992

(Scope Note 2 has been revised and updated to reflect new material on advance directives.)

Medical technology can sustain indefinitely the vital functions of some people who are terminally ill or who exist in a persistent vegetative state. Legislation has been enacted in the District of Columbia and all states except Pennsylvania to allow competent persons to express choices about their treatment in the event that they become incompetent and/or terminally ill and cannot participate in decisions concerning their care. These choices when written are known as advance directives, living wills, or durable powers of attorney. In Deciding to Forego Life-Sustaining Treatment: Ethical, Medical and Legal Issues in Treatment Decisions, the President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research said that “an advance directive is a statement by a competent person indicating his wishes in the event of future incompetence.”

Public interest in cases involving patients who are unable to assist in care decisions has grown steadily since 1976 when Karen Ann Quinlan’s parents obtained permission from the court to remove their daughter’s ventilator (In the Matter of Karen Quinlan, 335 A.2d 647, N.J. 1976). Ms. Quinlan survived for ten more years in a persistent vegetative state, not needing a respirator, but receiving nutrition through a feeding tube.

Two more recent events indicate the increased interest in establishing some parameters for decision making when the patient becomes incompetent:

1) The first federal law about death decision making, the Patient Self-Determination Act of 1990 (contained in Sections 4206 and 4751 of the Omnibus Budget Reconciliation Act of 1990, P.L. 101-508, 42 U.S.C.A.§§1395cc & 1396a [West Supp. 1991]) took effect on December 1, 1991. All hospitals, nursing homes, home health agencies, and hospice programs receiving federal Medicare and Medicaid are now required to create formal procedures that provide written information at admission to patients about decision making and treatment refusal rights in their health care. The law also says that patient advance directives will be respected. Noncompliance will mean a loss of Medicaid and Medicare funds.
2) The United States Supreme Court acted on a case concerning a request for the withdrawal of a feeding tube from a patient in a persistent vegetative state. Nancy Cruzan’s parents requested that her feeding tube be considered medical treatment and that it be withdrawn. Ms. Cruzan had been in a persistent vegetative state since an automobile accident in 1983. The Supreme Court of Missouri had ruled in November 1988 that Mr. and Mrs. Cruzan could not remove their daughter’s tube (Cruzan v. Harmon, 760 S.W.2d 410, Mo. banc 1988). On June 25, 1990, the U.S. Supreme Court noted in a 5-4 decision that federal constitutional rights would grant a competent person’s right to refuse nutrition and hydration based on the 14th Amendment, but that a state could require clear evidence that an incompetent person had expressed desires that surrogates later used in decision making (Cruzan v. Director, Missouri Department of Health, 110 S.Ct. 2841,1990). The Cruzan parents’ request returned to the Jasper County court which had originally said that the feeding tube could be removed. The Missouri attorney general requested that the state be dismissed as a party to the action; this time no appeals followed the court’s decision that the tubes could be removed, and Ms. Cruzan died December 26, 1990.

To prevent apprehension about future treatment if one becomes terminally or critically ill and incompetent to communicate, many people execute written advance directives, often known as living wills. The laws governing these documents are known as “natural death” or “death with dignity” statutes, and offer a patient, the family, and the health care givers legal protection and directions for future treatment aimed at keeping health decisions free from court action.

Some persons are opposed to the living will on the basis that the documents may appear to erode established patient rights. Others, particularly physicians, indicate that those in charge of health care will be hampered in supplying appropriate treatment in situations that could not possibly have been foreseen by the writer of the advance directive. Pellegrino and Thomasma in FOR THE PATIENT’S GOOD: THE RESTORATION OF BENEFICENCE IN HEALTH CARE write:

“There are few absolutes at the bedside. For this reason, living will legislation in some states provides for directives to physicians that are merely advisory about the patient’s preference. Physicians may sometimes act against these preferences if conditions arise that may not have been foreseen by the patient. For example, patients may refuse the respirator (anticipating dying by heart failure or cancer.) They come to the hospital for a biopsy and acquire the iatrogenic disease of septic shock. The physician has, in a real way, caused this disease, and since it is under certain circumstances reversible, to benefit the patient a decision requires treatment until the patient can fully comprehend the actual circumstances and reassess his or her wishes in light of those circumstances” (p. 19).

Other persons disagree with the concept of living wills, and think that these documents allow an opening to acceptance of active mercy killing, either by the patient or by care givers, and eventually, by society in general.

Living Wills

In 1976 California was the first state to enact natural death legislation; now with the exception of Pennsylvania, all states and the District of Columbia have statutes concerned with advance directives. States that do not have living will legislation are Massachusetts, Michigan, New York, and Pennsylvania.

In the jurisdictions that do have statutes, there are
variations in instructions for those who wish to draw up an advance directive for treatment in the event they are unable to make their own decisions, Some states have stipulated or suggested texts (which can be found in the statute). Choice in Dying, 250 West 57th Street, New York, NY 10107, 212-246-6973, has specific texts available for those states requiring such documents, and also generic advance directive forms for the others. Inquiries about obtaining individual copies of these blank forms are welcomed by the organization, which maintains up-to-date files on the status of natural death acts across the nation.

Sample Generic Living Will

To my family, doctors and all those concerned with my care:

I, ________________________________, being of sound mind, make this statement as a directive to be followed if I become unable to participate in decisions regarding my medical care.

If I should be in an incurable or irreversible mental or physical condition with no reasonable expectation of recovery, I direct my attending physician to withhold or withdraw treatment that merely prolongs my dying. I further direct the treatment be limited to measures to keep me comfortable to relieve pain.

These directions express my legal right to refuse treatment. Therefore I expect my family, doctors, and everyone concerned with my care to regard themselves as legally and morally bound to act in accord with my wishes, and in so doing be free of any legal liability for having followed my directions.

I especially do not want: __________________________________________________________

(Here list specific treatment not wanted. Examples include: respirator support, intravenous or nasogastric feeding or fluids, cardiac resuscitation, organ transplantation, dialysis, or surgery.)

Other instructions: ______________________________________________________________

(Here list care that is desired, e.g. pain medicine.)

Proxy Designation Clause: Should I become unable to communicate my instructions as stated above, I designate the following person to act in my behalf:

Name: ______________________________________________________________________
Address: ____________________________________________________________________

If the person named above is unable to act in my behalf, I authorize the following person to do so:

Name: ______________________________________________________________________
Address: ____________________________________________________________________

This living will declaration expresses my personal treatment preferences. The fact that I may have also executed a document in the form recommended by state law should not be construed to limit or contradict this living will declaration, which is an expression of my common-law and constitutional rights.

Signed:_______ (name of person writing the living will)________________ Date_____________
Witness: ___________________________________________ Dat e_____________
Witness: ___________________________________________ Dat e_____________

(This generic directive is the one available from Choice in Dying, New York City.)

Other groups also have forms available. Part of the Catholic Health Association’s brief Christian Affirmation of Life is reprinted below

“To my family, friends, pastor, physician, and attorney: Because of my Christian belief in the dignity of the human person and my eternal destiny in God, I ask that if I become terminally ill I be fully informed of the fact so that I can prepare myself emotionally and spiritually to
I have a right to make my own decisions concerning treatments that might unduly prolong the dying process. If I become unable to make these decisions and have no reasonable expectation of recovery, then I request that no ethically extraordinary treatment be used to prolong my life but that my pain be alleviated if it becomes unbearable, even if this results in shortening my life. (‘Ethically extraordinary treatment’ is treatment that does not offer a reasonable hope of benefit to me or that cannot be accomplished without excessive expense, pain, or other grave burden.) However, no treatment should be used with the intention of shortening my life.”

The Midwest Bioethics Center and the Kansas City Metropolitan Bar Association have worked together to provide a form suitable for Missouri and Kansas that includes stipulations concerning care for “an incurable injury, disease, or illness certified to be a terminal condition by two physicians who have personally examined me, one of whom shall be my attending physician, and the physicians have determined that my death will occur whether or not life-sustaining procedures are utilized and where the application of life-sustaining procedures would serve only to artificially prolong the dying process, and I am unable to participate in decisions regarding my medical treatment, I direct that such procedures be withheld or withdrawn, and that I be permitted to die naturally with only the administration of medication or the performance of any medical procedure deemed necessary to provide me with comfort.” The document asks that the family and physicians honor the declaration as the patient’s right to refuse medical or surgical treatment and says that the patient is capable mentally and emotionally to make an advance directive. Additional instructions contain specific provisions. Three diagnostic situations are mentioned: a terminal condition; a condition, disease or injury without hope of significant recovery; and extreme mental deterioration.

Medical procedures cited include surgery, heart-lung resuscitation (CPR), antibiotics, mechanical ventilator, tube feedings, or intravenous feeding. Other instructions include requesting pain relief and comfort treatment even if this should shorten life, suppress appetite or breathing, or be habit-forming; and a request to live out life at home rather than in a hospital or nursing home.

Witnesses must be unrelated by blood or marriage, not entitled to any portion of the declarant’s estate, and not responsible financially for medical expenses.

All states with living will statutes require that the person executing the document be competent, and most require that the documents be signed by two witnesses who are neither responsible for the care of the patient nor would benefit from the death of the patient.

After execution of an advance directive, the person writing it should discuss the document with family or friends and with the personal physician, lawyer and religious advisor. Each may have a photocopy of the document, but to avoid confusion only one original is recommended, particularly if any subsequent changes are made. Choice in Dying literature indicates that in states having natural death acts, most statutes provide freedom from legal liability for health personnel who comply with the directive; physicians must carry out the provisions of the living will or make an effort to transfer the patient to another physician who will make such an effort; a terminal condition must be medically diagnosed; and other rights of the patient must not be restricted. Pregnancy restricts living will instructions in almost all states. Those wishing to draw up such a document should check any variations that may apply in their respective state. Advance directives which go beyond state statute provisions may be legal under constitutional or common law, and many statutes specifically acknowledge the right to modify the language of the directive.

An advance directive may be revoked at anytime by the person who wrote the directive, and often an oral revocation is sufficient to cancel the various treatment decisions. Again, however, interested persons should consult natural death statutes of the state of residence.

**Durable Power of Attorney**

Another method of planning for health care decisions in the event of incompetency is to name a durable power of attorney who can make proxy decisions to carry out the patient’s wishes. The general durable power of attorney is legal in 50 states and the District of Columbia. A durable power of attorney specifically for health care decisions has been recognized in 46 states and the
District of Columbia, and “is the agent who ‘stands in the shoes’ of the patient. This premise defines the agent’s obligations to the patient and the agent’s authority in relation to others: health care professionals, medical institutions and the patient’s family members.” (New York State Task Force on Life and the Law in its LIFE-SUSTAINING TREATMENT: MAKING DECISIONS AND APPOINTING A HEALTH CARE AGENT. New York: New York State Task Force on Life and the Law, 1987, p. 91). It is important for the person who selects a proxy health care decision maker to realize that this proxy has full authority to act as if he or she were the patient making these decisions (p. 157).

Sample Durable Power of Attorney for Health Care Form

This is an important legal document. Before signing this document, it is vital for you to know and understand these facts:

This document gives the person you name as your attorney in fact the power to make health-care decisions for you if you cannot make the decisions for yourself. After you have signed this document, you have the right to make health-care decisions for yourself if you are mentally competent to do so. In addition, after you have signed this document, no treatment may be given to you or stopped over your objection if you are mentally competent to make that decision.

You may state in this document any type of treatment that you do not desire and any that you want to make sure you receive. You have the right to take away the authority of your attorney in fact, unless you have been adjudicated incompetent, by notifying your attorney in fact. It is advisable to revoke in writing and to place copies of the revocation wherever this document is located.

If there is anything in this document that you do not understand, you should ask a social worker, lawyer, or other person to explain it to you. You should keep a copy of this document after you have signed it. Give a copy to the person you name as your attorney in fact. If you are in a health-care facility, a copy of this document should be included in your medical record.

I, ______________, hereby appoint: ____ (name, home address, home and work telephones)___ as my attorney in fact to make health-care decisions for me if I become unable to make my own health-care decisions. This gives my attorney in fact the power to grant, refuse, or withdraw consent on my behalf for any health-care service, treatment or procedure. My attorney in fact also has the authority to talk to health-care personnel, get information and sign forms necessary to carry out these decisions.

If the person named as my attorney in fact is not available or is unable to act as my attorney in fact, I appoint the following person to serve in the order listed below:

1. ______________________________________ (name, home address, home and work telephones).
2. ______________________________________ (name, home address, home and work telephones).

With this document, I intend to create a power of attorney for health care, which shall take effect if I become incapable of making my own health-care decisions and shall continue during that incapacity.

My attorney in fact shall make health-care decisions as I direct below or as I make known to my attorney in fact in some other way.

Statement of directives concerning life-prolonging care, treatment, services, and procedures:

___________________________________________________________________________

Special provisions and limitations: _____________________________________________

By my signature I indicate that I understand the purpose and effect of this document.

I sign my name to this form on __(date)__ at __(address)___________. Signature _______________.

Witnesses: I declare that the person who signed or acknowledged this document is personally known to me, that the person signed or acknowledged this durable power of attorney for health care in my presence, and
that the person appears to be of sound mind and under no duress, fraud, or undue influence. I am not the person appointed as the attorney in fact by this document, nor am I the health-care provider of the principal or an employee of the health-care provider of the principal.

First Witness: ______________________(Signature, print name on following line, home address, date)_____.
Second Witness: ____________________(Signature, print name on following line, home address, date)_____.

(March 16, 1989, D.C. Law 7-189, § 8, 35 DCR 8653). This form was supplied by Barbara Mishkin, Esq., and was taken from the District of Columbia Code Annotated, 1981 ed.; Volume 5, 1989 replacement, Chapter 22 Health-Care Decisions, Sec. 21-2207.

State Statutes


(Citations were obtained from Choice in Dying’s November 24, 1991 compilation.)

State legislatures across the nation have pending living will legislation and the natural death laws are often amended. State courts can make decisions interpreting living will statutes. Anyone desiring information concerning state law containing advance directive instructions should be sure that the most recent provisions are included in the material.

Government Documents


The booklet provides thorough information about advance directives and offers a question and answer section for those interested in preparing such documents. There are three different forms included as well as a checklist of questions about health care desires and wallet cards for organ donation and to inform medical personnel that an advance directive exists.


The texts of the new 1991 Advance Directives for Health Care Act and Declaration of Death
Act are included along with relevant commentary. Three advance directive forms and a discussion of the brain dead or damaged patient make up the appendix.


The report is divided in two parts: Part 1 “The Social, Legal and Ethical Context for Treatment Decisions” which includes I. Choices and Dilemmas, II. The Right to Make Health Care Decisions: New York State Law, and III. The Ethical Dilemmas of Foregoing Treatment; Part 2 “The Health Care Proxy: Recommendations and Proposed Legislation” contains IV. Making Decisions in Advance: The Living Will and Health Care Proxy, V. The Health Care Proxy: The Agent’s Authority, Obligations, and Protection, VI. Creating a Health Care Proxy, VII. The Obligations of Physicians and Other Health Care Professionals, VIII. Health Care Proxies in the Long-Term Care and Mental Health Settings, IX. Making the Proxy Work: The Need for Public Education and X. Conclusion. Also included are minority reports, proposed legislation, and hospital and nursing home policies.


In this extensive study, the commission indicates that neither criminal nor civil law precludes the mutual counsel of patient, physician and family members to make decisions regarding those who are terminally ill. Decision making and informed choice are examined and careful attention is given to the decision process for incompetent patients or seriously ill newborns. Explicit policies for resuscitation decisions and the use of hospital ethics committees are both advocated. Appendices include natural death statutes (through 1982) and statutes relating to appointment of proxy decision makers. The report has served as a reference and resource document since its publication.


The Vermont Ethics Network has prepared an informative and useful handbook using a question and answer format and including advance directive and a durable power of attorney forms which follow Vermont law. The back cover has wallet cards similar to the ones described above. (The Vermont Ethics Network is a group of 60 citizens interested in ethical issues in health care delivery and sponsored by the Vermont Health Policy Council. It was founded in the spring of 1988 and this is its first publication.)

Court Decisions

In the Matter of Selma L. Saunders, 492 N.Y.S. 2d 510 (Sup. Ct. Nassau County, NY, July 16, 1985). A woman who had executed a living will requested that the court determine its validity and effectiveness. Her petition was granted in part and denied in part. The court said that only the state legislature has the authority to enact a statute recognizing the validity of living wills, and that the durable power of attorney transfers to another the responsibility for decisions while Ms. Saunders “strives to maintain her own right to self-determination.” The court deemed the document to be in the nature of an informed medical consent and the instructions could be fulfilled without additional expensive court proceedings in the course of the natural death process should she become incompetent to continue to express her wishes.


The Supreme Court of Florida reversed a lower district court decision that held in the case of Francis Landy, a comatose terminally ill patient who had executed a living will, that her guardian did not need to obtain court approval before removing her feeding tube in order for consenting family members, physicians, and the hospital to be relieved of civil and criminal liability. The higher court held that while patients have
the right to refuse extraordinary means of artificial support and that living wills are persuasive evidence of intention, the courts still are always open to hear about circumstances caused by disagreement or wrong motives or malpractice which may need judicial intervention.

Books/Manuals


The publication provides information about the Patient Self-Determination Act, the guiding principles of state law in the area of health decisions, and information about advance directives from the legal viewpoint of patients’ rights.


Prepared for hospitals, this guide provides information necessary for compliance with the federal Patient Self-Determination Act of 1990 and the Joint Commission on Accreditation of Healthcare Organizations’ 1992 manual, which will require accredited hospitals to have policies and procedures on written advance directives in patient care. The document includes a question and answer section, a glossary, sample forms, information about the new federal law as well as state laws, copies of the association’s Bill of Rights, and Patient’s Choice of Treatment options, an annotated resource list, and a pamphlet suitable for patients.


The author urges discussion of practical issues concerning health care and death along with philosophical issues for members of Catholic religious groups.


A publication from the Communications Policy Studies of Northwestern University’s Annenberg Program, the document discusses the act in relation to the Cruzan case, implementation of the new law, and unresolved issues. The appendix offers information sources, a copy of the law, sample advance directives and other pertinent material.


Journalist Colen says that he was originally opposed to the use of living wills, but has changed his position, and now thinks that it is absolutely necessary to have an explicit directive as the only way one has a good chance to be cared for in the manner desired. He says that having a health care directive does not guarantee avoiding the courts, but does provide physicians and family with the patient’s competent wishes. He suggests a videotaped living will that would portray the actual patient spelling out his desires clearly. The book has a sample dialogue between the patient and a family member.


The manual explains the federal act and general protocols, offering five different specific protocols adopted by individual hospitals across the United States as well as one nursing home’s protocol. The appendix reprints parts of Sections 4206 and 4751 of the Omnibus Budget Reconciliation Act of 1990 which contain The Patient Self-Determination Act.


The 14 essays in this book were originally presented at a conference on advance directives
held in Little Rock, Arkansas, in May 1985. Discussions of directives combined with specific topics include: choosing among alternative formats, interpreting proxy directives in clinical decision making, living wills as public policy, legal analysis, financial enforcement, the elderly, healthy patients, the primary care physician, the denial of death, and self determination.


Attorney Smith explains the importance of the living will and provides anecdotal cases to illustrate situations where a living will could have changed the care received by patients. He offers an easy to read format for describing the state statutes and there are 30 different sample forms included in the book.


A comprehensive collection of all the extant living will and durable power of attorney for health care statutes from 1976 to 1991 act, this work supersedes their three earlier works, the *HANDBOOK(S) OF LIVING WILL LEGISLATION.* Published in a ring-binder format for updating, it contains an introductory overview, the laws, synopses, and the Uniform Rights of the Terminally Ill Act, drafted by the National Conference of Commissioners on State Laws.

**Parts of Books/Journals**


The section on advance directives offers definitions, a full description of how to develop, execute, and implement a directive as well as material concerning review, revision or revocation of these documents. Proxy decision makers are discussed, but the report notes that one of the major goals of the document is to have persons plan their own treatment decisions while capable and competent.


Lawyer Mishkin points out that advance directives do not create rights but allow one to exercise the fundamental right to make choices in health care. She says written instructions spare the family pain and guilt and relieve them of the burden of deciding what should be the chosen treatment. A sample living will form, typical provisions covered in statutes as well as living will limitations, witness requirements, revocation, durable power of attorney and special requirements for creating such powers of attorney, and a sample durable power of attorney form are all discussed in detail.


The authors note that the advance directive movement will continue to grow, but say that the more helpful type will be the one that appoints a proxy who can have a meaningful and competent dialogue with health care personnel about the desires and values of the incompetent patient. The authors discuss burdensome care, the question of the validity of the documents, patient competency when the documents were written, and other problems faced by hospitals and institutions in this area of living wills and durable power of attorney.


According to the authors, problems can arise that make “simplistic appeals to living wills and patient preferences so dangerous in the ethics of medicine.” (p. 84), underscoring the need for the
physician to act in the best interests of the patient. Those given durable power of attorney can act on behalf of the patient without having to anticipate every circumstance. The authors suggest a series of steps to follow to ensure that patient, physician and family arrive at an outcome pleasing to all, pointing out that the physician should not feel less responsibility because a living will exists. The question of economic standards of care raises further questions according to the authors.

Rouse, Fenella, et al. Practicing the PSDA. Special Supplement, Hastings Center Report 21(5): S1-S16, September-October 1991. Nine authors contributed to this special section which was prepared as part of the Hastings Center project “Making Advance Directives Work: Implementing the Patient Self-Determination Act”. The PSDA section includes a general background of the Act; a discussion of its effect on nursing homes and in acute care; an analysis of not following a patient’s advance directive, a broad view of other law available for patients’ rights; information about surrogate authority; community education, institutional questions and answers; and a view of other ways to understand this new law.

Scully, Thomas and Scully, Celia. The Living Will, the Durable Power of Attorney and Naming a Proxy: The Pluses of Thinking Ahead. In their: PLAYING GOD: THE NEW WORLD OF MEDICAL CHOICES. New York: Simon and Schuster, 1987, pp. 92-123. The Scullys emphasize the patient’s freedom to accept all treatment or to say no, but point out that since legal matters are important, the person who wishes to direct health care must discuss all facets with an attorney, the physician, one’s family and any other person the patient believes should participate. They urge selectivity in choice of a physician and health care setting and say that after institutional admission, the patient should relay exact feelings about life support systems to everyone concerned. These statements should be backed up by written directives.


Veatch provides some of the background development of the advance directive movement which was begun to shift health decision making from physicians to patients. He mentions written correspondence as early forms of such documents, and goes on to describe fully the elements of advance directives. A sample form is included along with basic provisions of legislation and information about the model uniform natural death act.

Articles

Anderson, Gene C., et al. Living Wills: Do Nurses and Physicians Have Them? American Journal of Nursing 86(3): 271-275, March 1986. This report of a survey of 500 nurses and 500 physicians indicates that 20% had advance directives and 48% were seriously considering executing such documents even if they had not done so. About 7% said that they would never sign such a document.

Annas, George J. The Health Care Proxy and the Living Will. New England Journal of Medicine 324(17): 1210-1213, 25 April 1991. Writing that medicine is ‘awash’ in forms, Annas offers information about the background of living wills and notes their limitations. He notes the trend to designate health care proxies for decision making and says physicians should enter into the process with their patients. A model Massachusetts health care proxy is appended.

Areen, Judith. The Legal Status of Consent Obtained from Families of Adult Patients to Withhold or Withdraw Treatment. Journal of the American Medical Association 258(2): 229-235, 10 July 1987. Georgetown University Law Center Dean Areen’s review article discusses emerging legal standards concerning the withholding or withdrawing of medical treatment. She recommends the living will or durable power of attorney as a good way to avoid legal uncertainty surrounding family consent, and urges health care providers to encourage patients to prepare such advance directives.

Father Barry thinks that living wills give physicians legal protection when they remove medical treatments and offer no guarantee that a patient won’t be “manipulated into rejecting treatments.” He notes that the Catholic Health Association suggested form does not guarantee that patients will be treated according to their wishes and instead guarantees “normal care and ordinary medical treatments” The author calls such documents “a bad solution to a difficult problem.”


The National Conference of Catholic Bishops (NCCB) responded to the Uniform Rights of the Terminally Ill Act in 1986, indicating its preference that the act apply only to patients in the final stage of a terminal condition and including other specific concerns, such as protection of the fetus and the need for family communication.


In this extensive article philosophy professor Buchanan reviews the value and moral authority of advance directives. He discusses the difficulty of maintaining an individual’s continuing personal identity if the person becomes incompetent.

Buchanan, Alien and Brock, Dan W. **Deciding for Others.** *Milbank Quarterly* 64(Supp. 2): 17-94, 1986.

The concept of personal competence, standards of competence, and the criteria for determining these standards are presented by the authors prior to their discussion of the scopes and limits of advance directives. They also focus on various principles of authority when proxy health decisions are needed.


Law/medical student Cantor says that physicians must “educate themselves and their patients about the need for advance directive and the laws in their state.” He suggests that they draft their own documents as samples for their patients.


In this survey of nursing home residents, 103 persons were offered an opportunity to execute durable powers of attorney for health care and indicate their preferences about life support treatments under hypothetical levels of cognition. They tended to prefer sons or daughters as agents for decision making, but only about 25% executed a durable power of attorney for health care. The level of future function and the permanence of the treatment procedure were the determinants of their care choices. The authors point out the need to discuss such decisions while patients are still competent.


The authors interviewed 97 Georgetown University hospital patients, aged 64-97, and learned that 65% would choose their nearest relative to make health care decisions; 16% had already done so and 46% intended to appoint such a surrogate.


The author views Maryland’s 1988 law among the most liberal in the area of health decision making. He urges stringent governance of the powers of surrogacy, particularly since the consideration of economics is a relatively new concept in health decisions.

In a study in one nursing home over a two year period, 126 competent residents and 49 family members of incompetent residents were interviewed and their preferences for care were placed in the medical record. An analysis of 96 ‘events’ (hospitalization or death at the nursing home) indicated that care followed preference 75% of the time. Where differences occurred, six cases were given more aggressive care and 18 less aggressive care (largely because CPR was withheld). Inconsistencies were more likely in the nursing home. The sample patient preference form used in this study is appended.


The authors urge that the family physician have an active role in identifying patients who would benefit from writing an advance directive, noting that the physician could advise the most effective medical terminology for stating the document’s provisions. The patient’s physician could also explain the directive to specialists or to the patient’s family.


The authors surveyed 1,293 Arkansas physicians and found that 80% had a positive attitude toward the use of living wills, 55.9% had actual experience with the documents and 83.5% of these physicians had a more positive attitude following the experience. The authors indicate that benefits such as improved communication and trust, promotion of patient autonomy, and easier and more confident treatment decision making, were substantiated by the results of the survey.


The authors offer an advance directive they prepared which reflects the view that advance directives, like other important life decisions, should be consistent with a person’s religious faith and values.

Doukas, David J. and McCullough, Laurence B.


After a brief explanation of the living will and durable power of attorney, the authors recommend that physicians take a ‘value history’ from their patients to identify a patient’s preferences and to give direction to medical decision making. Then an advance directive could be prepared based on these values. A three-page sample of such a questionnaire is included.


Ms. Downie provides information about Canadian legislation and discusses the legal status of advance directives. She offers cogent general arguments in favor of and against respecting such directives, and for and against advance directive legislation.


Competent patients are urged to fill out advance directives, but the authors say that the question of competence in a particular patient may present a problem. Noting that family, physicians and the courts can all be involved, the authors suggest that the physician may be the appropriate person to choose a surrogate for a patient with limited competence or to make decisions for the totally incompetent patient.


Pointing out changes in definitions of advance directives in the past few years, the Emanuels discuss the deficiencies of the living will which pertains only to termination of treatment in the dying. They include a copy of their ‘medical directive’ which provides treatment options for categories of conditions as well as an attempt to assess a patient’s values.

Emanuel, Linda L., et. al. Advance Directives for Medical Care—A Case for Greater Use. *New
The authors studied 405 patients and 102 persons from the general public in the Boston area and found that 93% of the patients and 89% of the public would like to have advance directives. About 70% of those queried indicated that if they were incompetent with a poor prognosis they would not want life-sustaining treatment. The authors recommend that physicians initiate discussion of advance directives with patients during regular office visits, and include a sample questionnaire.


Saying that a healthy doctor patient relationship easily includes advance directive planning, Dr. Emanuel suggests a range of alternative plans to discuss with a patient, and provides a copy of a health care directive which covers actual situations and has pertinent questions and answers.


The authors explain what the law requires from various health facilities and briefly evaluate its strengths and weaknesses. An outline of the approach to the law which is planned at the University of Virginia Hospitals is discussed.


Seventy-five elderly North Carolinians were interviewed: 64% were aware of their state’s living will law, but none had signed any advance directive and only 3% had discussed such a document with a physician. The authors say that 86% (65 persons) wanted only comfort care in terminal illness and 93% wanted their family to make decisions about terminal care if they were unable to do so. Improved physician patient relationship in the area of advance directives and medical care at the end is recommended and the authors consider it appropriate for physicians to initiate such a discussion.


Discussing two innovations in advance directives, Ms. Gibson describes a medical directive which offers 12 medical interventions for the signer to consider and also a values history for the person to select beliefs, values, and preferences to aid in medical decision making. A sample four-page values form is part of the article.


Gillon notes the growing interest in living wills in Great Britain and cites the 1988 Working Party Report on Living Wills, which rejected the British Medical Association view that no laws were needed since physicians may make decisions and patients may inform them verbally or in writing. The author thinks that avoiding legislation is preferable and that in England use of proxy decision makers could be combined with the living will in a single document without a need for statutes.


The authors developed a training program for medical residents to practice discussion of advance directives. Goals were to provide technical knowledge of such directives, improve communication skills, to become aware of the need to discuss advance directives before onset of a critical illness, and to learn of possible problems which could arise in such talks.


Hackler writes that it is often impossible to refuse medical treatment unless the patient clarifies his desires at an early stage. He urges care in defining ‘terminal’ and suggests the use of a proxy decision maker instead of trying to
provide for every possibility. Frequently family members assume this role, but anyone who has knowledge of the patient’s preferences and can be trusted to follow them would be suitable. The author suggests that refusing to pay medical and hospital bills for treatment rendered but not wanted might be an effective means of enforcing a patient’s wishes.


The author indicates that living will legislation can erode patient rights by insisting that the patient be qualified by others before interventions are withheld or withdrawn and urges that great care be taken to avoid a “legal morass.”


Conducting a survey among 40 non-institutionalized elderly, High questioned them on their knowledge and preferences about advance directives and proxies. About 90% knew of such documents but only 18% had living wills and 15% had appointed a proxy health decision maker. He thinks that legislatures and advocacy groups should aid in helping family involvement and be alert to the moral power and dimension of family care giving.


After explaining advance directives, Ms. House urges churches to discuss the issues presented by these documents and to offer counseling by educated clergy.


The article says that the most significant problem for the AIDS patient who executes a living will is whether the disease can be defined as a terminal condition. The author discusses various state regulation definitions concerning life-sustaining procedures and notes that the AIDS patient will continue to have difficulty exercising the right to refuse treatment. She recommends broader natural death acts which would protect hospitals from liability and patients from unwanted treatment.

Lambert, P.; Gibson, J.M.; and Nathanson P. The Values History: An Innovation In Surrogate Medical Decision-Making. Law, Medicine & Health Care 18(3): 202-212, Fall 1990.

Expressing the values held by the patient is complementary to drawing up advance directives according to the authors. They have drawn up a six page Values History which includes such questions as how a person would like an obituary to read. They think taking such a history is an important process which can inform surrogate decision making.


The authors point out that living wills have a narrow focus and their value may lie mainly in raising public consciousness. Although not problem free, durable powers of attorney are more practical. Incompetence will be an increasing problem as the population ages and physicians should play a leading role in education concerning the problem. The article is an informative discussion of the relevant issues for the patient, for the proxy decision maker, and for the physician.


Physician McIntyre urges physicians to learn effective use of advance directives, and to overcome their reluctance to deal with death in the patient’s clinical life. Physicians should participate in facilitating the patient’s wishes, he says, and recommends a well-prepared proxy decision maker as the means to accomplish these ends.


The Catholic Health Association’s senior attorney urges those making advance directives to be precise and to understand their choices. For health care providers, he urges awareness of varied cultural and social backgrounds; a
sample durable power of attorney form is part of the article.

Miles, John. *Protecting Patient Self-Determination*. *Health Progress* 72(3): 26-30, April 1991. Miles uses a question and answer format to clarify the part of the 1990 Omnibus Budget Reconciliation Act which requires that institutional health care providers give patients and residents written information about their rights to make decisions affecting medical treatment; He also provides information about institutional policies used in the implementation of patients’ rights.


Murphy thinks that the term ‘DNR’ should be changed to ‘No ACLS’ (Advanced Cardiac Life Support) to make clear what treatments the patient wants or does not want. The author says that more advance directives will be executed when physicians give their time and knowledge to discussing these documents with their patients. He recommends Medicare reimbursement for this primary care, and thinks savings will be made by “reducing expensive, undesired care for older people.”


Noting that the Patient Self-Determination Act applies only to adult patients, the article says that advance directives are problematic in two respects: 1) most documents are too general to be helpful and are poor substitutes for physician-patient dialogue; and 2) federal and state agencies are authorized to produce descriptions of subjects such as informed consent, power of proxy decision makers, or applicability of nutrition or hydration, which are broad in scope and controversial in subject.


Lawyer Nelson points out that although the generic living will does not have the same legal effect as advance directives made in states with natural death act directives, such documents can have important legal significance offering ethical and legal expressions of the patient’s wishes. He says hospital ethics committees will encounter such documents ever more frequently and must consider if the directives are applicable to the case being reviewed, if the patient’s wishes are indicated, if the family confirms the content as consistent with the patient’s known desires, and if the document has legal status, complying with the state’s natural death act.


Quoting various health and legal sources, Obade agrees with them that the goals of the Patient Self-Determination Act are supported by almost everyone, but she says that the hospital is not the place to make decisions about advance directives. The appropriate source of such information is the physician, not an institution, since “physicians have a duty to counsel and guide their patients to a greater degree than the regular vendor of good or services.”


A physician and a lawyer write to urge physicians to counsel patients and family as soon as there is a diagnosis of Alzheimer’s disease. The issues of informed consent, competency, powers of attorney, guardianship, wills, and living wills are discussed. Planning ahead helps the family’s burden and also the caretakers.


The article discusses fully the legal basis of living wills from the point of view of the right of self-determination. Peters points out their narrow focus and interpretative problems, and also the advantages as well as the worries found in durable power of attorney documents.

Roe, Joy M., *et al*. *Durable Power of Attorney*
A study of 59 healthy aged persons found that only 21 or 36% had durable powers of attorney; 13 of them had not given a copy to their physician. The authors comment that the new PSDA will provide impetus for execution of advance directives, but note that their subjects had difficulty in choosing a proxy to make health decisions.

Rouse, director of Choice in Dying, comments on legal cases where courts ruled on the right to die. She says that the U.S. Supreme Court in the Cruzan case did not require clear and convincing evidence that treatment could be withheld, but held that states could constitutionally require such evidence. She thinks that state legislatures must respond by giving guidance to patients and families to make informed choices.

Singer was chairman of the Advance Directives Seminar Group at the University of Toronto’s Centre for Bioethics, which prepared a paper with arguments for and against the principle of advance directives. The group suggests how such documents should be designed, when they should be updated, and how they should be used and enforced. It concludes that advance directives are a valuable method for people to express preferences about life-sustaining treatments.

Seventy ambulatory veterans were interviewed; 43% had never heard of advance directives. After the interview 4% had one, 33% intended to make a living will, 54% were undecided and 9% did not want one. Almost all (91%) believed that their treatment would not be affected by signing a living will.

Wachter says that physicians should be well informed on outcome data for AIDS patients and use well-established ethical principles to have patients express preferences about intensive care. Such patients should be encouraged to provide advanced directives or to designate surrogate decision makers.

Audiovisuals

Helen Hayes and attorney Peter Strauss discuss living wills and durable power of attorney as a means of insuring personal choice in decision making.

Using different formats, this film explains the Patient Self-Determination Act by having a woman read the law and explain it, various possible “users” discuss what they think about living wills or durable power of attorney, a physician speaks on doctor patient communication, and concludes with all of them participating in a question and answer segment.

A short drama features discussion between family members about health care decisions, advance directives, and surrogate decision making.

The Right to Die...The Choice is Yours. 1987, VHS, 14 min., color. Society for the Right to Die (now Choice in Dying), 250 W. 57th St., New York, NY 10107, tel. 212-246-6973.
The film presents two “allowing to die” situations, and discusses living wills and proxy health care decision makers.

Additional Readings


Scope Note 2 was prepared originally by Judith Adams Mistichelli (now Judith Adams), former reference librarian at the National Reference Center for Bioethics Literature, who updated the paper in August 1984. The paper was completely revised in February 1990 by Pat Milmoe McCarrick a reference librarian at the National Reference Center, who updated it in September 1991, and also prepared this revision of Scope Note 2.