The New Jersey Advance Directives for Health Care and Declaration of Death Acts

Statutes, Commentaries and Analyses

State of New Jersey

A Publication of the New Jersey Commission
on Legal and Ethical Problems in
the Delivery of Health Care

The New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care

In 1985 the New Jersey Legislature created the Commission on Legal and Ethical Problems in the Delivery of Health Care (the New Jersey Bioethics Commission). The Commission is a permanent legislative study body mandated to "provide a comprehensive and scholarly examination of the impact of advancing technology on health care decisions [in order to] enable government, professionals in the fields of medicine, allied health care, law, and science, and the citizens of New Jersey and other states to better understand the issues presented, their responsibilities, and the options available to them."

The Commission is comprised of a diverse and multidisciplinary group of 27 appointed volunteer members. Its membership is designed to bring to the public policy process a broad spectrum of expertise, opinions and perspectives including medicine, nursing, health care administration, law, ethics, theology, natural science, social science, the humanities, and public affairs. By law the Commission includes representatives of the legislative and executive branches of state government, of major statewide professional and health care associations, and of New Jersey's professional and public communities.

On the basis of its findings, the Commission offers recommendations to the Legislative and Executive branches. For each of the areas the Commission studies it publishes reports designed to provide a thorough explanation of the intent and spirit of its recommendations. Through these publications and other educational activities the Commission seeks to enhance understanding and promote discussion of bioethical issues by policymakers, members of the legal and health care communities and by all New Jersey citizens.

To obtain additional copies of this and other Commission publications please refer to the inside back cover.

The New Jersey Advance Directives for Health Care and Declaration of Death Acts

Statutes, Commentaries and Analyses

State of New Jersey
James J. Florio, Governor

A Publication of the New Jersey Commission
on Legal and Ethical Problems in
the Delivery of Health Care

November 1991

This is a publication of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (The New Jersey Bioethics Commission).

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State of New Jersey

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November 27, 1991

The Honorable James J. Florio
Governor, State of New Jersey
State House
Trenton, New Jersey 08625

The Honorable Joseph V. Doria
Speaker, New Jersey General Assembly
State House
Trenton, New Jersey 08625

The Honorable John A. Lynch
President, New Jersey Senate
State House
Trenton, New Jersey 08625

The Honorable Robert N. Wilentz
Chief Justice of the Supreme Court
Richard J. Hughes Justice Complex
Trenton, New Jersey 08625

Dear Governor Florio, President Lynch, Speaker Doria
and Chief Justice Wilentz:

On behalf of the New Jersey Bioethics Commission it is our privilege to transmit a copy of the Commission's publication, *The New Jersey Advance Directives for Health Care and Declaration of Death Acts: Statutes, Commentaries and Analyses*. These statutes, which were enacted by the Legislature and signed by the Governor this year, are based on the work of the Commission and closely follow recommendations developed during approximately two years of Commission study and deliberation.

As you know, the Commission was established in 1985 as a diverse, multidisciplinary legislative study commission with a mandate to study and make recommendations regarding the difficult ethical and legal dilemmas posed by advances in modern science and medicine. It is comprised of 27 volunteer members who ably represent the health care and legal professions, as well as a wide array of moral and religious perspectives. In keeping with the purposes of our enabling legislation, this publication has been prepared for the benefit of all our citizens. The analyses contain a comprehensive discussion of the legal and ethical principles animating the statutes, such as regard for the rights, wishes and well-being of patients, concern for the integrity of health care professionals, and respect for religious and moral diversity. Moreover, it is the Commission's belief that any understanding of these laws which did not take full account of these fundamental moral, social and professional concerns would be incomplete.

It is our sincere hope that this publication provides useful guidance to all who will play a central role in seeing that the purposes of the legislation are realized for all New Jerseyans. Thank you very much for your continuing interest and support. We look forward to being of service to you and your colleagues as we strive to continue to fulfill our legislative mandate.

Very truly yours,

(P. W. Armstrong)
Chairman

Sister Jane Frances Brady
Vice-Chairman

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THE NEW JERSEY ADVANCE DIRECTIVES FOR HEALTH CARE ACT

P.L. 1991, Chapter 201

To be codified as Chapter 2H, sections 53 through 78 of Title 26 and as Chapter 27G, sections 5.1 and 25.1 of Title 52 of the Revised Statutes

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*THE NEW JERSEY ADVANCE DIRECTIVES FOR HEALTH CARE ACT With Commentary**

Historical Note

The New Jersey Advance Directives for Health Care Act was signed into law by Governor James J. Florio on July 11, 1991. The bill was passed, as amended, by the New Jersey Senate on June 20, 1991. The primary sponsor of the bill (S-1211) was Senator Gabriel M. Ambrosio (a Commission member). The companion bill (A-16) was passed by the General Assembly on June 10, 1991. The bill's primary sponsors in the Assembly were Assemblyman Gerard S. Naples and Assemblywoman Maureen Ogden. The New Jersey Advance Directives for Health Care Act is based upon the work of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (the New Jersey Bioethics Commission). The bill was originally approved by the Commission on December 29, 1988, and was first introduced in the legislature on February 9, 1989.

Prefatory Note

The act provides a comprehensive approach to "living wills" and "medical durable powers of attorney" which allows competent adults to specify in writing their treatment preferences and to entrust a family member, friend, or other person with legal authority to carry out their wishes and to make health care decisions on their behalf in the event of subsequent decisionmaking incapacity. The act resolves prior uncertainties regarding the legal status of advance directives and the obligations of health care providers to honor such documents. Advance directives are currently recognized by statute in 48 states and the District of Columbia. (The sole exceptions are Pennsylvania and Nebraska.)

The New Jersey Advance Directives for Health Care Act assures respect for patients' previously expressed wishes when the capacity to actively participate in decisionmaking is lost or impaired; protects patients' rights to request or to refuse life-sustaining treatment; facilitates and encourages a sound decisionmaking process in which patients, health care representatives, families, physicians, and other health care professionals are active participants; properly considers patients' interests both in self-determination and in well-being; respects professional and institutional conscience while assuring that patients are not abandoned; and provides appropriate safeguards concerning the termination of life-sustaining treatment for patients who have lost the ability to make their own health care decisions.

This document, prepared by the Bioethics Commission, provides a section-by-section analysis of the New Jersey Advance Directives for Health Care Act. Section headings are supplied by the Bioethics Commission.

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* This publication supercedes prior analyses prepared by the Bioethics Commission.

AN ACT concerning health care decisionmaking and supplementing Title 26 and Title 52 of the Revised Statutes.

BE IT ENACTED by the Senate and General Assembly of the State of New Jersey:

Section 1: Short Title

This act shall be known and may be cited as the "New Jersey Advance Directives for Health Care Act."

Section 2: Legislative Findings

The Legislature finds and declares that:

a. Competent adults have the fundamental right, in collaboration with their health care providers, to control decisions about their own health care. This State recognizes, in its law and public policy, the personal right of the individual patient to make voluntary, informed choices to accept, to reject, or to choose among alternative courses of medical and surgical treatment.

b. Modern advances in science and medicine have made possible the prolongation of the lives of many seriously ill individuals, without always offering realistic prospects for improvement or cure. For some individuals the possibility of extended life is experienced as meaningful and of benefit. For others, artificial prolongation of life may seem to provide nothing medically necessary or beneficial, serving only to extend suffering and prolong the dying process. This State recognizes the inherent dignity and value of human life and within this context recognizes the fundamental right of individuals to make health care decisions to have life-prolonging medical or surgical means or procedures provided, withheld, or withdrawn.

c. In order that the right to control decisions about one's own health care should not be lost in the event a patient loses decisionmaking capacity and is no longer able to participate

actively in making his own health care decisions, this State recognizes the right of competent adults to plan ahead for health care decisions through the execution of advance directives, such as living wills and durable powers of attorney, and to have the wishes expressed therein respected, subject to certain limitations.

d. The right of individuals to forego life-sustaining measures is not absolute and is subject to certain interests of society. The most significant of these societal interests is the preservation of life, understood to embrace both an interest in preserving the life of the particular patient and a related but distinct interest in preserving the sanctity of all human life as an enduring social value. A second, closely related societal interest is the protection of individuals from direct and purposeful self-destruction, motivated by a specific intent to die. A third interest is the protection of innocent third parties who may be harmed by the patient's decision to forego therapy; this interest may be asserted to prevent the emotional and financial abandonment of the patient's minor children or to protect the paramount concerns of public health or safety. A fourth interest encompasses safeguarding the ethical integrity of the health care professions, individual professionals, and health care institutions, and maintaining public confidence and trust in the integrity and caring role of health care professionals and institutions. Finally, society has an interest in ensuring the soundness of health care decisionmaking, including both protecting vulnerable patients from potential abuse or neglect and facilitating the exercise of informed and voluntary patient choice.

e. In accordance with these State interests, this State expressly rejects on both legal and moral grounds the practice of active euthanasia. No individual shall have the right to, nor shall any physician or other health care professional be authorized to engage in, the practice of active euthanasia.

f. In order to assure respect for patients' previously expressed wishes when the capacity to participate actively in decisionmaking has been lost or impaired; to facilitate and encourage a sound decisionmaking process in which patients,

health care representatives, families, physicians, and other health care professionals are active participants; to properly consider patients' interests both in self-determination and in well-being; and to provide necessary and appropriate safeguards concerning the termination of life-sustaining treatment for incompetent patients as the law and public policy of this State, the Legislature hereby enacts the New Jersey Advance Directives for Health Care Act.

Comment

Section 2 identifies the fundamental principles, concerns and objectives which underlie and inform the approach taken in the act. Of special importance, the act seeks to achieve an appropriate balance between respect for patients' rights to control decisions about their own health care, in particular the right to forego life-sustaining treatment, and other sometimes competing societal interests, in particular society's interests in the preservation of life and in the integrity of the health care professions.

Section 3: Definitions

As used in this act:

"Adult" means an individual 18 years of age or older.

"Advance directive for health care" or **"advance directive"** means a writing executed in accordance with the requirements of this act. An "advance directive" may include a proxy directive or an instruction directive, or both.

"Attending physician" means the physician selected by, or assigned to, the patient who has primary responsibility for the treatment and care of the patient.

"Decisionmaking capacity" means a patient's ability to understand and appreciate the nature and consequences of health care decisions, including the benefits and risks of each, and alternatives to any proposed health care, and to reach an informed decision. A patient's decisionmaking capacity is evaluated relative to the demands of a particular health care decision.

"Declarant" means a competent adult who executes an advance directive.

"Do not resuscitate order" means a physician's written order not to attempt cardiopulmonary resuscitation in the event the patient suffers a cardiac or respiratory arrest.

"Emergency care" means immediate treatment provided in response to a sudden, acute and unanticipated medical crisis in order to avoid injury, impairment or death.

"Health care decision" means a decision to accept or to refuse any treatment, service or procedure used to diagnose, treat or care for a patient's physical or mental condition, including life-sustaining treatment. "Health care decision" also means a decision to accept or to refuse the services of a particular physician, other health care professional or health care institution, including a decision to accept or to refuse a transfer of care.

"Health care institution" means all institutions, facilities, and agencies licensed, certified, or otherwise authorized by State law to administer health care in the ordinary course of business, including hospitals, nursing homes, residential health care facilities, home health care agencies, hospice programs operating in this State, mental health institutions, facilities or agencies, or institutions, facilities and agencies for the developmentally disabled. The term "health care institution" shall not be construed to include "health care professionals" as defined in this act.

"Health care professional" means an individual licensed by this State to administer health care in the ordinary course of business or practice of a profession.

"Health care representative" means the individual designated by a declarant pursuant to the proxy directive part of an advance directive for the purpose of making health care decisions on the declarant's behalf, and includes an individual designated as an alternate health care representative who is acting as the

declarant's health care representative in accordance with the terms and order of priority stated in an advance directive.

"Instruction directive" means a writing which provides instructions and direction regarding the declarant's wishes for health care in the event that the declarant subsequently lacks decisionmaking capacity.

"Life-sustaining treatment" means the use of any medical device or procedure, artificially provided fluids and nutrition, drugs, surgery or therapy that uses mechanical or other artificial means to sustain, restore or supplant a vital bodily function, and thereby increase the expected life span of a patient.

"Other health care professionals" means health care professionals other than physicians and nurses.

"Patient" means an individual who is under the care of a physician, nurse or other health care professional.

"Permanently unconscious" means a medical condition that has been diagnosed in accordance with currently accepted medical standards and with reasonable medical certainty as total and irreversible loss of consciousness and capacity for interaction with the environment. The term "permanently unconscious" includes without limitation a persistent vegetative state or irreversible coma.

"Physician" means an individual licensed to practice medicine and surgery in this State.

"Proxy directive" means a writing which designates a health care representative in the event the declarant subsequently lacks decisionmaking capacity.

"State" means a state, territory, or possession of the United States, the District of Columbia, or the Commonwealth of Puerto Rico.

"Terminal condition" means the terminal stage of an irreversibly fatal illness, disease or condition. A determination

of a specific life expectancy is not required as a precondition for a diagnosis of a "terminal condition," but a prognosis of a life expectancy of six months or less, with or without the provision of life-sustaining treatment, based upon reasonable medical certainty, shall be deemed to constitute a terminal condition.

Comment

The comments to section 3 address those definitions of particular importance in the act, the meaning of which may not be readily apparent. Further elaboration and discussion of the implications of defined terms is found in the substantive provisions and accompanying comments in the subsequent sections of the act.

The act uses the terms **"advance directive for health care"** and **"advance directive"** to refer to a written document executed in accordance with the requirements of the act. The individual who has executed (who executes) an advance directive is referred to in the act as the "declarant". A **"declarant"** must be a competent adult of at least 18 years of age. An advance directive may designate another individual to make health care decisions on the declarant's behalf (a **"proxy directive"**), may contain an **"instruction directive"** which states the declarant's personal wishes regarding health care in the event of subsequent decisionmaking incapacity, or both (a "combined directive"). The term **"health care representative"** refers to the individual designated by the declarant to make health care decisions on the declarant's behalf, and to an alternate designee serving in the capacity of health care representative.

The act does *not* use the terms "medical durable power of attorney" or "living will." This represents an effort to provide a comprehensive statutorily recognized means of planning for one's health care in the event of incapacity, through an integrated approach encompassing *both* the designation of a personally-selected health care representative (more commonly known as a "proxy directive" or a "medical durable power of attorney") and the statement of one's general and specific wishes regarding health care (popularly known as a "living will"). The act also avoids use of the popular term "living will" because of its ambiguous and possibly confusing references to both a general concept of foregoing life-sustaining treatment and to a specific model document which often is structured only to permit the declarant to direct the foregoing of life-sustaining treatment and to do so only in a narrowly defined set of circumstances.

The concept of **"decisionmaking capacity"** is at best vaguely defined in existing statutory and common law. The definition adopted in the act is based

upon an understanding of the several interrelated factors ordinarily involved in the decisionmaking process for the typical patient. A patient's decisionmaking capacity may be assessed in terms of three interrelated abilities the patient should possess and exercise in order to reach an informed decision: 1) the ability to understand and to evaluate information relevant to his or her medical condition, including (in lay terms) diagnosis, prognosis, and the risks, benefits and burdens (and associated uncertainties) of the proposed treatment alternatives (including the option of no treatment); 2) the ability to reason and deliberate about available medical information and a course of treatment; and 3) though not expressly stated in the definition, the ability to act upon personal values and objectives in evaluating relevant information, including the risks and benefits of the proposed treatment and its alternatives.

The second sentence of the definition states that, as used in the act, decisionmaking capacity is primarily a functional and decision-specific concept. The act rejects inflexible concepts of capacity based upon the patient's advanced age or general mental status, short of extreme circumstances. Patients should not be presumed to lack capacity merely on the basis of fitting into a category, such as being elderly, mentally ill, retarded or disabled. Furthermore, a patient may possess the capacity to make some health care decisions but not others. Thus, decisionmaking capacity may vary with the demands of a particular health care decision, and should be evaluated relative to the demands of that particular decision.

The act intentionally uses the terms "capacity" and "incapacity" rather than "competence" and "incompetence" to characterize the patient's abilities to make health care decisions. The term competence is most often thought of as a legal concept associated with a threshold determination by a court of a person's capacity to make particular types of decisions, usually business or financial decisions. In the context of health care decisionmaking, the concepts of competence and incompetence are sometimes employed to separate patients into two sharply differentiated groups: Those from whom consent must be obtained (absent, for example, medical emergency) and those who, in blunt terms, can be and often are ignored in the decisionmaking process. The decision-specific approach adopted here rejects the concept of competence as one which separates patients into two sharply differentiated groups; the act therefore avoids use of the terms "competence" and "incompetence" which ordinarily convey this meaning.

The term **"health care decision"** is intended to be defined broadly. "Health care decision" refers to a decision to accept or to refuse any form of treatment, service or procedure used for either the diagnosis or treatment of the patient's physical or mental condition. While the term is specifically defined to include

"life-sustaining treatment", the definition is much broader and encompasses diagnostic procedures and services, as well as treatment that is not life-sustaining. The act is intended to afford individuals the right to consent to or to refuse by an advance directive a broad range of health care services, whether diagnostic or therapeutic, necessary to sustain life, to treat non-life-threatening conditions, or to relieve pain or suffering. Recognizing that an important part of health care is the choice of a health care professional, such as a physician, and of a health care institution, the second sentence of the definition expressly includes decisions about transfers of care in the meaning of "health care decision".

The term **"life-sustaining treatment"** is also intended to be defined broadly. "Life-sustaining treatment" refers to a broad range of medical devices or procedures, drugs, surgery or therapy, where providing such treatment to the patient would continue a vital bodily function and increase the life expectancy of the patient. The definition of life-sustaining treatment expressly includes artificially provided fluids and nutrition. Thus, the act makes no distinction between artificially provided fluids and nutrition (such as by nasogastric tube or intravenous infusion) and other forms of medical treatments (such as respirators or kidney dialysis). As provided by section 15 of the act, the patient has the same right to direct that a feeding tube be withheld or withdrawn as to direct foregoing of a respirator, and to have his or her stated wishes respected. The act adopts a decision-specific approach to decisions to forego life-sustaining treatment, and sets forth, in section 15, those medical conditions in which withholding or withdrawing of life-sustaining treatment is authorized by the act.

In contrast to some states, the act does not exclude "comfort care" from the definition of "life-sustaining treatment". Since many measures which make the patient more comfortable are also life-sustaining, such an exclusion can be confusing. The act seeks to avoid this confusion by allowing that life-sustaining treatment may be withheld or withdrawn pursuant to the act, even if the treatment to be foregone would also make the patient more comfortable. At the same time, section 15b. expressly states that the act does not impair professional obligations to alleviate pain and make the patient comfortable when life-sustaining treatments are foregone.

The term **"patient"** is used in its ordinary and commonly understood sense, to refer to an individual who is under the care of a physician or other health care professional. In contrast, many states use the term "qualified patient", often defining a "qualified patient" as a patient who has executed an advance directive and who has been determined by one or more physicians to be in a terminal condition. Typically, the central purpose of this approach is to permit an advance directive to be used only to direct the withholding or withdrawal of life-

sustaining treatment, and only in circumstances where the patient has been determined to be in a terminal condition. The scope of this act is not restricted in either of these respects, and avoiding the term "qualified patient" (and not structuring the act around such a definition) serves to avoid an important potential confusion with the approach taken in other states.

The term **"permanently unconscious"** refers to a patient who has *totally* and *irreversibly* lost consciousness and capacity for interaction with the environment. While the definition states that permanent unconsciousness includes a persistent vegetative state and the similar (but not identical) condition of irreversible coma, permanent unconsciousness is not to be taken as a medical or scientific term which labels a specific set of diagnostic criteria. The term "permanently unconscious" is intended to avoid the technical complexities of accurately defining medical conditions in favor of a more common sense understanding of what it means for a patient to have irreversibly lost capacity for a cognitive sapient state. A diagnosis of permanent unconsciousness must be made in accordance with currently accepted medical standards and with reasonable medical certainty.

The term "permanently unconscious" does not include patients who meet neurological criteria for the declaration of death. The newly enacted New Jersey Declaration of Death Act, to be codified as *N.J.S.A.* 26:6A-1 through 6A-8 (West 1991), establishes by statute neurological criteria for determining death as a legal standard for declaring death. The Declaration of Death Act also recognizes a "religious exemption" from such a determination which prohibits a declaration of death on the basis of neurological criteria for those patients whose sincerely held personal religious beliefs would be violated by a determination of neurological death and who believe that their death should only be declared on the basis of irreversible loss of cardiorespiratory function. Patients who exercise the religious exemption are to be treated as permanently unconscious until such time as death occurs from irreversible loss of heart and lung function. (Generally in the adult patient this will occur within a matter of days, or in rare cases weeks, of the diagnosis of neurological death.)

In most cases the bodily functions of a patient in a state of permanent unconsciousness can be maintained with artificial life-support for many years. Thus, with rare exceptions, a permanently unconscious patient will not meet the criteria for a diagnosis of a "terminal condition" (discussed below). Use of the terms "permanent unconsciousness" and "terminal condition" in the substantive provisions of the act recognizes the current understanding of these terms as referring to distinct medical conditions and avoids unnecessary and unhelpful debate concerning whether the permanently unconscious patient should be regarded as "terminal".

The definition of **"terminal condition"** requires a diagnosis that the patient's illness, disease or condition is *irreversible* and *fatal*. The key phrase here is that the patient be diagnosed to be in the "terminal stage" of the illness or disease process. The concept of irreversibility, not that of incurability, expresses the fundamental concern about the dying process. Under this definition a reversible condition is not terminal; an irreversible condition is by definition incurable. (A patient could have an "incurable" but "reversible" condition.) Since there are terminal "conditions" not attributable to disease processes, the term "condition" is used rather than "illness", as "illness" is ordinarily identified with a disease process.

Diagnosis of a terminal condition does not require a specific prognosis of length of life remaining as a necessary element of such a determination. In contrast to the law of some other states, the act does not require that the patient's prognosis be "imminent" death, nor does the act use the phrase "death within a relatively short time", which appears to be a more flexible standard yet conveys a sense of imminence. A requirement that death be imminent or within a short time is rejected as too restrictive of the patient's right to refuse treatment and to choose a less burdensome dying process.

The act also rejects use of a fixed and inflexible time period (such as one year) established by statute. The circumstances and inevitable variations in a patient's condition and prognosis make a fixed time period both artificial and unrealistic. It is intended that physicians not be unduly constrained by a fixed time period in the exercise of professional judgment. Nor are physicians compelled to announce that a patient either does or does not have a terminal condition based upon a prognosis of a specific life expectancy fixed by statute. However, the definition of terminal condition does set forth a *guideline* for prognosis of life expectancy--six months or less. Patients whose life expectancy is determined, with reasonable medical certainty, to be six months or less are clearly within the meaning of "terminal condition", and should be considered terminal for purposes of the act. The six month guideline for prognosis of life expectancy corresponds to current federal and state law governing reimbursement of health care costs, *e.g.*, under Medicare and hospice regulations. It is important to note that this is intended only as a guideline. Where the physician cannot state with reasonable medical certainty that the patient has a life expectancy of six months or less the patient's condition may, nonetheless, be terminal within the meaning of the definition. By not adopting the requirement that to be "terminally ill" a patient's life expectancy must be determined to be one year or less, the act modifies existing law under *In re Conroy*, 98 N.J. 321, 486 A.2d 1209 (1985).

The patient's prognosis is to be determined "with or without the provision of life-sustaining treatment". This follows the approach taken in the majority of states, and rejects the position taken in some states that the physician's judgment should be based upon the patient's prognosis "regardless of" (*i.e.*, with) the administration of life-sustaining treatment. This does not mean, however, that the patient's prognosis with the provision of life-sustaining treatment should be considered irrelevant to the decisionmaking process.

Subpart A: Execution and Effectuation of Advance Directives

Section 4: Executing an Advance Directive

A declarant may execute an advance directive for health care at any time. The advance directive shall be signed and dated by, or at the direction of, the declarant in the presence of two subscribing adult witnesses, who shall attest that the declarant is of sound mind and free of duress or undue influence. A designated health care representative shall not act as a witness to the execution of an advance directive. Alternatively, the advance directive shall be signed and dated by, or at the direction of, the declarant and be acknowledged by the declarant before a notary public, attorney at law, or other person authorized to administer oaths. An advance directive may be supplemented by a video or audio tape recording. A female declarant may include in an advance directive executed by her, information as to what effect the advance directive shall have if she is pregnant.

Comment

Subpart A prescribes the formal requirements for execution, reaffirmation, modification, revocation, and suspension of an advance directive, as well as the basic nature and content of such documents. This subpart also states when an advance directive becomes legally operative and how this is to be determined. By expressly stating formalities for the legal validity of advance directives and the process to be followed to determine when a patient's advance directive becomes legally operative, the act resolves uncertainties under current case law as to whether advance directives are legally valid and the legal basis for the obligations of health care providers to honor such documents (*see In re Conroy*, 98 N.J. 321, 486 A.2d 1209, 1229-30 & n.5 (1985)), and also clarifies the legal

status of durable powers of attorney for health care (*see In re Peter*, 108 N.J. 365, 529 A.2d 419, 426 (1987)).

Section 4 sets forth the minimum requirements for execution of a valid advance directive. The execution requirements follow substantially those for execution of a testamentary will in New Jersey (*N.J.S.A.* 3B:3-1 *et seq.*) and are similar to the requirements for execution of advance directives in the majority of other states.

Section 4 provides that a declarant, *i.e.*, any competent individual of 18 or more years of age (*see* definitions in section 3), may execute an advance directive. The act contemplates that, as is the case under existing law, an adult will be presumed competent unless determined by a court to be incompetent. The advance directive must be signed and dated by the declarant, or by another person directed by the declarant to sign on his or her behalf.

Section 4 requires that two witnesses sign the advance directive, attesting by their signatures that the declarant is of sound mind and free of duress or undue influence. In the alternative, the declarant's signature may be acknowledged before a notary public, an attorney, or any other person authorized to administer oaths, without the need for two witnesses. Witnesses and notaries need only attest to the declarant's state of mind at the time of signing, and are not required to know or attest to the contents of the advance directive. The act does not require any specific qualifications for those who may serve as witnesses, so long as they are adults. For example, family members and friends, as well as health care providers, may serve as witnesses. The attending or family physician is not disqualified from serving as a witness, as is the case in some other states. However, anticipating a potential conflict of interest situation, section 4 provides that designated health care representatives (including alternate designees) may not serve as witnesses. Though not expressly stated here, by the same reasoning the notary or attorney who attests the declarant's signature and state of mind ought not be the declarant's health care representative (nor an alternate designee). In this regard, the act provides greater protection than New Jersey's testamentary wills statute, which places no statutory restrictions on who may serve as a witness (*N.J.S.A.* 3B:3-8).

Under section 4 a declarant may execute an advance directive at any time. Consistent with the approach of the vast majority of other states, the right and opportunity to write advance directives is not limited to the time of onset of a serious (life-threatening) condition, nor is the declarant required to reaffirm or re-execute a directive periodically, or following admission to a health care institution. While an individual's periodic and more contemporaneous re-evaluation of the terms of his or her advance directive is advisable, the act does

not make this practice a condition of a directive's legal validity; to do so would be unduly restrictive of individuals' rights to plan ahead for their health care decisions and would undermine the efficacy of directives as advance planning documents. Once validly executed, an advance directive is legally valid for an indefinite period of time, subject to the declarant's revocation or suspension of the document in accordance with section 5 of the act.

A declarant may choose to supplement his or her advance directive with a video or audio tape recording. Video and audio recordings may be desirable for those who seek greater assurance that their advance directive will not later be challenged as inauthentic, or may simply be preferred by some. However, video and audio tape recordings do not modify or substitute for the formal execution requirements of section 4; an advance directive must be in writing.

The last sentence of section 4 expresses a commitment to informed consent by suggesting that women specifically consider what treatment they would choose to accept or reject in the event of pregnancy. (This commitment is iterated in the last clause of section 6a.(5).) The act does not impair the effect of an advance directive in the case of pregnancy, nor does it require that a woman's advance directive specifically address treatment decisions during pregnancy in order to be legally operative. The act takes no position on the issue of a woman's constitutionally protected right to an abortion, and this question should continue to be governed by existing law.

Section 5: Reaffirming, Modifying and Revoking an Advance Directive

a. A declarant may reaffirm or modify either a proxy directive, or an instruction directive, or both. The reaffirmation or modification shall be made in accordance with the requirements for execution of an advance directive pursuant to section 4 of this act.

b. A declarant may revoke an advance directive, including a proxy directive, or an instruction directive, or both, by the following means:

(1) Notification, orally or in writing, to the health care representative, physician, or other health care professional, or other reliable witness, or by any other act evidencing an intent to revoke the document; or

(2) Execution of a subsequent proxy directive, or instruction directive, or both, in accordance with section 4 of this act.

c. Designation of the declarant's spouse as health care representative shall be revoked upon divorce or legal separation, unless otherwise specified in the advance directive.

d. An incompetent patient may suspend an advance directive, including a proxy directive, an instruction directive, or both, by any of the means stated in paragraph (1) of subsection b. of this section. An incompetent patient who has suspended an advance directive may reinstate that advance directive by oral or written notification to the health care representative, physician, nurse or other health care professional of an intent to reinstate the advance directive.

e. Reaffirmation, modification, revocation or suspension of an advance directive is effective upon communication to any person capable of transmitting the information including the health care representative, the attending physician, nurse or other health care professional responsible for the patient's care.

Comment

Section 5 sets forth the minimum requirements for reaffirmation or modification of an advance directive, and states the means by which an advance directive may be revoked. This section also provides for suspension of an advance directive by an incompetent patient.

Reaffirmation and modification. Under section 5a., a declarant may reaffirm or modify a previously executed advance directive by following the same formalities as are required for execution of an advance directive under section 4 (*e.g.*, signing and attested by two witnesses, a notary, or an attorney). As noted in comment to section 4, neither reaffirmation nor modification of an advance directive are required, though either may be advisable where it would serve to make the written statement of the declarant's wishes more accurate or more current, and less subject to question on the ground that the statements contained in it were remote in time, not properly informed, or otherwise fail to represent what the patient's current wishes would be.

Revocation. Section 5b. states the means by which an advance directive may be revoked, and is intended to freely allow revocation. A legally valid revocation can be made, for example, by oral or written notification to an appropriate

individual. Both the provision for oral or written notification and for "any other act evidencing an intent to revoke" (section 5b.(1)), which would include, for example, a physical sign communicating an intent to revoke or physical destruction of the document, are designed to recognize a range of actions as legal means of revocation.

In contrast to the requirements for execution, reaffirmation and modification of an advance directive, section 5b. provides that an individual need not be competent to revoke an advance directive. This provision contemplates that advance directives will most often be used to instruct the foregoing or limiting of health care, in particular life-sustaining treatment. Consequently, a patient's expressed desire to revoke a directive, even when incompetent, may be construed in many cases as a desire to have life-sustaining treatment continued, and this wish should be respected.

Sections 5b.(2) and 5c. recognize two circumstances in which automatic revocation of a prior directive would occur by operation of law. In order to assure that an individual's most recent written statement of his or her wishes is legally operative, section 5b.(2) provides that the current execution of an advance directive shall effect the automatic revocation of a previously executed advance directive. It should be noted, however, that execution of a later document is intended to effect the automatic revocation only of a prior document of the same type. In other words, execution of a proxy directive does not by operation of law revoke a prior instruction directive. Of course, the declarant should be aware of his or her prior directive, and the declarant's intent to revoke, or give effect to, a prior directive, as stated in the later document or evidenced in some other way, should control.

Section 5c. provides for the automatic revocation of the designation of a spouse as the declarant's health care representative where that spouse becomes divorced or legally separated from the declarant. In this event, legal authority as health care representative belongs to any alternate designees, in accordance with their stated priority. If the declarant does not wish the legal authority of a spouse to be automatically revoked upon divorce or legal separation, he or she must state this in the advance directive. The declarant's instruction directive is unaffected by section 5c.

Suspension. Although revocation is freely allowed, the act also contemplates that in some cases the acts or expressions of a patient with impaired capacity may be misinterpreted, or the patient may act out of anger or depression and later change his or her mind. In these circumstances a patient's prior competently expressed wishes, in particular the designation of a health care representative, should not be invalidated. Seeking to address this situation,

section 5d. provides that an incompetent patient may suspend an advance directive by evidencing an intent to revoke in any of the ways stated in section 5b.(1), but may subsequently reinstate that directive by oral or written notification of this intent, provided to the health care representative, physician, nurse or other health care professional. In practice, when an incompetent patient manifests the intent to revoke his or her advance directive, the document should be treated "as if" revoked, until such time as the patient takes action to reinstate the directive. When it is believed that the patient's intent to revoke was a response to depression, anger or other factors and may not represent a settled judgment, further conversation with the patient would be appropriate. (Indeed, this may be an advisable response for all patients who lack decisionmaking capacity and who seek to revoke their advance directive.)

When effective. Section 5e. provides that a reaffirmation, modification, revocation, or suspension is effective when "communicated to any person capable of transmitting the information including the health care representative, the attending physician, nurse or other health care professional responsible for the patient's care". Though not expressly stated here, section 5e. recognizes that those responsible for acting upon a change in the patient's advance directive must become aware of this information. Thus, health care representatives, physicians, and others should not be legally or morally responsible for failure to act on a reaffirmation, modification or suspension when they have no reason to believe that the declarant has taken such action. Knowledge of the declarant's action need not be communicated directly by the declarant, and may be communicated by another person. The act does not require that the person conveying knowledge of a reaffirmation, modification or revocation be acting on the declarant's behalf, a requirement in some states with respect to communication of a revocation. Where the declarant's intention is not communicated directly by the declarant, communication is assumed to be in good faith, but the health care representative and the attending physician should make additional inquiry to assure that the declarant's wishes have been properly conveyed.

Sections 4 and 5 provide that the designation of a health care representative and the writing of an instruction directive may be viewed as severable acts. If an individual who has previously executed an advance directive wishes to change the designated health care representative (to modify or revoke the designation) or to change the contents of an instruction directive (to modify or revoke the instructions), it is not necessary to re-execute the entire document, and the unchanged part remains legally valid. Section 5b. would, for example, allow an individual to orally revoke an instruction directive while retaining the written legal authority of a health care representative. However, where substantial

changes are contemplated (*i.e.*, modification of an advance directive), the document should be re-executed in accordance with section 4.

Section 6: Advance Directives for Health Care

a. A declarant may execute a proxy directive, pursuant to the requirements of section 4 of this act, designating a competent adult to act as his health care representative.

(1) A competent adult, including, but not limited to, a declarant's spouse, adult child, parent or other family member, friend, religious or spiritual advisor, or other person of the declarant's choosing, may be designated as a health care representative.

(2) An operator, administrator or employee of a health care institution in which the declarant is a patient or resident shall not serve as the declarant's health care representative unless the operator, administrator or employee is related to the declarant by blood, marriage or adoption.

This restriction does not apply to a physician, if the physician does not serve as the patient's attending physician and the patient's health care representative at the same time.

(3) A declarant may designate one or more alternate health care representatives, listed in order of priority. In the event the primary designee is unavailable, unable or unwilling to serve as health care representative, or is disqualified from such service pursuant to this section or any other law, the next designated alternate shall serve as health care representative. In the event the primary designee subsequently becomes available and able to serve as health care representative, the primary designee may, insofar as then practicable, serve as health care representative.

(4) A declarant may direct the health care representative to consult with specified individuals, including alternate designees, family members and friends, in the course of the decisionmaking process.

(5) A declarant shall state the limitations, if any, to be placed upon the authority of the health care representative including the limitations, if any, which may be applicable if the declarant is pregnant.

b. A declarant may execute an instruction directive, pursuant to the requirements of section 4 of this act, stating the declarant's general treatment philosophy and objectives; or the declarant's specific wishes regarding the provision, withholding or withdrawal of any form of health care, including life-sustaining treatment; or both. An instruction directive may, but need not, be executed contemporaneously with, or be attached to, a proxy directive.

Comment

Section 6 provides for the nature and basic content of an advance directive. The act goes beyond existing legislation in most other states in its applicability to a broad range of health care decisions, and in its recognition that patients should be permitted to request, in an advance directive, the continued provision of life-sustaining treatment as well as the foregoing of life-sustaining treatment. This approach is a significant departure from the laws of most other states, which often provide that instruction directives (living wills) may only be used to direct the foregoing of life-sustaining treatment, typically limited to the single condition of terminal illness.

The act gives priority to the designation of a health care representative (such as a trusted family member or friend) to make decisions on the declarant's behalf as the essential means of achieving the objectives of a sound decisionmaking process respectful of patient wishes and well-being; several provisions of the act are designed to structure a decisionmaking process in which the health care representative is actively involved on the patient's behalf. This approach is grounded in the fact that a health care representative selected by the patient, who most often will be a trusted and loving family member, will generally be best situated to understand and evaluate the patient's wishes in a flexible and realistic way, duly attentive to the patient's actual and contemporaneous medical circumstances, including changing medical information and possible courses of treatment and care, and to give due weight to these factors in reaching a treatment decision. In contrast, an instruction directive alone is inherently a static and inflexible document. The act is intended to strongly encourage individuals to designate a health care representative *and* to provide their chosen health care representative with general and specific instructions for their future health care (a combined directive).

The act also permits individuals to choose to execute a proxy directive alone, or an instruction directive alone, thereby affording individuals important flexibility in planning ahead for their future health care. (Section 6a.) Although the act does not require consultation with or the assistance of others in the process of preparing an advance directive, given the importance of health care decisions at the end of life it is strongly recommended that individuals give careful and thoughtful consideration to the writing of an advance directive, and that they consult with others, such as family members, a physician, or an attorney, in this process. As stated in comment to section 4, a properly executed advance directive is a legally valid document, unless and until revoked.

Designation of a health care representative. Section 6a. states the scope and limitations regarding who may be designated as a health care representative. While the act is intended to afford individuals a broad range of choice in selecting a health care representative (and any alternate designees), including but not limited to a spouse, adult child, parent, friend, or any other person (provided he or she is an adult and competent), the act also identifies and seeks to prevent certain potential conflict of interest situations from arising. Thus, section 6a.(2) places certain restrictions on who may be designated as health care representative. Where the declarant is a patient or resident of a health care institution, or has applied for admission to a health care institution, the declarant may not designate an operator, administrator or employee of that institution as his or her health care representative, unless the person chosen is also a member of the declarant's family. If a health care representative is disqualified from service, health care providers should look to alternate designees to serve as health care representative, in accordance with their stated order of priority in the directive.

The act permits a physician to serve as the patient's health care representative, but does not permit a physician to serve as both attending physician and as health care representative at the same time. (Section 6a.(2)) Therefore, where possible the declarant should discuss with his or her physician which role (attending physician or health care representative) is preferred in advance of designating a physician as health care representative. A physician who has previously been selected as health care representative should choose one role or the other, either by disqualifying himself or herself from service as health care representative, or by assuming that role and effecting an appropriate transfer of care to another attending physician.

In some circumstances the declarant's first choice as health care representative will be unavailable, unable or unwilling to serve in that capacity. Anticipating this possibility, section 6a.(3) provides that a declarant may designate one or more persons as an alternate health care representative, listing

each in order of priority. An alternate designee is authorized to serve as health care representative, in accordance with the stated order of priority in the directive. An alternate designee may also serve as health care representative if the primary designee is disqualified from assuming this role, such as under section 6a.(2) or section 5c. (designation of a health care representative revoked by legal separation or divorce), or by operation of other law. If the declarant's primary designee later becomes available and able to serve as health care representative, that individual may serve in that capacity, if it is practicable for him or her to do so.

Section 6a.(4) is intended to encourage a declarant to direct his or her health care representative to consult with specified individuals in the course of making health care decisions on the declarant's behalf. Section 6a.(5) permits the declarant to state any desired limitations upon the health care representative's authority.

Instruction directives. Section 6b. sets forth guidelines for the nature and content of a declarant's statement of personal views and specific instructions for health care. The act permits the declarant broad discretion to state his or her instructions and directions for health care in a manner suited to the declarant's personal wishes. An instruction directive may contain a statement of the declarant's general treatment philosophy and objectives, a statement of the declarant's specific instructions regarding particular forms of health care, or both. A declarant may direct the provision of particular forms of health care, including life-sustaining treatment, or may direct the withholding or withdrawal of particular forms of health care, including life-sustaining treatment; and a declarant may request one form of health care while refusing another.

The act does not require that the patient's wish that artificially provided fluids and nutrition be withheld or withdrawn under certain conditions be indicated explicitly in an instruction directive (such as by an express written statement, or by otherwise completing a form in a manner that clearly instructs that artificially provided fluids and nutrition be withheld or withdrawn), and failure to do so creates no presumption about the patient's wishes and no legal bar to foregoing a feeding tube on the patient's behalf. However, experience suggests that patients' prior written instructions can be unclear or ambiguous with respect to decisions to forego artificially provided fluids and nutrition. It is therefore advisable that the declarant's wishes regarding the provision or foregoing of artificially provided fluids and nutrition be specifically stated in order to avoid potential ambiguities.

Advance directive forms. In contrast to some other states, the act does not include an advance directive form as part of the text of the law. The act does not require that a declarant use any particular advance directive form, and any properly executed document will be recognized as legally valid. It is important to note in this regard that the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care and its Task Force on Public and Professional Education have developed three advance directive forms modeled after the act (a proxy directive, an instruction directive, and a combined advance directive which integrates the proxy and instruction directive approaches in a single document). These forms, along with accompanying informational materials, are contained in the publication entitled *Advance Directives For Health Care: Planning Ahead For Important Health Care Decisions* (New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care 1991), which is available to the public and the health care community.

Section 7: When an Advance Directive Becomes Operative

a. An advance directive becomes operative when (1) it is transmitted to the attending physician or to the health care institution, and (2) it is determined pursuant to section 8 of this act that the patient lacks capacity to make a particular health care decision.

b. Treatment decisions pursuant to an advance directive shall not be made and implemented until there has been a reasonable opportunity to establish, and where appropriate confirm, a reliable diagnosis and prognosis for the patient.

Comment

Section 7 establishes the preconditions to an advance directive becoming legally operative. Under section 7a., two conditions must be met before an advance directive is operative. First, the advance directive must become known to the attending physician or to the health care institution. Initially, it is the responsibility of the patient, or of another acting on the patient's behalf, to transmit an advance directive to health care providers. The obligations of inquiry imposed upon the attending physician (section 10) and upon the health care institution (section 13) are intended to assure that if the patient has executed an advance directive, it will be transmitted to physicians and health care institutions responsible for the patient's care. However, neither the patient nor others acting for the patient are required to "communicate" the contents of the advance directive to health care providers, as has been required by some other

states. Once transmitted, it is the responsibility of health care providers to become familiar with the contents of a patient's advance directive.

Second, before an advance directive becomes operative it must be determined, in accordance with section 8, that the patient lacks capacity to make a particular health care decision on his or her own behalf. If the patient possesses decisionmaking capacity, the patient has the right to make his or her own health care decisions, and there is no reason to look to an advance directive.

When the two preconditions of section 7a. are met, the legal operation of an advance directive is "triggered", and health care representatives and health care providers should look to an advance directive and to the provisions of this act to determine their rights and responsibilities.

Section 7b. establishes an important precondition to treatment decisionmaking pursuant to an advance directive, and makes explicit what often, but not always, occurs in practice. This section seeks to assure that health care representatives and physicians do not make treatment decisions that are uninformed or hasty, by requiring that there be a reasonable opportunity to clearly understand the patient's diagnosis and prognosis before implementing a treatment decision. Establishing a reliable diagnosis and prognosis may warrant consultation and confirmation by another physician, as is required by the act in specified cases involving life-sustaining treatment (section 15). What constitutes "reasonable opportunity" to establish the patient's diagnosis and prognosis will necessarily depend on the circumstances.

Section 8: Determination of Incapacity to Make Health Care Decisions

a. The attending physician shall determine whether the patient lacks capacity to make a particular health care decision. The determination shall be stated in writing, shall include the attending physician's opinion concerning the nature, cause, extent, and probable duration of the patient's incapacity, and shall be made a part of the patient's medical records.

b. The attending physician's determination of a lack of decisionmaking capacity shall be confirmed by one or more physicians. The opinion of the confirming physician shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician.

Confirmation of a lack of decisionmaking capacity is not required when the patient's lack of decisionmaking capacity is clearly apparent, and the attending physician and the health care representative agree that confirmation is unnecessary.

c. If the attending physician or the confirming physician determine that a patient lacks decisionmaking capacity because of a mental or psychological impairment or a developmental disability, and neither the attending physician or the confirming physician has specialized training or experience in diagnosing mental or psychological conditions or developmental disabilities of the same or similar nature, a determination of a lack of decisionmaking capacity shall be confirmed by one or more physicians with appropriate specialized training or experience. The opinion of the confirming physician shall be stated in writing and made a part of the patient's medical records in the same manner as that of the attending physician.

d. A physician designated by the patient's advance directive as a health care representative shall not make or confirm the determination of a lack of decisionmaking capacity.

e. The attending physician shall inform the patient, if the patient has any ability to comprehend that he has been determined to lack decisionmaking capacity, and the health care representative that: (1) the patient has been determined to lack decisionmaking capacity to make a particular health care decision; (2) each has the right to contest this determination; and (3) each may have recourse to the dispute resolution process established by the health care institution pursuant to section 14 of this act.

Notice to the patient and the health care representative shall be documented in the patient's medical records.

f. A determination of lack of decisionmaking capacity under this act is solely for the purpose of implementing an advance directive in accordance with the provisions of this act, and shall

not be construed as a determination of a patient's incapacity or incompetence for any other purpose.

g. For purposes of this section, a determination that a patient lacks decisionmaking capacity shall be based upon, but need not be limited to, evaluation of the patient's ability to understand and appreciate the nature and consequences of a particular health care decision, including the benefits and risks of, and alternatives to, the proposed health care, and to reach an informed decision.

Comment

Section 8 establishes the process and criteria to be followed for determining whether a patient lacks decisionmaking capacity. Consistent with existing law, unless determined to lack decisionmaking capacity the patient is presumed to have capacity (to be competent), and has the legal authority to make health care decisions on his or her own behalf. As stated in comment to section 7, the purpose of a determination of incapacity is to trigger the operation of an advance directive.

Who determines (in)capacity. The act provides for an "informal" (non-judicial) process which places responsibility for determining decisionmaking incapacity with physicians. Under section 8a., the initial determination of a patient's decisionmaking incapacity is to be made by the attending physician. The attending physician's determination is to be confirmed by at least one additional qualified physician, unless the patient's incapacity is clearly apparent (for example, the patient is permanently unconscious) and the attending physician and the health care representative agree that a confirming opinion is unnecessary. (Section 8b.) Since proper diagnosis and evaluation of a mental or psychological condition, or of a developmental disability, which impairs a patient's decisionmaking capacity may require specialized training or experience, the act makes special provision for such cases, by requiring that if neither the attending nor the confirming physician possesses the relevant expertise, a physician with appropriate expertise is to be called in to evaluate the patient and to provide a confirming (or disconfirming) opinion of the patient's incapacity. (Section 8c.) To protect against a potential conflict of interest, section 8d. prohibits a physician who is designated as the patient's health care representative from making a determination of the patient's incapacity.

The act's approach to determining decisionmaking capacity is intended to be adaptable to existing medical practices and to the need for flexibility in response to changing medical circumstances, particularly for those patients with impaired

capacity whose decisionmaking abilities may change from time to time. Where the act applies, *i.e.*, where the patient has executed an advance directive and decisionmaking capacity is in question, it is not necessary to seek a court determination of the patient's decisionmaking capacity. In placing with physicians responsibility for determining a patient's decisionmaking capacity, the act is consistent with *In re Farrell*, 108 N.J. 335, 529 A.2d 404, 415 & n. 8 (1987). The act departs from *Farrell* in requiring only one, not two, non-attending physicians to confirm the patient's incapacity.

Notice and documentation. Given the important consequences of a determination of incapacity, it is essential for the patient and health care representative to be promptly notified and for this determination to be properly documented. Section 8e. requires that upon a determination of incapacity the patient (if the patient is not comatose and has some ability to understand) and health care representative be given prompt notice of this determination by the attending physician. Under section 8e., both the patient and the health care representative are to be informed that if either disagrees with the determination of incapacity, either may invoke an institutional dispute resolution process (*see* section 14) in an effort to resolve the disagreement. Section 8e. is intended to set an outside limit upon the time within which notification must be made. The physician may notify the health care representative of the patient's condition at an earlier time, before a formal determination (of record) of incapacity is made, where this would better enable the health care representative to become involved in the patient's care at an early stage.

Sections 8a., b. and c. require the attending physician and any additional physicians who evaluate the patient's capacity to document in writing their opinions, including the nature, cause, extent and probable duration of the patient's incapacity, and to enter their evaluations in the patient's medical records. The attending physician should also document the notice of such a determination provided to the patient and health care representative. (Section 8e.)

Effect of determinations of incapacity. Section 8f. provides that a determination of incapacity to make health care decisions in accordance with section 8 does not mean that the patient lacks capacity, or is incompetent, to make other types of decisions, such as financial decisions. It should be noted that the process for determining patient capacity established by the act is intended to apply only in the context of advance directives, and is not intended to change existing law in other areas where a different process, such as a formal court determination, may be required.

Criteria for determining incapacity. Section 8g. states the criteria for determining that a patient lacks decisionmaking capacity. This section makes operative the definition of decisionmaking capacity in section 3, stating that a determination of a patient's decisionmaking incapacity shall be based upon an evaluation of the patient's ability to understand and appreciate information regarding the nature and consequences of a particular health care decision, including the benefits and risks of the proposed health care and its alternatives, and to reach an informed decision. The act recognizes that some patients may appear to properly understand and evaluate relevant information, and to do so in accordance with personal values and objectives, yet the patient's deliberative process may be impaired by hidden fears or denial, or by some other psychological factor or disorder. Other patients may be capable of making a health care decision, but be unable to adequately assimilate particular information or to express a decision due to a developmental disability or impaired ability to communicate. Thus, section 8g. provides that a determination of incapacity need not be strictly limited to assessment of the patient's abilities to understand and evaluate relevant information, and may and should take other factors into account as well.

The act contemplates that the question of capacity should be raised, and a more thorough assessment made, where there is substantial evidence of a deficit in any of these abilities. For example, a patient's apparent inability to offer intelligible reasons for a decision, or to indicate the major factors in his or her decision and the weight given to these factors, *i.e.*, weighing of the risks, benefits and burdens of the proposed treatment and its alternatives, is a call to more thorough evaluation of the patient's decisionmaking capacity. Physicians responsible for assessing and determining the patient's decisionmaking capacity should also be alert to the presence of underlying psychological impairments or developmental disabilities. Such apparent impairments of decisionmaking capacity are not, however, in themselves ground for a determination of incapacity. Rather, evidence of psychological impairments or disorders, or of developmental disability, should be taken as a call to further conversation with the patient and a more extensive evaluation of the patient's abilities.

Standards of capacity. While section 8g. states the criteria to be applied in determining decisionmaking incapacity, it does not provide specific statutory guidance regarding a standard or standards to govern determinations of decisionmaking incapacity, *i.e.*, what level of abilities the patient must possess and be able to act upon in order to make a particular health care decision. The act's decision-specific approach recognizes that the level of ability required for the exercise of decisionmaking capacity will vary with the task of making particular health care decisions. The act also contemplates that decisionmaking capacity will vary with the significance and irreversibility of the consequences

of particular treatment choices; when the consequences for patient well-being are serious, *e.g.*, in the case of a patient's decision to forego life-sustaining treatment, physicians should be especially circumspect in assessing the patient's capacity to make an informed decision.

Thus, the critical factors are that the decision, including the relative importance the patient assigns to the risks, benefits and burdens of the treatment alternatives, is grounded in the patient's personal values and objectives, and that the decision results from a rational deliberative process that is based upon intelligible (even if not universally shared) reasons. As the complexity of relevant medical information increases and as the potential consequences of a particular health care decision become more serious, the necessary level of abilities needed to make an informed decision may increase as well. Physicians responsible for assessing and determining decisionmaking capacity should be attentive to these concerns and to the decision-specific nature of capacity determinations under the act. It should not be assumed that a patient who lacks capacity to make one health care decision also lacks capacity to make other health care decisions.

Furthermore, the fact that physicians or other health care professionals may disagree with the patient's decision is not itself ground for a determination of incapacity. The act rejects a so-called "maximalist" or "outcome-based" approach to decisionmaking capacity which would require that the patient reach the "correct" decision, purportedly determined by objective third party judgment, often thought of in terms of medical judgment. In particular, a patient's decision to reject a burdensome intervention and to accept a shorter life expectancy when confronted with a serious life-threatening condition, or to reject an undesired prolongation of a burdensome dying process, is not in and of itself sufficient evidence of decisionmaking incapacity. The act also rejects a so-called "minimalist" approach to decisionmaking capacity which would require of the patient only the ability to express a preference for a particular course of health care, without regard to the patient's ability to understand and evaluate relevant information.

Subpart B: Rights and Responsibilities of the Parties

Section 9: Rights and Responsibilities of the Health Care Representative

a. If it has been determined that a patient lacks decisionmaking capacity, a health care representative shall have authority to make health care decisions on behalf of the patient. The health care representative shall act in good faith and within the bounds of the authority granted by the advance directive and by this act.

b. If a different individual has been appointed as the patient's legal guardian, the health care representative shall retain legal authority to make health care decisions on the patient's behalf, unless the terms of the legal guardian's court appointment or other court decree provide otherwise.

c. The conferral of legal authority on the health care representative shall not be construed to impose liability upon the health care representative for any portion of the patient's health care costs.

d. An individual designated as a health care representative or as an alternate health care representative may decline to serve in that capacity.

e. The health care representative shall exercise the patient's right to be informed of the patient's medical condition, prognosis and treatment options, and to give informed consent to, or refusal of, health care.

f. In the exercise of these rights and responsibilities, the health care representative shall seek to make the health care decision the patient would have made had he possessed decisionmaking capacity under the circumstances, or, when the patient's wishes cannot adequately be determined, shall make a health care decision in the best interests of the patient.

Comment

Subpart B sets forth the rights and responsibilities of those responsible for the patient's care and the decisionmaking process to be followed when making

health care decisions in accordance with an advance directive. The act adopts the shared decisionmaking model of the physician-patient relationship as developed in the work of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, and applies this model to the situation in which a health care representative participates in the decisionmaking process on the patient's behalf. The act is intended to structure and facilitate a process in which the physician, health care representative and patient work together with complementary and interactive roles in order to establish greater mutual understanding and an effective basis for active participation in the decisionmaking process by both the health care representative and the patient. While the act is primarily addressed to the roles of the attending physician, health care representative and patient, other family members and other members of the health care team should also be appropriately involved as collaborative participants in the decisionmaking process. The shared decisionmaking approach is designed to promote a sound decisionmaking process which best advances the patient's right to and interest in both self-determination and well-being with respect to health care decisions.

Section 9 sets forth the authority and core rights and responsibilities of the health care representative. This section should be read cumulatively with the other provisions of the act; the health care representative also has rights and obligations under other applicable provisions of the act, including in particular the responsibility to follow the decisionmaking process set forth in section 11. The authority granted to the health care representative is grounded in the view that most often the individual chosen by the patient (usually a close family member or friend) is best situated to understand and evaluate the patient's values and objectives, and to do so in a flexible and realistic way duly attentive to the patient's actual and contemporaneous medical circumstances, including changing medical information and possible courses of treatment and care.

Legal authority. Section 9a. provides that the valid designation of a health care representative confers upon that person the legal authority to make health care decisions on the patient's behalf when the patient has been determined, in accordance with section 8, to lack decisionmaking capacity. It is not required that the health care representative be appointed by a court as the patient's legal guardian. Health care providers are to look to the health care representative as the person with legal authority to make decisions on the patient's behalf, and need not seek further recourse to a guardianship proceeding to confirm the health care representative's legal authority. This is consistent with the practice under existing law pursuant to *In re Peter*, 108 N.J. 365, 529 A.2d 419, 429 (1987).

Section 9b. anticipates that, in some circumstances, another individual will have been appointed as the patient's legal guardian. In such cases, the health

care representative nonetheless has legal authority to make health care decisions on the patient's behalf, unless the court's appointment of a legal guardian, or some other court order, provides that the health care representative does not have this authority.

Section 9d. recognizes that the responsibilities of serving as health care representative may impose heavy burdens (*e.g.*, psychological and emotional burdens) and that some individuals will wish to decline (and perhaps should decline) this responsibility. Neither the health care representative nor any alternate designee is absolutely bound to assume the role and responsibilities of health care representative; both may decline to serve in that capacity. In such cases, an alternate designee may assume the role of health care representative, in the order of priority stated in the advance directive. (*See* section 6a.(3)) A health care representative should not be concerned that assuming these responsibilities will also bring financial obligations for the costs of the patient's care, nor should treatment decisions be unduly influenced by personal responsibility for health care expenses. Thus, section 9c. provides that designation of a health care representative does not make the health care representative, or any alternate designee, responsible for any of the patient's health care costs, nor may health care providers seek to impose payments on a health care representative by virtue of his or her status as health care representative. (Of course, if the health care representative is a member of the patient's family, as will often be the case, there may be financial responsibilities that derive from this familial relationship.)

Decisionmaking authority. Section 9e. provides that once the legal role of health care representative is assumed, the health care representative essentially "steps into the shoes" of the patient, and has the same right to make informed health care decisions as the patient would have if able to do so. The health care representative has the right to be informed of the patient's medical condition and prognosis, and of the recommended treatment and its alternatives, and has the right to consent to or to refuse health care on the patient's behalf. (The attending physician has a correlative obligation to seek informed consent from the health care representative, in accordance with section 11a.) The health care representative has broad authority to make the same kinds of health care decisions the patient would have the right to make on his or her own behalf, such as decisions to accept or to refuse diagnostic and therapeutic measures, including life-sustaining treatment, to accept or to reject the care of a particular physician or health care institution, and to accept, reject or request a transfer of care. (*See* the definition of "health care decision", section 3.)

Section 9f. provides that in the exercise of his or her authority, the health care representative should seek, first and foremost, to make the health care

decision the patient would make under the circumstances, if able to do so. In cases in which the direction provided by an advance directive is uncertain or ambiguous as applied to the patient's current medical condition and circumstances, it is intended here, and under section 11, that the health care representative have authority to exercise informed and reasonable judgment to interpret the patient's wishes, and that the health care representative not be rigidly constrained to make an unduly mechanistic interpretation of the terms of the directive. At times, however, it may not be possible to adequately determine what the patient's wishes would be. For example, there may be no instruction directive or other clear evidence of the patient's wishes; or the instruction directive may be ambiguous or otherwise fail to provide clear guidance, perhaps because the patient's medical circumstances have changed radically from those previously contemplated by the advance directive. In such cases, section 9f. gives the health care representative full authority to make a health care decision he or she believes to be in the patient's best interests based upon what is known of the patient's wishes.

As stated in section 9a., the health care representative is obligated at all times to act in good faith to carry out his or her responsibilities in accordance with the terms and limitations of an advance directive and of the act. The health care representative's rights and responsibilities in the decisionmaking process are set forth at greater length in section 11.

Section 10: Rights and Responsibilities of Physicians and Other Health Care Professionals

In addition to any rights and responsibilities recognized or imposed by, or pursuant to, this act, or by any other law, physicians, nurses, and other health care professionals shall have the following rights and responsibilities:

a. The attending physician shall make an affirmative inquiry of the patient, his family or others, as appropriate under the circumstances, concerning the existence of an advance directive. The attending physician shall note in the patient's medical records whether or not an advance directive exists, and the name of the patient's health care representative, if any, and shall attach a copy of the advance directive to the patient's medical records. The attending physician shall document in the same manner the reaffirmation, modification, or revocation of an advance directive, if he has knowledge of such action.

b. A physician may decline to participate in the withholding or withdrawing of measures utilized to sustain life, in accordance with his sincerely held personal or professional convictions. In such circumstances, the physician shall act in good faith to inform the patient and the health care representative, and the chief of the medical staff or other designated institutional official, of this decision as soon as practicable, to effect an appropriate, respectful and timely transfer of care, and to assure that the patient is not abandoned or treated disrespectfully.

In the event of transfer of a patient's care, the attending physician shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

c. A nurse or other health care professional may decline to participate in the withholding or withdrawing of measures utilized to sustain life, in accordance with his sincerely held personal or professional convictions. In these circumstances, the nurse and other health care professional shall act in good faith to inform the patient and the health care representative, and the head of the nursing or other professional staff or other designated institutional official, of this decision as soon as practicable, to cooperate in effecting an appropriate, respectful and timely transfer of care, and to assure that the patient is not abandoned or treated disrespectfully.

d. Nothing in this act shall be construed to require a physician, nurse or other health care professional to begin, continue, withhold, or withdraw health care in a manner contrary to law or accepted professional standards.

Comment

Section 10 sets forth certain rights and responsibilities of physicians and other health care professionals. This section should be read cumulatively with the other provisions of the act, and does not substitute for or modify the rights and responsibilities of physicians and other health care professionals under other provisions of the act.

Section 10a. is intended to facilitate implementation of advance directives. This section requires the attending physician to make an affirmative inquiry of

the patient, family or others to determine whether the patient has executed an advance directive. The attending physician's role should be complementary to the routine inquiry about advance directives at the time of admission (and subsequently) undertaken in accordance with institutional policies, pursuant to section 13a. and the federal Patient Self-Determination Act. (*See* the comment to section 13.) Where intake documents in the admission process indicate that the patient has an advance directive, the attending physician should follow up and verify this information, and should obtain a copy of the advance directive. The timing and nature of the conversation with the patient or family should be appropriate to the circumstances, and not formalistic or insensitive; section 10a. is designed to permit the attending physician discretion in conducting this conversation.

It is important for all members of the health care team to be made aware of whether or not an advance directive is operative for the patient, and of whether there is a health care representative involved in the patient's care. To facilitate this process, section 10a. provides that following receipt of an advance directive the attending physician is required to attach a copy of the document to the patient's medical records, and to note in the patient's medical records that there is an advance directive, as well as the name of the health care representative. Ordinarily, notation in the records should also include how to contact the health care representative, or other important identifying information. Other relevant information, including the absence of an advance directive, or knowledge of a reaffirmation, modification or revocation of the patient's advance directive, is also to be documented in the patient's medical records by the attending physician. In contrast to some states, which permit the attending physician to record the known terms of an advance directive when the written document is unavailable, the act does not accord legal significance to an advance directive unless a copy of the document itself is available to those responsible for the patient's care.

Professional conscience. In the practice of their profession, health care professionals, in particular physicians and nurses who are primarily responsible for implementing treatment decisions, should and do have the right to remain true to certain morally or religiously based personal and professional convictions, and to decline or withdraw from participation in a particular course of treatment, or in the care of a particular patient. Sections 10b. and 10c. anticipate that at times strongly and sincerely held differences in values and objectives between a health care professional and the patient or family regarding a proposed decision to forego life-sustaining treatment may lead to (perhaps intractable) dispute about the proper course of treatment for the patient. In these circumstances, the right to decline or withdraw from the patient's care, for reasons of conscience, honors the personal and professional integrity of the

health care professional. Thus, sections 10b. and 10c. accord specific statutory recognition, in limited circumstances, to a right of professional conscience for physicians, nurses and other health care professionals, generally recognized (most often for physicians) under common law and codes of professional responsibility. A claim of professional conscience under the act should always be based upon "sincerely held personal or professional convictions". The act does not permit physicians, nurses or other health care professionals to withdraw from the care of a patient on grounds of personal distaste or prejudice, or fear of potential legal liability or unfavorable publicity. Section 10 should be read in conjunction with section 15, which states the scope and limitations for the conditions in which the act authorizes the foregoing of life-sustaining treatment pursuant to an advance directive.

Sections 10b. and 10c. also provide that in cases of intractable dispute, physicians, nurses, and other health care professionals seeking to exercise their right of professional conscience have certain obligations. The health care professional should act in good faith to inform the patient and the health care representative, as well as an appropriate member of the staff (*e.g.*, chief of the medical or nursing staff or other designated official) of this decision as soon as possible. An appropriate and respectful transfer of care must be effected in a timely fashion not harmful to the patient's well-being and interests before a health care professional may withdraw from responsibility for the patient's care. The primary responsibility for effecting an appropriate transfer of care, including timely transfer of the patient's medical records (with the patient's advance directive) where necessary, rests with the attending physician and the health care institution. (Sections 10b. and 13a.(4))

These obligations regarding transfers of care are grounded in the act's fundamental commitment to protecting patient well-being. The act does not permit patient abandonment under any circumstances. A physician, nurse or other health care professional who seeks to withdraw from the patient's care under this section must continue to care for that patient until a transfer of care is effected. (However, there is no obligation to withhold or withdraw life-sustaining treatment during this time.) In those hopefully rare cases in which an appropriate transfer of care cannot be effectuated, the health care professional must continue to care for the patient. If disagreement cannot be resolved at the institutional level, judicial intervention may be necessary.

Section 10d. makes clear that the act does not require physicians, nurses and other health care professionals to provide, withhold or withdraw health care for a patient in a manner contrary to law or accepted medical standards.

Section 10 should not be construed to modify or limit existing legal rights of physicians, nurses or other health care professionals to refuse to accept a patient's care or to decline the continued care of a patient under other circumstances not addressed by the act.

Section 11: The Decisionmaking Process

a. The attending physician, the health care representative and, when appropriate, any additional physician responsible for the patient's care, shall discuss the nature and consequences of the patient's medical condition, and the risks, benefits and burdens of the proposed health care and its alternatives. Except as provided by subsection b. of this section, the attending physician shall obtain informed consent for, or refusal of, health care from the health care representative.

(1) Discussion of the proposed treatment and its alternatives shall include, as appropriate under the circumstances, the availability, benefits and burdens of rehabilitative treatment, therapy, and services.

(2) The decisionmaking process shall allow, as appropriate under the circumstances, adequate time for the health care representative to understand and deliberate about all relevant information before a treatment decision is implemented.

b. Following a determination that a patient lacks decisionmaking capacity, the health care representative and the attending physician shall, to a reasonable extent, discuss the treatment options with the patient, and seek to involve the patient as a participant in the decisionmaking process. The health care representative and the attending physician shall seek to promote the patient's capacity for effective participation and shall take the patient's expressed wishes into account in the decisionmaking process.

Once decisionmaking authority has been conferred upon a health care representative pursuant to an advance directive, if the patient is subsequently found to possess adequate decisionmaking capacity with respect to a particular health care decision, the

patient shall retain legal authority to make that decision. In such circumstances, the health care representative may continue to participate in the decisionmaking process in an advisory capacity, unless the patient objects.

Notwithstanding any other provision of this act to the contrary, if a patient who lacks decisionmaking capacity clearly expresses or manifests the contemporaneous wish that medically appropriate measures utilized to sustain life be provided, that wish shall take precedence over any contrary decision of the health care representative and any contrary statement in the patient's instruction directive.

c. In acting to implement a patient's wishes pursuant to an advance directive, the health care representative shall give priority to the patient's instruction directive, and may also consider, as appropriate and necessary, the following forms of evidence of the patient's wishes:

(1) The patient's contemporaneous expressions, including nonverbal expressions;

(2) Other reliable sources of information, including the health care representative's personal knowledge of the patient's values, preferences and goals; and

(3) Reliable oral or written statements previously made by the patient, including, but not limited to, statements made to family members, friends, health care professionals or religious leaders.

d. If the instruction directive, in conjunction with other evidence of the patient's wishes, does not provide, in the exercise of reasonable judgment, clear direction as applied to the patient's medical condition and the treatment alternatives, the health care representative shall exercise reasonable discretion, in good faith, to effectuate the terms, intent, and spirit of the instruction directive and other evidence of the patient's wishes.

e. Subject to the provisions of this act, and unless otherwise stated in the advance directive, if the patient's wishes cannot be

adequately determined, then the health care representative shall make a health care decision in the patient's best interests.

Comment

Section 11 sets forth the decisionmaking process to be followed by the health care representative and the physician in making health care decisions on the patient's behalf. As stated above, along with sections 9 and 10, this section is designed to facilitate a process of shared decisionmaking among the health care representative, the physician and the patient (wherever reasonable). Decisions to withhold or withdraw life-sustaining treatment are subject to the scope and limitations of section 15.

Joint responsibilities of the health care representative and physician. Section 11a. states the core responsibilities of the health care representative and physician in the process of informed consent. The attending physician is obligated to obtain informed consent or refusal from the health care representative before a course of treatment is implemented (unless a recognized exception to the requirement of informed consent applies, such as a medical emergency). This section provides that the health care representative and the attending physician (and with respect to particular health care decisions any other physician(s) responsible for the patient's care), shall discuss the nature and consequences of the patient's medical condition, and the risks, benefits and burdens of the proposed health care and its alternatives. Section 11a.(1) is intended to assure that where appropriate (for example, where the patient has suffered a traumatic and disabling injury) this discussion addresses whether rehabilitative treatment and services would be of potential benefit to the patient, and whether such care and support is available. In many circumstances, it may be appropriate for the health care representative and the attending physician to view the patient's care as involving a continuing process designed to facilitate on-going dialogue, rather than to view treatment decisions as isolated, episodic events. The basis for this process ideally would be an agreed upon treatment plan for the patient which is sufficiently flexible to accommodate changes in clinical circumstances over time. Section 11a.(2) makes clear that the decisionmaking process should always be sensitive to allowing adequate time for understanding and deliberation before a treatment decision is made.

As provided elsewhere in the act (*see* sections 3 and 8), a determination of decisionmaking incapacity does not mean that a patient may be ignored as someone whose expressed wishes no longer count. Many patients who lack full decisionmaking capacity experience intermittent periods of lucidity and mental function (sometimes referred to as "fluctuating capacity"), or are able to exercise the requisite abilities to make some, perhaps less complex or consequential, decisions but not others (sometimes referred to as "diminished capacity"). In

short, many patients possess impaired decisionmaking capacity. Section 11b. is designed to maximize the patient's capacity for self-determination and effective participation in the decisionmaking process. This section provides that in these circumstances the health care representative and the attending physician are jointly obligated to involve the patient with impaired capacity as an active participant in the decisionmaking process, to the extent it is reasonable to do so. Often this will mean efforts to talk with the patient about the treatment options; it may also mean at times treating secondary conditions which impair the patient's cognitive abilities, or employing assistive devices or other mechanisms to improve the patient's ability to communicate effectively. The patient's expressed wishes, including for example expressions of pain or discomfort, or apprehension about invasive procedures, should be taken into account, even though the patient lacks capacity to make that treatment decision on his or her own behalf. (Section 11b.) It is intended that this section be construed broadly to apply to most, if not all, patients who have some level of ability to communicate with others and who are neither permanently unconscious nor severely demented. (Though unable to participate meaningfully in decisionmaking, the severely demented will at times show responsiveness to pain or discomfort.)

Limitations on the health care representative's authority. Consistent with the decision-specific nature of decisionmaking (in)capacity adopted by the act, section 11b. recognizes that in some cases a patient will in fact have the capacity to make one or more, but not all, health care decisions, even though a health care representative has become involved on the patient's behalf. In these circumstances, the patient's right to self-determination should be respected. Thus, section 11b. provides that when the patient possesses decisionmaking capacity the patient's legal authority to make that particular health care decision should be recognized.

Section 11b. may appear to create some uncertainty about whether it is the patient or the health care representative who has the legal authority to give informed consent. It is important to note that the act is not intended to create a situation of sequential authority which shifts the locus of decisionmaking back and forth between the patient (where the patient has capacity to make a health care decision) and the health care representative (where the patient lacks capacity to make a health care decision). Once the role of the health care representative has been triggered under the act, the health care representative should continue to be actively involved in the decisionmaking process for all health care decisions, including those particular decisions regarding which the patient possesses decisionmaking capacity and legal authority. If the patient objects to the health care representative's continued participation, this objection should be respected. (A patient's objection to the health care representative's participation

in a particular decision does not in itself constitute a revocation of the health care representative's legal authority under the act.)

Physicians should be aware that under this section, if both the patient and the health care representative agree on the decision to be made, legally valid consent or refusal has been obtained. Thus, it would be advisable in these circumstances to expressly seek consent from both the patient and the health care representative. In the event of disagreement, and in the face of uncertainty about who has the legal authority to give informed consent or refusal, recourse to a dispute resolution mechanism, pursuant to section 14, may be appropriate.

Section 11b. also states an important limitation on the authority of the health care representative and the attending physician to implement a decision to forego life-sustaining treatment on the patient's behalf. This section states that the patient's current and clearly expressed wish for continued life must be respected, even if the health care representative would otherwise have reached a decision that (a particular) life-sustaining treatment should be withheld or withdrawn, and even if the patient's instruction directive states the patient's prior wish that (a particular) life-sustaining treatment be withheld or withdrawn. However, section 11b. requires only the provision of medically appropriate treatment; it does not require physicians to provide medically inappropriate treatment to patients. This section is grounded in a commitment to the preservation of life, and to the principle that a patient's contemporaneous wish to continue living should override prior written instructions or the judgments of others. Uncertainties with respect to the meaning of the patient's expressions and behavior should be resolved in favor of preserving life.

Determining the patient's wishes. Section 11c. sets forth the basic approach to be followed by the health care representative to implement an advance directive. In particular, this section states the manner in which the health care representative should seek to make a health care decision based upon the patient's previously expressed wishes. Section 11c. provides that if the patient has executed a combined advance directive (or a separate instruction directive), the health care representative should look first to the instruction directive, and should give the terms of the instruction directive priority. Where the instruction directive provides clear and unambiguous direction for the health care decision to be made, it should be followed in accordance with its terms. (Section 11c.) However, the health care representative is not rigidly bound by the terms of the instruction directive alone. It is intended that the health care representative have broad discretion to evaluate other sources of knowledge about the patient's wishes, including but not limited to the patient's contemporaneous expressions, the health care representative's personal knowledge of the patient, and the several other likely reliable types of evidence identified in section 11c.

Past experience with instruction directives demonstrates that prior written instructions, often written remotely in time from their actual use, may fail to contemplate the patient's current medical circumstances or may otherwise fail to provide clear direction for the health care decision to be made. In these circumstances, the health care representative is granted discretion to evaluate available evidence of the patient's wishes and to seek to reach a decision that he or she reasonably judges to be consistent with the terms, intent and spirit of what is known of the patient's wishes, including in particular the patient's instruction directive. (Section 11d.)

In some cases, such as where the patient has not executed an instruction directive or where medical circumstances have changed radically from those originally contemplated by the instruction directive, it may not be possible to determine the patient's wishes. Section 11e. provides that in these circumstances the health care representative has the full authority (and the responsibility) to exercise reasonable judgment to make a health care decision in the patient's best interests, based upon what is known of the patient's wishes, including the health care representative's personal knowledge of the patient. This authority is grounded in the fact that the patient has designated a trusted family member or friend (or other person), and ordinarily wants his or her health care representative to exercise sound judgment in the patient's best interests based upon what is known of the patient's wishes. In the exercise of this authority, the health care representative should seek out the participation and counsel of the attending physician, as well as others.

Protecting patient well-being. In some cases the health care representative may misinterpret or misapply the instruction directive or other evidence of the patient's wishes, or may fail to exercise sound and informed judgment. In rare cases the health care representative may find it emotionally difficult or impossible to accept personal responsibility for carrying out the patient's wishes, or may feel that effecting the patient's wishes is contrary to the dictates of personal morality or conscience. There is also the possibility of the health care representative acting on the basis of improper or selfish motivations, financial or otherwise.

In the first instance the physician-patient-health care representative relationship plays a critical role in safeguarding the patient's interests. It is the responsibility of the attending physician (and other members of the health care team), both legally and ethically, to safeguard the patient against possible errors in judgment or wrongdoing, by scrutinizing both the decision and the decisionmaker to assure that decisions are made in accordance with sound medical practice and legal and ethical norms. Health care providers, especially physicians, should be attentive to these concerns throughout the course of the

patient's care. The act contemplates that in most cases discussions with the patient, health care representative and family will reveal any suspicion of improper judgment, undue influence or other wrongdoing. In the event discussion fails to resolve misunderstandings or disagreements, or suspicion of wrongdoing remains, further inquiry should be handled initially through established institutional procedures; it may be appropriate to seek recourse to an institutional dispute resolution mechanism, pursuant to section 14. In some cases it may be necessary to refer the matter to an appropriate governmental agency, such as the Ombudsman for the Institutionalized Elderly.

Section 12: Instruction Directives in the Absence of a Designated Health Care Representative

a. If the patient has executed an instruction directive but has not designated a health care representative, or if neither the designated health care representative or any alternate designee is able or available to serve, the instruction directive shall be legally operative. If the instruction directive provides clear and unambiguous guidance under the circumstances, it shall be honored in accordance with its specific terms by a legally appointed guardian, if any, family members, the physicians, nurses, other health care professionals, health care institutions, and others acting on the patient's behalf.

b. If the instruction directive is, in the exercise of reasonable judgment, not specific to the patient's medical condition and the treatment alternatives, the attending physician, in consultation with a legally appointed guardian, if any, family members, or others acting on the patient's behalf, shall exercise reasonable judgment to effectuate the wishes of the patient, giving full weight to the terms, intent, and spirit of the instruction directive. Departure from the specific terms and provisions of the instruction directive shall be based upon clearly articulable factors not foreseen or contemplated by the instruction directive, including, but not limited to, the circumstances of the patient's medical condition.

c. Nothing in this act shall be construed to impair the legal force and effect of an instruction directive executed prior to the effective date of this act.

Comment

Section 12 sets forth the decisionmaking process to be followed where the patient has executed an instruction directive, but has no health care representative. In such cases, instruction directives should be respected as legally operative documents, in accordance with this section and the other provisions of the act. In this regard, the act gives instruction directives greater force and effect than is the case under existing case law, which characterizes instruction directives as the "best evidence" of the patient's wishes. *In re Peter*, 108 N.J. 365, 529 A.2d 419, 426 (1987); *see also In re Conroy*, 98 N.J. 321, 486 A.2d 1209, 1229 &n.5 (1985) (a living will is "relevant evidence" of the patient's wishes). As provided by section 12c., the act does not retroactively impair the legal validity of instruction directives executed before the act takes effect. Thus, section 12 applies with equal force to instruction directives executed prior to the effective date of the act. The interpretation and application of the terms of such documents is to be in accordance with the provisions of the act.

Section 12a. states that where an instruction directive provides clear and unambiguous direction for the health care decision to be made, those responsible for the patient's care are obligated to follow the specific terms of the instruction directive. As noted in comment to section 11, the act also anticipates that an instruction directive may not give specific direction. In particular, a prior written document may not foresee or contemplate certain medical conditions. In these circumstances, section 12b. authorizes the exercise of reasonable judgment to effectuate the patient's wishes, with particular emphasis to be accorded the terms, intent and spirit of the instruction directive. In order to assure faithful interpretation and implementation of the patient's expressed wishes, a course of treatment which departs from the specific terms of an instruction directive should be based upon relevant and identifiable factors the patient has not foreseen and addressed in his or her instructions, most significantly, the patient's current medical condition. Those responsible for the patient's care should be able to clearly identify and state those factors, as well as why this provides sufficient reason not to follow the instruction directive.

This section does not alter the obligations of health care professionals to involve the patient in the decisionmaking process and to take the patient's expressed wishes into account, in accordance with section 11. Nor does this section impair the obligations of health care professionals under section 11b. to respect the patient's clear and contemporaneous expression or manifestation that life-sustaining treatment be provided, even if the instruction directive directs the foregoing of such measures.

It is important to recognize that section 12 does not authorize, nor does it prohibit, the foregoing of life-sustaining treatment in the *best interests* of the patient when an instruction directive fails to provide adequate means to determine what the patient would want under the circumstances. Only the health care representative, in consultation with the attending physician, is given this authority under the act. Thus, in such cases, in the absence of a health care representative, a decision to forego life-sustaining treatment in the patient's best interests will be governed by other law, and families and health care professionals should look to existing New Jersey law for guidance.

Section 12 does not specifically identify who has the legal authority to make health care decisions on the patient's behalf when there is no health care representative. It is intended that in such cases existing law and practice will continue to govern this question; often this will mean that decisions are made (as has traditionally been the case) within the physician-patient-family relationship. Since one of the individuals responsible for the patient's care will always be the attending physician, section 12b. places with the attending physician the lead responsibility for interpreting an unclear or ambiguous instruction directive, and for doing so in light of other evidence of the patient's wishes including the patient's contemporaneous expressions.

Section 13: Rights and Responsibilities of Health Care Institutions

a. In addition to any rights and responsibilities recognized or imposed by, or pursuant to, this act, or any other law, a health care institution shall have the following rights and responsibilities:

(1) A health care institution shall adopt such policies and practices as are necessary to provide for routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive.

(2) A health care institution shall adopt such policies and practices as are necessary to provide appropriate informational materials concerning advance directives to all interested patients and their families and health care representatives, and to assist patients interested in discussing and executing an advance directive.

(3) A health care institution shall adopt such policies and practices as are necessary to educate patients and their families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services, including but not limited to family and social services, self-help and advocacy services, employment and community living, and use of assistive devices. A health care institution shall, in consultation with the attending physician, assure that such information is discussed with a patient and his health care representative and made a part of the decisionmaking process set forth in section 11 of this act, as appropriate under the circumstances.

(4) In situations in which a transfer of care is necessary, including a transfer for the purpose of effectuating a patient's wishes pursuant to an advance directive, a health care institution shall, in consultation with the attending physician, take all reasonable steps to effect the appropriate, respectful and timely transfer of the patient to the care of an alternative health care professional or institution, as necessary, and shall assure that the patient is not abandoned or treated disrespectfully. In such circumstances, a health care institution shall assure the timely transfer of the patient's medical records, including a copy of the patient's advance directive.

(5) A health care institution shall establish procedures and practices for dispute resolution, in accordance with section 14 of this act.

(6) A health care institution shall adopt such policies and practices as are necessary to inform physicians, nurses and other health care professionals of their rights and responsibilities under this act, to assure that such rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this act.

b. A private, religiously-affiliated health care institution may develop institutional policies and practices defining circumstances in which it will decline to participate in the withholding or withdrawing of specified measures utilized to sustain life. Such policies and practices shall be written, and shall be properly communicated to patients and their families and health care representatives prior to or upon the patient's admission, or as soon after admission as is practicable.

If the institutional policies and practices appear to conflict with the legal rights of a patient wishing to forego health care, the health care institution shall attempt to resolve the conflict, and if a mutually satisfactory accommodation cannot be reached, shall take all reasonable steps to effect the appropriate, timely and respectful transfer of the patient to the care of another health care institution appropriate to the patient's needs, and shall assure that the patient is not abandoned or treated disrespectfully.

c. Nothing in this act shall be construed to require a health care institution to participate in the beginning, continuing, withholding or withdrawing of health care in a manner contrary to law or accepted medical standards.

Comment

Section 13 sets forth the core rights and responsibilities of health care institutions governed by the act. This section should be read cumulatively with the other provisions of the act, and does not substitute for or modify the rights and responsibilities of health care institutions under other provisions of the act. The obligations of health care institutions under this section are statutory and are not contingent upon regulatory action taken by the Department of Health pursuant to its authority under section 19. (Of course, health care institutions are obligated to comply with the rules and regulations promulgated by the Department of Health.)

The act anticipates and is complementary to the institutional obligations set forth in the federal Patient Self-Determination Act, P.L. 101-508, which takes effect December 1, 1991. In a number of respects the act imposes more proactive responsibilities upon health care institutions than are set forth in the federal law.

Institutional responsibilities and policies. Section 13a.(1) is intended to assure that patients' advance directives become known to health care providers. This section requires health care institutions to establish institutional policies and practices designed to make routine inquiry of patients, families or others to determine whether the patient has executed an advance directive, and if so, how the document may be located. Under section 13a.(1), routine inquiry should focus upon the admission process, making this information part of a patient's intake documentation, and thereby assuring that the attending physician and other health care professionals are properly informed. It is intended, however, that institutional policy and practice be sufficiently flexible to accommodate the needs and interests of patients and families so as not to impose pro forma questioning at an inappropriate time (for example, upon an emergency admission). Institutions should also assure that subsequent conversation with patients and families takes place when necessary, particularly where this inquiry has not occurred previously at the time of admission. This section also requires that patients and families be asked whether the patient has an advance directive "at such other times as are appropriate under the circumstances". This provision contemplates that routine inquiry upon admission together with information and assistance offered by health care providers will encourage many patients to choose to execute advance directives after being admitted to the hospital or nursing home. The attending physician's correlative obligation of inquiry under section 10a. should be incorporated into the development of institutional policy and practice.

Complementing the process of routine inquiry, section 13a.(2) recognizes that if advance directives are to be widely and effectively used as a method of advance planning, active steps must be taken to inform and educate patients and families. This section places some of these responsibilities of education and assistance with health care institutions. It should be noted that while the act mandates that interested patients, families, and health care representatives be given written informational materials about advance directives, provision of advance directive forms is not required by the express terms of the act. Nonetheless, making forms available is strongly suggested and advisable; indeed not to offer the formal documents to patients and families may be inappropriate patient care. As noted in comment to section 6, the Bioethics Commission has published a brochure containing three types of advance directive forms and supporting informational materials which is available to health care providers and members of the public. It is important to recognize that while section 13a.(2) requires that patients and families receive assistance and education about advance directives, the act does not require health care institutions to give specific legal advice to those who wish to execute an advance directive.

As a corollary to physicians' obligations under section 11a.(1), section 13a.(3) establishes an institutional responsibility to provide information, education and support to patients, health care representatives and families about rehabilitative treatment, therapy and services, where appropriate to the patient's care. It is intended that in fulfilling its educational responsibilities the health care institution have broad discretion to develop policies and practices appropriate to its own institutional needs and concerns.

Transfers of care. Section 13a.(4) states an institution's responsibilities in the event it is necessary to transfer a patient's care, either to another health care professional or to another health care institution. As part of its responsibility to provide quality compassionate care for all patients, the health care institution should, in consultation with the attending physician, cooperate in and facilitate a transfer of care requested or authorized by the health care representative, including when the transfer is for the purpose of carrying out the patient's wishes to forego life-sustaining treatment. Any decision to transfer should give priority to patient well-being and should be timely and sensitive to the patient's needs. In many cases this will mean transfer to another physician or institution who shares more closely the patient's treatment objectives and is prepared to honor the patient's wishes. Under the act, health care institutions share with the attending physician responsibility for assuring appropriate transfers of care, and also for assuring that the process includes prompt transfer of the patient's medical records, with a copy of the patient's advance directive. Ultimate responsibility for assuring that the transfer process is respectful of patients' wishes and interests rests with the health care institution. In no event does the act permit patient abandonment. If efforts to resolve disagreements prove unsuccessful and an appropriate transfer of care cannot be accomplished with the consent of the health care representative, the institution must continue to care for the patient, and has the option of seeking court intervention.

Dispute resolution. Section 13a.(5) makes clear that all health care institutions governed by the act are required to establish an institutional dispute resolution mechanism available to patients, families, physicians, nurses and others, in accordance with section 14. As stated in comment to section 14, this mechanism may, but need not, be an ethics committee. In fact, making one or more individuals responsible for this role offers a more flexible and preferable approach for many institutions. While not expressly required by the act, developing an institutional policy to establish and implement a dispute resolution mechanism may be advisable.

Professional education. Section 13a.(6) calls upon institutions to inform physicians, nurses and other health care professionals of their rights and responsibilities under the act. Health care institutions should seek to assure that

health care professionals understand how the new law affects them and the provision of care within the institution. The institution is also required to establish and make available to professionals a forum for discussion and consultation designed to facilitate continued education and understanding about the meaning of the act.

Institutional conscience. Section 13b. provides for a limited right of institutional conscience which in many respects parallels the individual right of professional conscience provided in section 10. This right of institutional conscience applies only to private religiously-affiliated health care institutions.

This section recognizes that some health care institutions may hold strong formal commitments to a particular philosophy of care, or to particular principles, and that such formal commitments can forcefully shape the character of an institution. As a general matter, the act acknowledges that those institutions grounded in certain religious traditions are the most likely candidates to embody an institutional philosophy of care taking a particular position with respect to the foregoing of life-sustaining treatment. Religiously-affiliated institutions have more often been active in formulating policies or codes of ethics to govern the provision of care. However, the scope of section 13b. does not rest ultimately on a conclusion about which health care institutions have "consciences" nor wholly on conclusions of constitutional law. It rests as well on the judgment that, given the reality that effectuating transfers of care in controversial cases has often been difficult for patients and families, and the concern that private institutions might invoke claims of conscience to avoid potentially troublesome situations, over-extending legal recognition of institutional conscience risks greatly decreasing the number of institutional settings in which patients and families can properly expect their rights and wishes to prevail. While section 13b. recognizes a right of "institutional conscience", its exercise and benefits are primarily intended to honor the philosophy of care and professional commitments shared, both individually and collectively, by those who constitute and exemplify that health care institution.

Thus, section 13b. provides that private religiously-affiliated health care institutions may adopt policies and practices stating the circumstances in which the institution (more precisely, its health care professionals) does not intend to comply with a patient's wishes that life-sustaining treatment be withheld or withdrawn. A statement of policy grounded in institutional conscience should be based upon sincerely held religious and moral beliefs reflected in the institution's charter, policies or practices, and shared by those responsible for the delivery of health care at that institution in a way which embodies a particular institutional philosophy of care. It bears emphasis that the act does

not permit any health care institution to refuse to honor advance directives *per se*.

In order to protect patient rights and to avoid potential conflict and burdensome litigation, section 13b. requires that patients, families and health care representatives be given proper notice of the institution's policies and practices, generally before or upon admission and acceptance of care. A private religiously-affiliated health care institution wishing to adopt such a policy must do so in writing. In cases of conflict between a patient's wishes and institutional policy, an institution may not rely upon its policy if it has not made proper efforts to put the policy in writing and to give notice to the patient, family, and health care representative.

Where institutional policy appears to conflict with a patient's wishes that life-sustaining treatment be withheld or withdrawn, section 13b. provides that the institution's first responsibility is to seek to resolve this conflict, initially by facilitating further discussion, and perhaps by recourse to the institution's dispute resolution mechanism. If a mutually agreeable approach to the patient's care cannot be found, the institution is responsible for making reasonable efforts to effect a timely and respectful transfer of the patient's care to another institution. Efforts to transfer care should endeavor to place the patient in a health care institution appropriate to the patient's needs, *i.e.*, an institution which has not adopted a formal policy in conflict with the patient's wishes to forego treatment and which has a philosophy of care more compatible with the patient's wishes. Private religiously-affiliated institutions choosing to exercise this right of institutional conscience may wish to maintain a list of possible transfer institutions which have not adopted policies similar to their own.

In the event suitable transfer (with the consent of the health care representative) cannot be effectuated, judicial review may be appropriate. As with other provisions of the act, in no event does this section permit patient abandonment. Under section 13b. the institution is obligated to continue to care for the patient, pending any further action to resolve the conflict, though it is not obligated during this time to comply with the patient's wishes in violation of its stated policies and practices.

Similarly to section 10d., which applies to physicians, nurses and other health care professionals, section 13c. makes clear that the act does not require health care institutions to provide, withhold or withdraw health care for a patient in a manner contrary to law or accepted medical standards.

Section 14: Dispute Resolution

a. In the event of disagreement among the patient, health care representative and attending physician concerning the patient's decisionmaking capacity or the appropriate interpretation and application of the terms of an advance directive to the patient's course of treatment, the parties may seek to resolve the disagreement by means of procedures and practices established by the health care institution, including but not limited to, consultation with an institutional ethics committee, or with a person designated by the health care institution for this purpose or may seek resolution by a court of competent jurisdiction.

b. A health care professional involved in the patient's care, other than the attending physician, or an administrator of a health care institution may also invoke the dispute resolution process established by the health care institution to seek to resolve a disagreement concerning the patient's decisionmaking capacity or the appropriate interpretation and application of the terms of an advance directive.

Comment

Section 14 provides for an institutional dispute resolution mechanism to be established by the health care institution. The purpose of this section is to make available to patients, family members, physicians and others an internal and accessible process for seeking to resolve misunderstandings and disagreements without the necessity for more formal and burdensome resort to the courts. Institutional review should obviate the need for judicial review. Where disagreements cannot be resolved, court review may be appropriate.

Section 14a. specifically contemplates two types of potential disagreements which may arise in the course of the patient's care--those concerning the patient's decisionmaking capacity and those concerning the interpretation and application of an advance directive (including clarification and confirmation of the patient's medical condition, where necessary). Where the patient, health care representative or attending physician disagree on either of these questions, section 14a. provides that such disagreements may be brought to an institutional dispute resolution process, established by the health care institution. While section 14 expressly contemplates that disagreements may arise regarding the patient's decisionmaking capacity or the patient's course of treatment, nothing in this section is intended to discourage those responsible for the patient's care

from seeking assistance in resolving disagreements on other matters. Section 14b. provides that the dispute resolution process may also be invoked by other health care professionals involved in the patient's care, and by administrators of the facility.

Although health care institutions are required (here and by section 13a.(5)) to establish a dispute resolution mechanism to serve the purposes stated in this section, the precise nature of this process is left to the institution to develop, in accordance with institutional needs and concerns. The process might involve consultation with an institutional ethics committee or with a single individual (such as an "ethics consultant"). It is important to note that an ethics committee established for the purposes of dispute resolution under this section is not necessarily subject to the requirements of section 17, which apply to institutional or regional reviewing bodies, such as ethics committees, engaged in prospective case consultation.

Subpart C: Scope and Limitations Regarding Life-Sustaining Treatment

Section 15: Decisions to Forego Life-Sustaining Treatment

a. Consistent with the terms of an advance directive and the provisions of this act, life-sustaining treatment may be withheld or withdrawn from a patient in the following circumstances:

(1) When the life-sustaining treatment is experimental and not a proven therapy, or is likely to be ineffective or futile in prolonging life, or is likely to merely prolong an imminent dying process;

(2) When the patient is permanently unconscious, as determined by the attending physician and confirmed by a second qualified physician;

(3) When the patient is in a terminal condition, as determined by the attending physician and confirmed by a second qualified physician; or

(4) In the event none of the above circumstances applies, when the patient has a serious irreversible illness or condition, and the likely risks and burdens associated with the

medical intervention to be withheld or withdrawn may reasonably be judged to outweigh the likely benefits to the patient from such intervention, or imposition of the medical intervention on an unwilling patient would be inhumane. In such cases prior to implementing a decision to withhold or withdraw life-sustaining treatment, the attending physician may promptly seek consultation with an institutional or regional reviewing body in accordance with section 17 of this act, or may promptly seek approval of a public agency recognized by law for this purpose.

b. Nothing in this section shall be construed to impair the obligations of physicians, nurses and other health care professionals to provide for the care and comfort of the patient and to alleviate pain, in accordance with accepted medical and nursing standards.

c. Nothing in this section shall be construed to abridge any constitutionally-protected right to refuse treatment under either the United States Constitution or the Constitution of the State of New Jersey.

Comment

Subpart C governs the foregoing of life-sustaining treatment, as defined in section 3. The act takes a situation-specific approach to the circumstances in which life-sustaining treatment may be withheld or withdrawn pursuant to a patient's advance directive. Section 15 provides important conditions and limitations for the withholding or withdrawal of life-sustaining treatment, including specific procedures to be followed before decisions to forego life-sustaining treatment may be implemented. The act's approach is grounded in careful consideration of the appropriate role of societal interests as sources of limitation upon the duty of health care providers and of society to comply with patients' expressed wishes to forego life-sustaining treatment. The act is consistent with existing case law in New Jersey and virtually all other states, as well as the United States Supreme Court decision in *Cruzan v. Director, Missouri Department of Health*, 110 S.Ct. 2841 (1990), all of which have made little or no distinction between the foregoing of artificially provided fluids and nutrition and other forms of life-sustaining treatment, in accordance with the patient's wishes. The patient has the same right to direct the withholding or withdrawal of artificially provided fluids and nutrition, such as a feeding tube, as he or she does to direct the foregoing of other forms of life-sustaining

treatment, such as a respirator. In contrast, statutory law in some other states takes a different and more restrictive approach to the foregoing of artificially provided fluids and nutrition pursuant to an advance directive than is taken to other forms of life-sustaining treatment.

Section 15a. identifies the four categories of medical circumstances in which the act authorizes the withholding or withdrawal of life-sustaining treatment, pursuant to the terms of the patient's advance directive. This section codifies widespread societal consensus regarding the circumstances in which a patient's expressed wishes to forego life-sustaining treatment should be respected. The act's approach is substantially (though not necessarily completely) in accord with the views of the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, the Hastings Center, and numerous court decisions across the country, including the decisions of the New Jersey Supreme Court. The act rejects the approach taken in the statutes of many other states which have limited the patient's right to refuse life-sustaining treatment pursuant to an advance directive to the medical circumstance in which the patient is in a terminal condition. This approach is overly restrictive of patients' rights and contrary to widely held societal values.

Ineffective, futile or experimental treatments. Section 15a.(1) provides that when life-sustaining treatment is likely to be ineffective or futile, or is likely to merely prolong an imminent dying process, a patient's expressed wishes to forego such treatment should be honored. This section codifies widely shared societal judgments that a patient should not be required to accept ineffective, futile and possibly intrusive and burdensome treatment contrary to his or her expressed wishes. This section also provides, consistently with widely shared values, that a patient should not be compelled to accept experimental treatment of unproven therapeutic value contrary to his or her expressed wishes. In the circumstances contemplated by section 15a.(1), a confirming diagnosis of the patient's medical condition is not required prior to implementing the patient's wishes to forego life-sustaining treatment.

Permanent unconsciousness. Section 15a.(2) provides that when the patient is permanently unconscious and the provision of life-sustaining treatment serves only to maintain bodily functions in the absence of any realistic medical prospect for return to a cognitive sapient state, the patient's expressed wishes to forego such treatment should be honored. In this regard, the act follows existing New Jersey law under *Quinlan*, *Peter* and *Jobes*. However, this section alters existing law in one important respect. Section 15a.(2) provides that where the patient has an advance directive, the attending physician's diagnosis and prognosis that the patient is permanently unconscious must be confirmed by a second qualified physician; most often this will mean a neurologist. In contrast,

current case law requires confirmation of the patient's condition by a prognosis committee, *In re Quinlan*, 70 N.J. 10, 355 A.2d 647, *cert. denied sub nom. Garger v. New Jersey*, 429 U.S. 922 (1976), or by two independent physicians where no prognosis committee is available, *In re Peter*, 108 N.J. 365, 529 A.2d 419, 429 (1987). The requirement of only one confirming medical opinion is responsive to concerns that the New Jersey Supreme Court guidelines in this regard may be overly burdensome in practice, and too often result in unreasonable delays in respecting patient wishes. The act seeks to establish a workable procedure for confirming the accuracy of a diagnosis while at the same time providing meaningful safeguards for patients through the shared decisionmaking process set forth in other provisions of the act. While this section would not require confirmation of the patient's condition by a prognosis committee, resort to a prognosis committee is certainly appropriate where one is available. The act places no limitations upon the number of physicians who may examine the patient and give their medical opinion.

Terminal condition. Section 15a.(3) provides that when the patient is in a terminal condition, as defined in section 3, the patient's expressed wishes to forego life-sustaining treatment should be honored. This section is consistent with existing New Jersey law under *Conroy*, though as discussed in comment to section 2, the act's definition of "terminal condition" departs slightly from *Conroy's* definition of "terminal illness". Similarly to section 15a.(2), the requirement in section 15a.(3) that the patient's condition be confirmed by one non-attending physician is intended to assure practicable and accurate evaluation of the patient's diagnosis and prognosis without making respect for patient wishes unduly burdensome. When needed, consultation with additional physicians to determine the patient's medical condition is appropriate.

Other life-threatening illness or condition. Section 15a.(4) provides for a fourth category of medical circumstances in which the foregoing of life-sustaining treatment pursuant to the patient's advance directive is authorized by the act. This section applies only in cases in which the patient does not meet the criteria of sections 15a.(1) through 15a.(3), *i.e.*, when the patient is not imminently dying, not permanently unconscious, and not in a terminal condition. Section 15a.(4) addresses foregoing of life-sustaining treatment when the patient has a serious and *irreversible* (but not terminal) condition, and the likely risks and burdens of providing the treatment in question may reasonably be judged to outweigh its likely benefits, *or* imposing this intervention on the patient contrary to his or her wishes would be inhumane.

Like the other provisions of section 15a., section 15a.(4) is grounded in shared societal consensus regarding the circumstances in which a patient's expressed wishes to forego life-sustaining treatment should be honored.

However, this fourth circumstance presents a more morally problematic situation; one in which societal interests favoring continued provision of treatment may carry greater weight. Therefore, the act recommends, but does not require, that to further assure a sound decisionmaking process another level of review take place, before a decision to forego life-sustaining treatment is implemented. Section 15a.(4) provides that an institutional or regional reviewing body (such as an institutional ethics committee), or an appropriate public agency (such as the Ombudsman for the Institutionalized Elderly or a court), *may* be consulted before a decision to forego life-sustaining treatment is implemented. This process must be initiated promptly by the attending physician. The process to be followed by an institutional or regional reviewing body engaged in prospective case consultation pursuant to section 15a.(4) is set forth in section 17.

It bears emphasis that the act does not establish a mandatory prospective case consultation role for an ethics committee or like body. The option (and encouragement) of a local review process is intended to provide appropriate protection for patients in a potentially morally problematic circumstance while being less burdensome, intrusive and time consuming than other review processes, such as the Office of the Ombudsman or the courts. Where this process of local review is implemented by nursing homes or other institutions within the Ombudsman's jurisdiction, the act provides that institutional or regional review is a legally recognized alternative to Ombudsman review.

Palliative care. In most cases, patients who refuse life-sustaining treatment desire a dignified and less burdensome dying process, and do not intend to refuse palliative and nursing care. In addition, health care providers have professional obligations to provide palliative measures to relieve patient suffering. In recognition of these concerns and of some existing confusion regarding the provision of palliative care when life-sustaining treatment is terminated, section 15b. makes clear that the withholding or withdrawal of a particular life-sustaining treatment under the act does not mean the cessation of all treatment and care for the patient. Physicians, nurses and other health care professionals should continue to alleviate pain and to take other steps to care for and comfort the patient, in accordance with accepted medical and nursing standards, unless such measures are contrary to the patient's clearly expressed wishes. Continued comfort care should ideally be a part of the patient's treatment plan, agreed upon among the attending physician, health care representative and patient.

Effect on other laws. Section 15c. provides that the act is not intended to alter or impair patients' constitutional rights to refuse treatment (or to accept treatment), under the United States Constitution and the Constitution of the

State of New Jersey. However, to the extent any provisions of this section are inconsistent with the existing common law rights of patients to forego life-sustaining treatment pursuant to an advance directive, *this act controls*. It is especially important to note here that the act applies to treatment decisions only when the patient has executed an advance directive, and *does not* limit patient rights under existing law in other circumstances.

Section 16: Do Not Resuscitate Orders

a. Consistent with the terms of an advance directive and the provisions of this act, the attending physician may issue a do not resuscitate order.

b. A do not resuscitate order shall be entered in writing in the patient's medical records prior to implementation of the order.

c. Nothing in this act shall be construed to impair any existing legal authority to issue a do not resuscitate order when the patient has not executed an advance directive.

Comment

Section 16 provides guidelines for the issuance of do not resuscitate orders pursuant to the terms of an advance directive. Under section 16a. the attending physician may issue an order that cardiopulmonary resuscitation not be attempted if the patient suffers a cardiac or respiratory arrest (a DNR order) if such an order is consistent with the terms of an advance directive and the provisions of the act. In order to be legally effective the DNR order must be put in writing in the patient's medical records (and chart) before it is implemented (section 16b.). This assures proper notice to health care professionals responsible for the patient's care, as well as the accountability of physicians for issuance of DNR orders.

Section 16c. makes clear that the requirements established by the act regarding issuance of DNR orders are applicable only within the context of the act, *i.e.*, only where the patient has executed an advance directive. The act does not alter or impair any existing legal authority of physicians to enter DNR orders, nor does it affect the manner in which they are issued in cases where the patient has no advance directive.

Section 17: Institutional and Regional Reviewing Bodies

a. An institutional or regional reviewing body which engages in prospective case consultation pursuant to paragraph (4) of subsection a. of section 15 of this act may be consulted by the attending physician, patient or health care representative as to whether it believes that the withholding or withdrawal of the medical intervention under consideration would be in conformity with the requirements of this act, including without limitation: whether such action would be within the scope of the patient's advance directive; whether it may reasonably be judged that the likely risks and burdens associated with the medical intervention to be withheld or withdrawn outweigh its likely benefits; and whether it may reasonably be judged that imposition of the medical intervention on an unwilling patient would be inhumane. The attending physician, patient and health care representative shall also be advised of any other course of diagnosis or treatment recommended for consideration.

Consultation with the institutional or regional reviewing body shall be documented in the patient's medical records.

b. Consultation with an institutional or regional reviewing body acting in accordance with subsection a. of this section is not required. Furthermore, nothing in this act shall be construed to impair the right of a patient, health care representative, physician, nurse, or other health care professional who consults with an institutional or regional reviewing body to:

(1) Seek review by a public agency recognized by law for this purpose; or

(2) Seek review by a court of competent jurisdiction.

c. Nothing in this section shall preclude the transfer of the patient to another appropriate health care professional or health care institution. In this case the health care institution responsible for the patient's care shall assure that the health care professional or health care institution to which the patient is

transferred is properly informed of the advice given by the institutional or regional reviewing body.

Comment

Section 17 sets forth the basic process to be followed when a prospective case consultation is requested under section 15a.(4). Under the act, section 17 applies only in the circumstances specified in section 15a.(4). The reviewing body may be institutional, such as an institutional ethics committee, or regionally based. The act is intended to permit, and indeed to encourage, health care institutions to consider participation in an ethics committee on an inter-institutional or regional basis. This may be especially important for some nursing homes and for home health agencies. Pursuant to Department of Health regulations, *N.J.A.C.* 8:43G-5.1(h), which became operative July 1, 1990, all hospitals are required to have a multidisciplinary ethics committee suited to participate in prospective case consultations. These committees would be the appropriate bodies to engage in a case consultation pursuant to the act.

Nature of committee review. Once a case consultation has been requested, the reviewing body should be convened in a timely fashion (promptly). While section 17a. provides that the committee is to render its advice, the act does not give the committee final decisionmaking authority. Furthermore, the committee's advice is not binding. Decisionmaking authority rests with the health care representative in collaboration with the attending physician. Where there is no health care representative, the locus of decisionmaking authority will be determined under other law, and not by the act, but generally will rest within the physician-patient-family relationship. (*See* the comment to section 12.)

Section 17a. states the standard of review to be applied by the committee. The committee should determine whether it finds the proposed withholding or withdrawal of a particular medical intervention to be within the scope of (consistent with) the terms of the patient's advance directive and in conformity with the requirements of the act, including in particular whether the proposal to forego life-sustaining treatment meets the substantive standards of section 15a.(4). Thus, the key question presented is whether the committee finds, in light of all the relevant factors--most importantly the terms of the patient's advance directive and the patient's current medical condition--that the proposed decision to withhold or withdraw the medical intervention is based upon a reasoned weighing of risks, burdens and benefits for the patient under the circumstances. The central issue for the committee is whether the decision to forego life-sustaining treatment falls within a range of reasonable and permissible decisions under the circumstances of the case. The committee is not called upon to determine whether it believes the withholding or withdrawal of the medical

intervention is "right" or "wrong", and the committee should not construe its role in this manner.

Upon completion of its deliberations, the committee is to advise the attending physician, the patient and the health care representative as to whether it believes the proposed decision to forego treatment is permissible under the act. The committee may also recommend an alternative course of diagnosis or treatment for the patient. (Section 17a.) The committee's recommendations are to be documented (entered in writing) in the patient's medical records. (Section 17a.)

Legal consequences. Section 17b. makes clear that consultation with an institutional or regional reviewing body is optional, not mandatory. (*See* section 15a.(4).) Furthermore, section 17 provides that the committee's role is advisory only. The act does not give the committee decisionmaking authority, and that authority continues to reside within the physician-health care representative-patient relationship. Those who choose not to follow the committee's recommendation(s) may pursue other courses of action, including acting on the previously proposed treatment decision, or seeking review by a state agency or a court. A patient, health care representative, physician, and others who choose not to follow the committee's recommendation(s) are *not* thereby subject to liability by virtue of having chosen to pursue a different course of action. Rejection of the committee's recommendation(s) in itself creates no presumption of lack of good faith and the act's protection against liability for good faith behavior should attach. (*See* section 21.) Conversely, a health care representative, physician, nurse or other health care professional who acts in good faith to follow the committee's advice would receive no additional statutory immunity from legal liability beyond that already provided by the act. Resort to an ethics committee for guidance on difficult treatment dilemmas and/or following the committee's advice may provide relevant evidence of good faith behavior in the event judicial proceedings become necessary.

Transfers of care. One possible consequence of the committee's recommendations is that a transfer of care will be sought by those who strongly disagree with those recommendations. For example, where the committee's advice does not support the decision proposed by the health care representative, or where the advice is contrary to the personal or professional convictions of a member of the health care team, such as the attending physician, transfer of care to another health care professional or institution may be requested. Section 17c. makes clear that those responsible for the patient's care retain this option. (Of course, the committee could also recommend a transfer of care.) However, the committee's consultation and recommendations are not nullified by a transfer of care and remain a part of the patient's medical records. In the event a transfer of care is effectuated, the health care institution is responsible for assuring that

the committee's recommendations are properly communicated to the health care professional or health care institution assuming responsibility for the patient's care, including transfer of the written statement of the committee's recommendations entered in the patient's medical records. Those responsible for the patient's care are free to seek another consultation with a committee of the transferee institution.

Nothing in the act should be construed to prevent or discourage health care representatives, patients, physicians, or others from seeking the advice and support of an ethics committee in a variety of other circumstances beyond those set forth in section 15a.(4).

Subpart D: Implementation and Legal Consequences

Section 18: Health Care Institutions Governed by This Act; Qualified Exemption For Providers of Emergency Care

a. Nothing in this act shall be construed to alter, amend or revoke the rights and responsibilities under existing law of health care institutions not governed by the provisions of this act.

b. The provisions of this act shall not be construed to require emergency personnel, including paid or volunteer fire fighters; paramedics; members of an ambulance team, rescue squad, or mobile intensive care unit; or emergency room personnel of a licensed health care institution, to withhold or withdraw emergency care in circumstances which do not afford reasonable opportunity for careful review and evaluation of an advance directive without endangering the life of the patient.

Comment

Subpart D provides for important aspects of the implementation and legal consequences of the act.

The act applies to all "health care institutions" as that term is defined in section 3. Under this definition, the act applies to all institutions, facilities and agencies licensed, certified or otherwise authorized to provide health care in New Jersey, including hospitals, nursing homes, residential health care facilities, and home health care agencies, and all hospice programs operating in the State. The act also governs state-administered mental health institutions, facilities or

agencies, and those state institutions, facilities and agencies devoted to care of the developmentally disabled. Thus, the act applies to most, but not all, health care institutions in New Jersey. The act and the definition should be construed broadly to assure respect for patients' advance directives in the various health care settings in this State and to provide appropriate protections to health care providers who honor advance directives in conformity with the provisions of the act. While the act would not effect any changes in the rights and obligations of institutions, facilities or agencies not governed by the act, nothing in the act would prohibit such institutions, facilities or agencies from respecting an advance directive that has been properly executed by one of its patients or residents.

Emergency personnel. Section 18b. provides a qualified exemption from the provisions of the act for emergency care providers. Emergency care providers, such as fire fighters, paramedics, and members of an ambulance team, are not obligated to seek to evaluate complex information in emergency circumstances where the patient's life may be endangered and should continue to act upon their professional commitments to preserve life. However, where the patient's wishes are clearly understood in advance of a medical crisis requiring immediate intervention, emergency care providers should act in good faith to carry out a patient's wishes that life-sustaining treatment not be provided. For example, where pursuant to a patient's advance directive there is a physician's order not to resuscitate which has been properly communicated to emergency personnel, this order should be respected. Where doubt exists, emergency care providers should err in favor of preserving life.

Section 19: Implementation of Advance Directives

In accordance with the "Administrative Procedure Act," *P.L.1968, c.410 (C.*52:14B-1 *et seq.)* the Department of Health shall establish rules and regulations:

a. For the annual reporting by health care institutions, and the gathering of such additional data as is reasonably necessary to oversee and evaluate the implementation of this act. The department shall seek to minimize the burdens of record-keeping imposed by the rules and regulations and shall seek to assure the appropriate confidentiality of patient records.

b. Requiring health care institutions to adopt policies and practices designed to:

(1) Make routine inquiry, at the time of admission and at such other times as are appropriate under the circumstances, concerning the existence and location of an advance directive;

(2) Provide appropriate informational materials concerning advance directives to all interested patients and their families and health care representatives, and to assist patients interested in discussing and executing an advance directive;

(3) Educate patients and their families and health care representatives about the availability, benefits and burdens of rehabilitative treatment, therapy and services, as appropriate;

(4) Inform physicians, nurses, and other health care professionals of their rights and responsibilities under this act, to assure that the rights and responsibilities are understood, and to provide a forum for discussion and consultation regarding the requirements of this act; and

(5) Otherwise comply with the provisions of this act.

Comment

Section 19 directs the Department of Health to promulgate rules and regulations to collect data necessary to evaluate the act, and to oversee and assure compliance with the act. The Department of Health is directed to collect reports, on an annual basis, from health care institutions regarding their experience with the implementation of the act. (Section 19a.) The collection of data should accord particular attention to the extent to which advance directives are being honored by health care providers, to the way in which the decisionmaking process is working, and to identification of particular concerns, including protection against possible abuse. While minimizing unnecessary paperwork, this process should provide an empirically sound basis for recognizing and correcting any difficulties. This section directs, but does not limit, the exercise of regulatory authority to enforcement of the obligations of health care institutions to facilitate implementation of advance directives. The regulatory provisions authorized by sections 19b.(1) through 19b.(4) parallel the obligations of health care institutions set forth in section 13a. of the act. Section 19b.(5) provides for a generalized authority in the Department of Health to establish rules and regulations as may be necessary to oversee and enforce compliance of health care institutions with any and all other obligations established by the act. In the exercise of its authority under this section the

Department of Health is required to follow the "Administrative Procedure Act", *N.J.S.A.* 52:14B-1, *et seq.*

Section 20: Evaluation and Reporting

The Department of Health and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care established pursuant to P.L.1985, c.363 (C.52:9Y-1 *et seq.*), shall jointly evaluate the implementation of this act and report to the Governor and the Legislature, including recommendations for any changes deemed necessary, within five years from the effective date of this act.

Comment

Section 20 establishes a mechanism for evaluating the effectiveness of the act in achieving its intended objectives and for proposing any necessary changes. This responsibility is to be undertaken jointly by the Department of Health and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care. These bodies are directed to report their conclusions to the Governor and the Legislature, including recommendations for any changes that may be necessary to better achieve the objectives of the act. The initial report is to be made within not more than five years from the effective date of the act. In the event serious difficulties arise, an earlier report should be made.

The requirement that the initial report be made to the Governor and Legislature within five years of the effective date of the act has no automatic effect upon the continued validity of the act; the act does not contain a formal "sunset" provision.

Section 21: Immunities

a. A health care representative shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive.

b. A health care professional shall not be subject to criminal or civil liability or to discipline by the health care institution or the respective State licensing board for professional misconduct for any actions performed in good faith and in accordance with the provisions of this act, any rules and regulations established by

the Department of Health pursuant to this act, and accepted professional standards to carry out the terms of an advance directive.

c. A health care institution shall not be subject to criminal or civil liability for any actions performed in good faith and in accordance with the provisions of this act to carry out the terms of an advance directive.

Comment

Section 21 provides a *good faith* immunity for health care representatives and health care providers who act in accordance with the provisions of the act (and in the case of health care providers any applicable rules and regulations) to carry out the terms of an advance directive.

Under section 21a. health care representatives who implement the terms of an advance directive in good faith and who do so in accordance with their responsibilities under the act (in particular sections 9 and 11) shall be immune from criminal and civil liability. This section is intended to make clear to health care representatives that good faith actions to carry out their responsibilities pursuant to an advance directive are insulated from potential liability.

Section 21b. extends to physicians, nurses, and other health care professionals, and applies to criminal or civil liability and to discipline for unprofessional conduct. Section 21c. extends immunity from criminal or civil liability to health care institutions governed by the act. The act does not provide a blanket or absolute immunity and does not absolve from liability or from professional discipline those whose actions are contrary to accepted professional standards or the requirements of the act. This section is intended to make clear to health care professionals that non-negligent actions undertaken in compliance with the act, applicable regulations, and professional standards to implement an advance directive are insulated from potential liability. Physicians and other health care providers should be confident that they may exercise sound professional judgment in seeking to follow the terms of an advance directive. The statutory grant of immunity is intended to calm existing concerns of unfounded and burdensome entanglements in legal proceedings, and to obviate any perceived need to seek advance approvals from courts prior to implementing a treatment decision pursuant to an advance directive and the requirements of the act.

While this section provides immunities for good faith behavior, section 28 imposes penalties for intentional failure to comply with advance directives or with the act.

technicalities of law which may differ from state to state. Section 24 is intended to require the honoring of advance directives that may not be in strict compliance with the procedural requirements of the laws of another state or the state of New Jersey, or a foreign country, but which are in substantial compliance with the law of either state, or with the law of a foreign country.

At the same time, this section recognizes that the substantive law of other states and countries may differ in important respects from the substantive provisions of the act. In order to protect this state's interest in the integrity of its public policy, section 24 would deny legal recognition of terms of an advance directive that rely upon rights or seek to impose obligations that are contrary to the public policy of New Jersey. For example, if an advance directive requests active euthanasia, as by lethal injection, such a request should not be honored. As noted in comment to section 25, assisting suicide is a crime in New Jersey.

Decisionmaking in accordance with the contents of an advance directive executed under the law of another state or country is to be in accordance with both the procedural and substantive provisions of the act.

Section 25: Effect on Other Laws

a. The withholding or withdrawing of life-sustaining treatment pursuant to section 15 of this act, when performed in good faith, and in accordance with the terms of an advance directive and the provisions of this act, shall not constitute homicide, suicide, assisted suicide, or active euthanasia.

b. To the extent any of the provisions of this act are inconsistent with P.L.1971, c.373 (C.46:2B-8 *et seq.*) concerning the designation of a health care representative, the provisions of this act shall have priority over those of P.L.1971, c.373 (C.46:2B-8 *et seq.*).

Durable powers of attorney for health care executed pursuant to P.L.1971, c.373 (C.46:2B-8 *et seq.*) prior to the effective date of this act shall have the same legal force and effect as if they had been executed in accordance with the provisions of this act.

c. Nothing in this act shall be construed to impair the rights of emancipated minors under existing law.

Comment

Section 25 states the impact of the act upon several other laws which are or may be affected by the act.

Homicide, suicide, and active euthanasia. Under section 25a. respecting a patient's wishes, as expressed in an advance directive, to reject a prolonged and burdensome dying process and to accept an earlier death is legally permissible and is not an unlawful taking of life, *i.e.*, such action does not constitute homicide. That a patient wishes to forego life-sustaining treatment in the circumstances specified in section 15 does not mean that the patient's wishes are motivated by a specific intent to die, *i.e.*, that the patient intends to commit suicide. Consequently, respecting the patient's wishes does not implicate a health care representative or health care provider in the assisting of suicide; *N.J.S.A.* 2C:11-6, which makes aiding suicide a crime, does not apply to the withholding or withdrawal of life-sustaining treatment in conformity with the act. Section 25a. follows the approach of the vast majority of statutes of other states and the uniform holdings of courts in New Jersey and elsewhere.

Section 25a. also provides that the termination of life-sustaining treatment pursuant to the act does not constitute "active euthanasia". As stated in section 2e., the act rejects as a matter of public policy the practice of "active euthanasia" (sometimes referred to as "mercy killing"), *i.e.*, the intentional causing of the patient's death, such as by deliberate lethal injection. Patients have no right to request a lethal injection, nor is any physician or health care provider obligated or authorized to engage in the practice of active euthanasia. In contrast, the withholding or withdrawal of life-sustaining treatment pursuant to the act may be characterized as "passive euthanasia". Although the term "euthanasia" is often used in ethical discourse, with the exception of distinguishing and rejecting active euthanasia, the act generally avoids use of the term "euthanasia", on the ground that it is frequently ambiguous and subject to misunderstanding, and increasingly has been used by some in a politically and morally controversial manner which mischaracterizes and confuses the issues. Furthermore, it is important to emphasize here that the right of patients recognized by the act is properly construed and characterized as a right to decide, including the right to refuse unwanted medical interventions, not as a so-called "right to die". The withholding or withdrawal of life-sustaining treatment in accordance with the terms of a patient's advance directive and the provisions of the act is both legally and morally permissible.

Durable powers of attorney for health care. Section 25b. provides that the act creates the preferred, but not the exclusive, method for the designation of a legally authorized health care representative. Under *In re Peter*, 108 N.J. 365, 529 A.2d 419 (1987), the New Jersey Powers of Attorney law may be used to

give an individual a durable power of attorney to make health care decisions (a durable power of attorney for health care). That ruling is not affected by the act, and nothing in the act is intended to invalidate designation of a health care representative made under the Powers of Attorney law. However, the act establishes more comprehensive requirements for such a designation and should be followed for this purpose. This section also provides that durable powers of attorney for health care executed pursuant to the provisions of the Powers of Attorney law and prior to the effective date of the act shall continue to be recognized as legally valid documents with the same legal force and effect as if they had been executed pursuant to the act. The rights and responsibilities of health care representatives and of health care providers are to be governed by the act, without regard to the time or manner of the designation of a health care representative (assuming the document is validly executed).

Emancipated minors. Section 25c. addresses the effect of the act upon the rights and responsibilities of emancipated minors. The act states that adults, *i.e.*, individuals 18 years of age or older, may execute advance directives, and that adults may serve as health care representatives. Adults are generally presumed to be competent to make health care decisions (as well as to make other types of decisions) absent a determination of incompetency. In contrast, under common law minors (those under the age of majority, ordinarily defined as the age of 18) have not been presumed competent to make health care decisions on their own behalf. Certain exceptions to this rule, both in statute and common law, have evolved, and emancipated minors have been recognized in some circumstances as having the legal authority to consent to (or refuse) health care (as well as to make other types of decisions). Section 25c. is intended to preserve the rights of emancipated minors under existing law, and to allow the competence of emancipated minors to execute an advance directive, or to serve as a health care representative on behalf of a family member or friend, to be determined on an individual basis.

Section 26: "Ombudsman for the Institutionalized Elderly," *N.J.S.A.* 52:27G-1, *et seq.*

The Office of the Ombudsman for the Institutionalized Elderly shall conform and implement procedures necessary to comply with the requirements of P.L. 1991, c. 210 (C.), and shall make a written statement of its obligations under that act available to the public.

Comment

Section 26 provides that the Office of the Ombudsman is bound by the requirements of the act and is obligated to adopt policies and practices necessary to carry out its obligations under the act. The act strongly suggests, though it does not mandate, that the Office of the Ombudsman change its current policy and practice, and no longer be involved in reviewing patients' advance directives. Given the statutory framework established by the act, including recognition of formalities for execution of directives and a decisionmaking process for implementation of patients' wishes, there is no need for review of patients' advance directives by a state agency. Local review mechanisms, such as an ethics committee, will be positioned to address problems or concerns at the local level. In addition, section 15a.(4) expressly provides that in the circumstances specified there a local review process would be a legally recognized alternative to Ombudsman review for cases within the Ombudsman's jurisdiction; this should be reflected in the Ombudsman's response to the act. The act does not require that the Ombudsman adopt regulations setting forth its obligations under the act, but does not preclude regulatory action. Whether or not policies and practices (or regulations) are formally adopted, the Ombudsman is required to adopt a written statement of its obligations under the act and to make this statement available to the public.

Section 27: "Public Guardian for Elderly Adults," *N.J.S.A.* 52:27G-20, *et seq.*

The Office of the Public Guardian for Elderly Adults shall conform and implement procedures necessary to comply with the requirements of P.L. 1991, c. 210 (C.), and shall make a written statement of its obligations under that act available to the public.

Comment

Section 27 provides that the Office of the Public Guardian for Elderly Adults (the "Public Guardian") is bound by the requirements of the act and is obligated to modify existing procedures as may be necessary to carry out its obligations under the act. Although the cases in which the Public Guardian becomes involved on behalf of a patient with an advance directive likely will be rare, in some cases the Public Guardian will be legally appointed to act on the patient's behalf. The act does not require that the Public Guardian adopt regulations setting forth its obligations under the act in such cases, but does not preclude regulatory action. Whether or not policies and practices (or regulations) are formally adopted, section 27 requires the Public Guardian to adopt a written statement of its obligations under the act and to make this statement available to the public.

Section 28: Penalties

a. A health care professional who intentionally fails to act in accordance with the requirements of this act is subject to discipline for professional misconduct pursuant to section 8 of P.L.1978, c.73 (C.45:1-21).

b. A health care institution that intentionally fails to act in accordance with the requirements of this act shall be subject to a fine of not more than $1,000 for each offense. For the purposes of this subsection, each violation shall constitute a separate offense. Penalties for violations of this act shall be recovered in a summary civil proceeding, brought in the name of the State in a court of competent jurisdiction pursuant to "the penalty enforcement law," *N.J.S.*2A:58-1 *et seq.*

c. The following acts constitute crimes:

(1) To willfully conceal, cancel, deface, obliterate or withhold personal knowledge of an advance directive or a modification or revocation thereof, without the declarant's consent, is a crime of the fourth degree.

(2) To falsify or forge an advance directive or a modification or revocation thereof of another individual is a crime of the fourth degree.

(3) To coerce or fraudulently induce the execution of an advance directive or a modification or revocation thereof is a crime of the fourth degree.

(4) To require or prohibit the execution of an advance directive or a modification or revocation thereof as a condition of coverage under any policy of health insurance, life insurance or annuity, or governmental benefits program, or as a condition of the provision of health care is a crime of the fourth degree.

d. Commission of any of the acts identified in paragraphs (1), (2), or (3) of subsection c., resulting in the involuntary earlier death of a patient, shall constitute a crime of the fourth degree.

e. The sanctions provided in this section shall not be construed to repeal any sanctions applicable under other law.

Comment

Section 28 provides for enforcement of the act and of patients' rights to have their advance directives respected by establishing penalties for the intentional failure of health care professionals and health care institutions to follow the act, and by visiting criminal penalties on those who with deceit and ill-motive seek to obstruct respect for a patient's advance directive. Under section 28a., physicians, nurses and other health care professionals who intentionally do not follow the practices and procedures established by the act (including for example, intentional refusal to recognize an advance directive or to transfer a patient in accordance with the requirements of the act), will be subject to disciplinary action for professional misconduct by the appropriate authority (such as the Board of Medical Examiners). Under section 28b., intentional failure on the part of a health care institution to follow the act is punishable by fine, recoverable in a summary civil proceeding that may be brought in the name of the State, for example by the Department of Health.

Section 28c. provides criminal penalties for actions clearly designed to undermine an individual's wishes as expressed in an advance directive, or by the modification or revocation of an advance directive. The prohibitions of this section apply to all persons, including but not limited to health care representatives, physicians, health care providers, family members, and others. Penalties established by section 28c. are intended to apply regardless of the eventual result of the unlawful actions. Thus, to be criminally sanctioned the conduct need not result in the unauthorized withholding or withdrawal of life-sustaining treatment, thereby hastening death; nor need it result in the continuation of treatment and the unauthorized prolongation of a burdensome dying process. However, section 28d. establishes a separate offense where the actions proscribed in sections 28c.(1) through 28c.(3) (*i.e.*, fraud, coercion and deceit) result in the earlier death of the patient, contrary to the patient's expressed wishes.

Section 28c.(4) provides sanctions for violations of section 23 of the act, by making it a criminal offense to require or prohibit the execution, modification or revocation of an advance directive as a condition of providing insurance coverage, or to condition the provision of health care upon the execution, modification or revocation of an advance directive.

Finally, section 28e. specifically states that the penalties established by the act do not repeal or replace any sanctions that might be applicable under other laws.

Section 29: Effective Date

This act shall take effect 180 days after the date of enactment.

Comment

The New Jersey Advance Directives for Health Care Act was signed into law on July 11, 1991.

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THE NEW JERSEY DECLARATION OF DEATH ACT

P.L. 1991, Chapter 90

To be codified as Chapter 6A of Title 26 of the Revised Statutes

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*THE NEW JERSEY DECLARATION OF DEATH ACT With Commentary**

Historical Note

The New Jersey Declaration of Death Act was signed into law by Governor James J. Florio on April 8, 1991. The bill was passed, as amended, by the New Jersey Senate on March 7, 1991. The primary sponsor of the bill (S-1208) was Senator Gabriel M. Ambrosio (a Commission member). The companion bill was passed by the General Assembly on February 28, 1991, sponsored by Assemblywoman Marlene Lynch Ford and Assemblyman C. Richard Kamin (a Commission member). The New Jersey Declaration of Death Act is based upon the work of the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (the New Jersey Bioethics Commission). The bill was originally approved by the Commission on June 8, 1988, and was first introduced in the legislature on June 16, 1988.

Prefatory Note

The act codifies existing New Jersey case law by providing a statutory basis for declaring death on the grounds of total and irreversible loss of all functions of the entire brain, including the brain stem (commonly known as "whole brain death"). In two important respects the act is unique among whole brain death laws currently in force by statute or court decision in 50 states across the country. First, the act mandates legally recognized uniform criteria for the determination of death on the basis of neurological criteria, by requiring the Department of Health and the Board of Medical Examiners to adopt rules and regulations setting forth currently accepted medical standards, including criteria, tests, and procedures, to govern such determinations. The act requires that these standards be periodically reviewed and updated to keep pace with developments in medical science and technology. Second, the act expresses an important commitment to respect for religious values by recognizing the legal right of an individual to claim an exemption from the application of neurological criteria for determining death if such a declaration would violate that individual's personal religious beliefs. New Jersey is the first state to recognize such an exemption in its statutory law.

This document, prepared by the Bioethics Commission, provides a section-by-section analysis of the New Jersey Declaration of Death Act. Section headings are supplied by the Bioethics Commission.

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* This publication supercedes prior analyses prepared by the Bioethics Commission.

AN ACT concerning the determination of death, enacting the New Jersey Declaration of Death Act and supplementing Title 26 of the Revised Statutes.

BE IT ENACTED by the Senate and General Assembly of the State of New Jersey:

Section 1: Short Title and Purpose

a. This act shall be known and may be cited as the "New Jersey Declaration of Death Act."

b. The death of an individual shall be declared in accordance with the provisions of this act.

Comment

The purpose of this act is to establish a fixed statutory basis for the declaration of death. The legislative standards for declaring that death has occurred are set forth in sections 2 and 3 of the act. These are the sole legal bases for declaring the death of an individual. In this regard, the act clarifies existing judicial precedent and establishes a statutory basis for New Jersey law.

Section 2: Recognition of Traditional Cardio-Respiratory Criteria

An individual who has sustained irreversible cessation of all circulatory and respiratory functions, as determined in accordance with currently accepted medical standards, shall be declared dead.

Comment

Section 2 recognizes the traditional criteria for the declaration of death, the irreversible cessation of all circulatory and respiratory functions. These traditional criteria will certainly continue to govern in the vast majority of cases in which death must be declared. It is important to note that in section 2, as throughout the act, the term "declaration" of death is used. ("Declaration" is used as synonymous with "pronouncement".) The act is intended to establish legally applicable standards for those authorized to declare that death has occurred; it does not attempt to "define" death in religious, metaphysical or philosophical terms. Upon the declaration of an individual's death by a qualified practitioner in accordance with the established legal standard, the individual is properly treated as legally dead. This section is not intended to modify either existing law relating to the qualifications of practitioners

(including nurses) currently authorized to declare death according to cardio-respiratory criteria or existing practices relating to determination of the "time of death" when death is declared upon the basis of cardio-respiratory criteria.

Section 3: Recognition of Modern Neurological Criteria

Subject to the standards and procedures established in accordance with this act, an individual whose circulatory and respiratory functions can be maintained solely by artificial means, and who has sustained irreversible cessation of all functions of the entire brain, including the brain stem, shall be declared dead.

Comment

Section 3 recognizes modern neurological criteria, popularly known as "whole brain death", as a legal basis for declaring death. The "whole brain death" standard complements the traditional cardio-respiratory criteria for the declaration of death recognized in section 2, by providing that neurological criteria are to be applied when the individual's circulatory and respiratory functions can only be maintained by artificial means. The provision thus explains the relationship between the traditional cardio-respiratory and modern neurological standards for declaring death, an explanation lacking in the Uniform Determination of Death Act ("UDDA") and in several other statutory formulations.

Section 3 defines the neurological basis for declaring death as the "irreversible cessation of all functions of the entire brain, including the brain stem". This follows the formulation of the UDDA, and rejects approaches based upon brain stem function alone (the British approach) or higher brain function alone. Irreversible loss of *all* brain functions must be established for death to be declared under the act. The act rejects so-called "higher brain" or "neocortical" death as a legal basis for declaring the death of an individual. Thus, the act *does not* permit a patient in a "persistent vegetative state" to be declared dead.

The act does not provide any current legal basis for permitting the use of so-called "anencephalic" newborns as organ donors, since there do not now exist any validated medical standards for the reliable determination of whole brain death in the immediate neonatal period. The act also does not provide any basis for the assertion that such infants should be regarded as entirely "brain absent", and therefore "brain dead".

Section 4: Standards and Procedures For Declaration of Death Based Upon Neurological Criteria

a. A declaration of death upon the basis of neurological criteria pursuant to Section 3 of this act shall be made by a licensed physician professionally qualified by specialty or expertise, in accordance with currently accepted medical standards and additional requirements, including appropriate confirmatory tests, as are provided pursuant to this act.

b. Subject to the provisions of this act, the Department of Health, jointly with the Board of Medical Examiners, shall adopt, and from time to time revise, regulations setting forth (1) requirements, by specialty or expertise, for physicians authorized to declare death upon the basis of neurological criteria; and (2) currently accepted medical standards, including criteria, tests and procedures, to govern declarations of death upon the basis of neurological criteria. The initial regulations shall be issued within 120 days of the enactment of this act.

c. If the individual to be declared dead upon the basis of neurological criteria is or may be an organ donor, the physician who makes the declaration that death has occurred shall not be the organ transplant surgeon, the attending physician of the organ recipient, nor otherwise an individual subject to a potentially significant conflict of interest relating to procedures for organ procurement.

d. If death is to be declared upon the basis of neurological criteria, the time of death shall be upon the conclusion of definitive clinical examinations and any confirmation necessary to determine the irreversible cessation of all functions of the entire brain, including the brain stem.

Comment

Section 4 establishes certain standards and procedures for the declaration of death upon the basis of neurological criteria.

Section 4a. states two basic statutory requirements: that a declaration of death upon the basis of neurological criteria is to be made by a licensed physician professionally qualified by specialty or expertise to make this determination, and

that the declaration is to be made in accordance with currently accepted medical standards. Section 4a. also contemplates that additional specific requirements, including such confirmatory tests as may be appropriate in particular circumstances, may be established by the Department of Health and the Board of Medical Examiners, pursuant to the express regulatory authority conferred by the act.

Section 4b. authorizes and requires the Department of Health, acting jointly with the Board of Medical Examiners, to establish appropriate professional qualifications for physicians authorized to declare death upon the basis of neurological criteria, and to designate and periodically update accepted medical standards for such declarations. The Department of Health and the Board of Medical Examiners are required to act through a formal regulatory process, in accordance with the "Administrative Procedure Act", *N.J.S.A. 52*: 14B-1 *et seq.* The act thereby fosters significantly greater certainty and uniformity in the standards and practices to be employed in declaring death than is typical of other state statutes, or provided by the UDDA (which relies upon unspecified "accepted medical standards"). The primary task, at least for most cases, is to recognize current and well-established medical standards already published in the medical literature. At the same time, the act mandates the Department of Health and the Board of Medical Examiners to update standards on a periodic basis in accordance with developments in medical understanding and technology. All such changes are to be adopted through the regulatory process, and must be consistent with the statutory standard of whole brain death. Updating of medical standards may be especially significant with respect to the development and availability of confirmatory techniques in areas that are currently less well understood, such as brain death in newborns and infants.

The initial regulations are to be issued within 120 days of enactment of the act. This period should be adequate for formal regulatory action; however, it may be advisable to begin the process at the time the act is adopted. It should be recognized that death is now being declared in accordance with whole brain death criteria in New Jersey (and throughout the United States and much of the world), on the basis of accepted medical standards, in the absence of any statutory or regulatory specification.

Standards for the declaration of death. The regulations are to address both the professional qualifications of persons authorized to declare death on the basis of neurological criteria, and the medical standards to be employed in making such determinations. Unlike the case with traditional criteria for declaring death, in which non-physicians have long played a role, neurological criteria for declaring death require specialized expertise. It is anticipated that legal authorization will be limited to licensed physicians with specialized training

(*e.g.*, neurologists and neurosurgeons), and perhaps those with special experience (*e.g.*, senior intensivists). Establishment of necessary credentials is left to the regulatory authorities.

With respect to currently accepted medical criteria for declaration of death on the basis of neurological criteria, medical literature addressing the relevant clinical procedures and appropriate confirmatory tests, when indicated, is extensive. The original criteria, developed by the Ad Hoc Committee of the Harvard Medical School and published in 1968, have since been superseded by the Report of the Medical Consultants on the Diagnosis of Death to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, "Guidelines for the Determination of Death," *Journal of the American Medical Association* 246 (1981): 2184-86. More recent literature extends these tests to population groups not fully covered by the earlier literature, such as children and older infants. The need to develop sound medical histories and to rule out complicating conditions, such as drug sedation or hypothermia, which may confound certain clinical or confirmatory tests, is well-established. It is also important to distinguish between those cases in which repeated clinical examinations provide a proper and sufficient basis for the declaration of death, and those cases in which one or another confirmatory test should be employed.

The literature also reflects certain professional disagreements concerning the indications for and relative advantages and disadvantages of alternative confirmatory tests. Once again, detailed specification of the range of approaches appropriate to New Jersey, consistent with the basic statutory standards established by the act, is left to the regulatory authorities. The act would permit specification of particular criteria, tests and procedures when, and to the degree that, the regulatory authorities conclude that such specificity is necessary and appropriate. The act avoids requiring particular confirmatory tests at the statutory level, as such specification is bound to be unduly rigid and to soon become outmoded as medical technology continues to advance. Section 4b. is intended to accord some flexibility to the regulatory authorities in establishing standards in order to allow the medical standards to address particular clinical circumstances and respond to continuing scientific advances in this area.

Conflicts of interest. Section 4c. requires that, in addition to meeting standards of professional qualification established pursuant to section 4b., any physician who is to declare death not be involved in a conflict of interest relating to organ procurement and transplantation. This is intended both to protect the patient to be declared dead from any hypothetical possibility that such conflicting obligations might impair the physician's judgment or otherwise result in error, and to assure necessary public confidence in the integrity of such determinations. This section also provides a clear legal basis for physicians to decline

inappropriate participation in potentially difficult situations of conflicting obligations.

While not conflating the standards for declaring death with an individual's suitability as a potential organ donor, section 4c. does recognize, realistically, that individuals who meet neurological criteria for the declaration of death constitute the primary pool of potential donors of viable organs for transplantation purposes. Cognizant of this reality, and of the need for justified public confidence, the act specifically identifies and disqualifies the organ transplant surgeon, and the attending physician of a patient in need of an organ transplant, from making the declaration of death. This reflects the fact that such physicians may be subject to potentially conflicting obligations to two patients--the patient to be declared dead (the potential donor) and the patient in need of an organ transplant (the potential recipient). In addition, the last clause of section 4c. provides for disqualification of others involved in organ procurement who are not in either of these categories, but who are subject to some other "potentially significant" conflict of interest. Only physicians not subject to a potentially significant conflict of interest with respect to organ procurement may make the declaration of death.

Time of death. Section 4d. provides statutory direction for fixing the time of death in cases in which death is declared on the basis of neurological criteria. Neither this section, nor any other provision of the act, modifies existing law or practice regarding the time of death in cases in which traditional cardio-respiratory criteria are employed.

Because the signs of "brain death" are neither as dramatic nor as readily apparent as the vital signs associated with cessation of breathing and heartbeat, there has been some confusion regarding the appropriate moment for fixing the time of death in such cases. The principal candidates are, first, the time at which the patient first meets the initial clinical criteria for irreversible cessation of all brain functions, and second, the time at which the repeated clinical examinations, together with the completion of any appropriate confirmatory tests, establish a definitive diagnosis of death.

Neither the UDDA, nor the report of the President's Commission, specifically resolves this issue. There are advantages and disadvantages to each approach. The act opts for the second approach because it stresses the importance of careful, repeated clinical examinations as a necessary prerequisite to a determination of death, and because it avoids unnecessary and anomalous after-the-fact determinations that a patient was legally dead during the interval (typically 6-24 hours, sometimes longer) between the initial clinical diagnosis and the subsequent, definitive diagnosis. This approach also avoids potential

disputes over the applicability of private and public health care coverage during that interval. Were time of death resolved in a different manner, there might be confusion over whether insurance coverage ceases prior to the actual declaration of death.

Section 4d. does not apply in cases in which the exemption to accommodate personal religious beliefs applies (section 5 of the act), in which event death is to be declared solely upon the basis of traditional cardio-respiratory criteria, and the time of death fixed accordingly.

Section 5: Exemption to Accommodate Personal Religious Beliefs

The death of an individual shall not be declared upon the basis of neurological criteria pursuant to sections 3 and 4 of this act when the licensed physician authorized to declare death, has reason to believe, on the basis of information in the individual's available medical records, or information provided by a member of the individual's family or any other person knowledgeable about the individual's personal religious beliefs that such a declaration would violate the personal religious beliefs of the individual. In these cases, death shall be declared, and the time of death fixed, solely upon the basis of cardio-respiratory criteria pursuant to section 2 of this act.

Comment

Section 5 provides an exemption from the applicability of neurological criteria for declaring death when such a declaration would violate the personal religious beliefs of the patient. In such cases, the traditional criteria of irreversible cessation of circulatory and respiratory functions are to be applied. This exemption constitutes a distinctive feature of the act's approach to the declaration of death, founded on an understanding of the respective roles of medical and scientific, and of social and philosophical, factors by which society adapts to new developments in medical science and technology.

Clearly, the identification of medical criteria for determining that certain bodily functions have ceased, and that such cessation is irreversible, must be based upon scientific understanding and medical techniques and technology. Such understandings have changed over time, and will continue to evolve and advance. However, the acceptance of particular medical criteria as the social and legal basis for declaring the death of an individual, although necessarily rooted in scientific understanding, is not itself a medical and scientific choice.

Rather, it is a societal decision which rests on social, philosophical and legal criteria, which may be informed by religious traditions and perspectives. As stated by the President's Commission, whose report on *Defining Death* provides the foundation for the UDDA and for brain death statutes in many jurisdictions, "the society as a whole must judge that these technical standards and the opinions they reflect conform to the society's settled values and accepted conceptions of human existence and personal rights." (*Defining Death: Medical, Legal and Ethical Issues in the Determination of Death*, p. 46 (U.S. Govt. P.O. 1981.)

The approach taken in this act is unique in its response to the recognition that legal adoption of neurological criteria for the declaration of death poses special challenges to the well-established and long-accepted beliefs and practices of some of New Jersey's diverse and pluralistic populace. Some of these individuals are members of communities whose religious traditions identify life with continued respiratory activity, even if that activity is artificially supported. The question is whether continued application of long-established traditional standards for determining death to those holding such personal religious beliefs would be so antithetical to the public order as to require the profound beliefs of those individuals to be disregarded. The act is predicated on a deep conviction that the societal need for uniformity in the application of neurological criteria is not so absolute as to preclude reasonable efforts to accommodate the important and constitutionally-valued religious beliefs of those who desire that their deaths be declared solely in accordance with long-accepted traditional criteria of the irreversible cessation of cardio-respiratory functions. It is important to recognize that the act does not accept any "novel" or "individually determined" standard for the declaration of death; rather, for some New Jersey citizens it merely assures application of the traditionally recognized criteria out of respect for their religious beliefs.

Implementation of the religious exemption. Section 5 provides that the exemption applies to situations in which the patient's religious beliefs have actually been communicated to the physician authorized to declare death, giving the physician "reason to believe" that the patient's religious beliefs would be violated by a declaration of death on the basis of neurological criteria.

The act places initial responsibility with the patient and/or family, or others who may be knowledgeable about the patient's religious beliefs, such as a personal physician, religious leader or close friend, to provide information about the patient's religious beliefs regarding the declaration of death. Those who on religious grounds do not accept neurological criteria for determination of death may choose to document their wishes in advance, such as in an advance directive or similar written document. The advance directive forms developed by the

Bioethics Commission are expressly designed to allow those with such religious objections to make their wishes known. Religious communities may choose to develop sample forms for use by their members, and may wish to maintain their own registries for consultation in time of need. A written statement of the patient's religious beliefs, however, is not required by the act. Oral statements about the patient's beliefs from family members, religious leaders or others with knowledge of the patient's religious beliefs on this issue are sufficient to invoke the exemption. Absolute certainty of the patient's religious beliefs is not required. A claim of exemption has been reasonably advanced on the patient's behalf and should be respected when available sources of information about the individual's religious beliefs appear to be trustworthy and reliable, and provide a reasonable basis for concluding that the declaration of death upon the basis of neurological criteria would indeed violate the patient's personal religious beliefs.

In this regard, it should be noted that declarations of death on the basis of neurological criteria rarely require action on an emergency basis. Medical protocols require a repeated clinical examination following a waiting period, during which time efforts may proceed to determine whether the individual would object to such a declaration. While section 5 provides that information about the patient's religious beliefs is to be communicated to the physician authorized to declare death, the act contemplates that conversations with the family may also be carried out by another responsible health care provider, such as a nurse, social worker, or other person experienced in bereavement counseling. Review of available medical records, which should include a copy of the patient's advance directive (if any), should be standard practice.

Recognizing the difficult and sensitive nature of conversations in such circumstances, the act affords a great deal of flexibility and discretion to those responsible for the patient's care. The act does not require a formal "informed consent" to the declaration of death; nor does it require that families receive detailed or legalistic recitations of the exemption established by the act. The conversation should be structured in a manner appropriate to the circumstances and the sensibilities of the family. Greater detail will be appropriate when information from family members or others revealed in the course of conversation suggests that there may be reason to believe that the exemption is potentially applicable. It is important to emphasize that the central question is the beliefs of the patient, not those of the family member or others speaking on behalf of the patient. Family members and others should clearly understand that they are being asked about the beliefs of the patient; they are not being asked for their own consent to declaring the patient dead or to withdrawing life-sustaining treatments.

When the physician authorized to declare death has reason to believe, based upon the available information about the patient's religious beliefs, that a

declaration of death on the basis of neurological criteria would violate that individual's religious beliefs, the physician is required to refrain from declaring the patient dead on the basis of neurological criteria. Life-support mechanisms used to maintain the individual's circulatory and respiratory functions (such as a respirator) are not to be discontinued solely on the ground of the individual's neurological status. Thus, physicians and other health care providers responsible for the individual's care should generally continue to provide cardio-respiratory support until it is determined, in accordance with currently accepted medical standards, that irreversible cessation of all circulatory and respiratory functions has occurred, and that death should be declared in accordance with the traditional cardio-respiratory criteria recognized by section 2.

While the act is not intended to establish priorities for allocation of scarce medical technologies in situations of emergency or triage, neither is it intended to preclude the application of existing decisionmaking processes generally applicable in emergency settings, insofar as such decisions might apply to any irreversibly comatose, terminally ill patients, regardless of whether they meet "brain death" criteria.

Section 6: Immunities

A licensed health care practitioner, hospital, or the health care provider who acts in good faith and in accordance with currently accepted medical standards to execute the provisions of this act and any rules and regulations issued by the Department of Health or the Board of Medical Examiners pursuant to this act, shall not be subject to criminal or civil liability or to discipline for unprofessional conduct with respect to those actions. These immunities shall extend to conduct in conformity with the provisions of this act following enactment of this act but prior to its effective date.

Comment

Section 6 provides a good faith immunity for health care professionals and institutions who act in accordance with accepted medical standards to carry out the provisions of the act and any rules and regulations issued pursuant to the act. Immunity extends to physicians, nurses, hospitals and other health care providers, and applies to criminal or civil liability and to discipline for unprofessional conduct. This section does not absolve from liability or from professional discipline those whose actions are contrary to accepted professional standards or the requirements of the act.

This section is intended to make clear to physicians, hospitals and other health care providers that non-negligent actions undertaken in compliance with the act are insulated from potential liability. Physicians should be confident that they may exercise sound professional judgment in making declarations of death in accordance with the requirements of this act and good medical practice. This statutory grant of immunity is intended to calm existing concerns of unfounded and burdensome entanglements in legal proceedings, and to obviate any perceived need to seek advance approvals from committees or courts prior to making a declaration of death in accordance with the provisions of the act.

These immunities are intended to become immediately effective upon the enactment of this act, and to apply to conduct in accordance with the requirements of the act and currently applicable law.

Section 7: Effect on Insurance and Health Benefits

Changes in pre-existing criteria for the declaration of death effectuated by the legal recognition of modern neurological criteria shall not in any manner affect, impair or modify the terms of, or rights or obligations created under, any existing policy of health insurance, life insurance or annuity, or governmental benefits program. No health care practitioner or other health care provider, and no health service plan, insurer, or governmental authority, shall deny coverage or exclude from the benefits of service any individual solely because of that individual's personal religious beliefs regarding the application of neurological criteria for declaring death.

Comment

Section 7 provides that neither the recognition of neurological criteria for the declaration of death, nor the exercise of the right of exemption from the application of neurological criteria to declare an individual's death, shall be a legally valid ground for the denial, impairment or modification of rights or obligations under the terms of existing policies of health insurance, life insurance or annuity, or any governmental benefits program. Section 7 protects the free exercise of personal religious beliefs by prohibiting health care practitioners and health care providers, health service plans, insurers, and governmental authorities from employing an individual's personal religious beliefs as a basis for the denial of coverage or for exclusion from the benefits of service. Nor can the availability of health coverage, benefits or services be conditioned upon the exercise or non-exercise of this right.

Section 8: Reporting and Monitoring

a. Pursuant to the "Administrative Procedure Act," P.L. 1968, c.410 (C.52:14B-1 *et seq.*) the Department of Health shall establish rules, regulations, policies and practices as may be necessary to collect annual reports from health care institutions, and to gather additional data as is reasonably necessary, to oversee and evaluate the implementation of this act. The department shall seek to minimize the burdens of record-keeping imposed by these rules, regulations, policies and practices, and shall seek to assure the appropriate confidentiality of patient records.

b. The Department of Health, the Board of Medical Examiners, and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care shall jointly evaluate the implementation of this act and report to the Legislature, including recommendations for any changes deemed necessary, within five years from the effective date of this act.

Comment

Given the innovative features of this act and concerns that have been expressed regarding aspects of its implementation, section 8 requires the collection of data necessary to evaluate the act's effectiveness in achieving its intended objectives and provides a mechanism for proposing any necessary changes. The Department of Health is directed to collect reports, on an annual basis, from health care institutions regarding their experience with the implementation of the act. While minimizing unnecessary paperwork, this process should provide an empirically sound basis for recognizing and correcting any difficulties, including any confusion regarding medical standards for the declaration of death upon the basis of neurological criteria or regarding the implementation of the exemption provision established by section 5.

Section 8b. provides that evaluation of the effectiveness of the act shall be undertaken jointly by the Department of Health, the Board of Medical Examiners and the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care. These three bodies are directed to report their conclusions to the New Jersey State Legislature, including recommendations for any changes that may be necessary to better achieve the objectives of the act. The initial report is to be made to the Legislature within not more than five

years from the effective date of the act. In the event serious difficulties arise, an earlier report should be made.

The requirement that the initial report be made to the Legislature within five years of the effective date of the act has no automatic effect upon the continued validity of the act; the act does not contain a formal "sunset" provision.

Section 9: Severability

If any provision of this act or its application to any individual or circumstance is held invalid, the invalidity shall not affect other provisions or applications of this act which can be given effect without the invalid provision or application, and to this end the provisions of this act are severable.

Comment

Section 9 states that should a particular provision of the act be held invalid, the other provisions that can be given effect without the invalid provision will continue to have legal force and effect. The invalidity of one provision will not invalidate the entire Declaration of Death Act. Section 9 follows widely used language enacted by a number of state legislatures and approved by the Uniform Law Commissioners in the Uniform Rights of the Terminally Ill Act (1985).

Section 10: Effective Date

This act shall take effect on the 180th day following the date of its enactment.

Comment

The New Jersey Declaration of Death Act was signed into law on April 8, 1991.

Since the act envisions a regulatory process to establish medical standards for the declaration of death on the basis of neurological criteria, time is allowed for this process to be completed and communicated to the relevant professional communities before the act becomes fully effective. However, since declarations of death on this basis are now taking place in New Jersey pursuant to court decision, it is intended that the act's immunity provisions be immediately effective with respect to conduct in conformity with the provisions of this act (including respect for the exemption provision).

§§§§§

APPENDIX

PROXY DIRECTIVE—(Durable Power of Attorney for Health Care) Designation of Health Care Representative

I understand that as a competent adult, I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction and they will turn to someone who knows my values and health care wishes. By writing this durable power of attorney for health care I appoint a health care representative with the legal authority to make health care decisions on my behalf and to consult with my physician and others. I direct that this document become part of my permanent medical records.

A) CHOOSING A HEALTH CARE REPRESENTATIVE:

I, _____, hereby designate _____,

of _____

_____.

(home address and telephone number of health care representative)

as my health care representative to make any and all health care decisions for me, including decisions to accept or to refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition and decisions to provide, withhold or withdraw life-sustaining measures. I direct my representative to make decisions on my behalf in accordance with my wishes as stated in this document, or as otherwise known to him or her. In the event my wishes are not clear, my representative is authorized to make decisions in my best interests, based on what is known of my wishes.

This durable power of attorney for health care shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations.

B) ALTERNATE REPRESENTATIVES: If the person I have designated above is unable, unwilling or unavailable to act as my health care representative, I hereby designate the following person(s) to act as my health care representative, in the order of priority stated:

1. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

2. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

C) SPECIFIC DIRECTIONS: Please initial the statement below which best expresses your wishes.

_____ My health care representative is authorized to direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion, be withheld or withdrawn.

_____ My health care representative does not have this authority, and I direct that artificially provided fluids and nutrition be provided to preserve my life, to the extent medically appropriate.

(If you have any additional specific instructions concerning your care you may use the space below or attach an additional statement.)

_____

_____

_____

_____

D) COPIES: The original or a copy of this document has been given to my health care representative and to the following:

1. *name* _____
   address _____
   city _____ *state* _____ *telephone* _____
2. *name* _____
   address _____
   city _____ *state* _____ *telephone* _____

E) SIGNATURE: By writing this durable power of attorney for health care, I inform those who may become entrusted with my care of my health care wishes and intend to ease the burdens of decisionmaking which this responsibility may impose. I have discussed the terms of this designation with my health care representative and he or she has willingly agreed to accept the responsibility for acting on my behalf in accordance with my wishes as expressed in this document. I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this _____ **day of** _____, **19**____.

signature _____

address _____

city _____ *state* _____

F) WITNESSES: I declare that the person who signed this document, or asked another to sign this document on his or her behalf, did so in my presence, that he or she is personally known to me, and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, and am not designated by this or any other document as the person's health care representative, nor as an alternate health care representative.

1. *witness* _____
   address _____
   city _____ *state* _____
   signature _____
   date _____

2. *witness* _____
   address _____
   city _____ *state* _____
   signature _____
   date _____

COMBINED ADVANCE DIRECTIVE FOR HEALTH CARE

[Combined Proxy and Instruction Directive]

I understand that as a competent adult I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction concerning my care and will turn to someone who knows my values and health care wishes. I understand that those responsible for my care will seek to make health care decisions in my best interests, based upon what they know of my wishes. In order to provide the guidance and authority needed to make decisions on my behalf:

I,_____ hereby declare and make known my instructions and wishes for my future health care. This advance directive for health care shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations. I direct that this document become part of my permanent medical records.

In completing Part One of this directive, you will designate an individual you trust to act as your legally recognized health care representative to make health care decisions for you in the event you are unable to make decisions for yourself.

In completing Part Two of this directive, you will provide instructions concerning your health care preferences and wishes to your health care representative and others who will be entrusted with responsibility for your care, such as your physician, family members and friends.

Part One: Designation of a Health Care Representative

A) CHOOSING A HEALTH CARE REPRESENTATIVE:

I hereby designate:

name _____

address _____

city _____ *state* _____

telephone _____

as my health care representative to make any and all health care decisions for me, including decisions to accept or to refuse any treatment, service or procedure used to diagnose or treat my physical or mental condition, and decisions to provide, withhold or withdraw life-sustaining measures. I direct my representative to make decisions on my behalf in accordance with my wishes as stated in this document, or as otherwise known to him or her. In the event my wishes are not clear, or a situation arises I did not anticipate, my health care representative is authorized to make decisions in my best interests, based upon what is known of my wishes.

I have discussed the terms of this designation with my health care representative and he or she has willingly agreed to accept the responsibility for acting on my behalf.

B) ALTERNATE REPRESENTATIVES: If the person I have designated above is unable, unwilling or unavailable to act as my health care representative, I hereby designate the following person(s) to act as my health care representative, in the order of priority stated:

1. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

2. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

Part Two: Instruction Directive

In Part Two, you are asked to provide instructions concerning your future health care. This will require making important and perhaps difficult choices. Before completing your directive, you should discuss these matters with your health care representative, doctor, family members or others who may become responsible for your care.

In **Sections C and D,** *you may state the circumstances in which various forms of medical treatment, including life-sustaining measures, should be provided, withheld or discontinued. If the options and choices below do not fully express your wishes, you should use* **Section E,** *and/or attach a statement to this document which would provide those responsible for your care with additional information you think would help them in making decisions about your medical treatment.* **Please familiarize yourself with all sections of Part Two before completing your directive.**

C) GENERAL INSTRUCTIONS. To inform those responsible for my care of my specific wishes, I make the following statement of personal views regarding my health care:

Initial ONE of the following two statements with which you agree:

1. _____ I direct that all medically appropriate measures be provided to sustain my life, regardless of my physical or mental condition.

2. _____ There are circumstances in which I would not want my life to be prolonged by further medical treatment. In these circumstances, life-sustaining measures should not be initiated and if they have been, they should be discontinued. I recognize that this is likely to hasten my death. In the following, I specify the circumstances in which I would choose to forego life-sustaining measures.

If you have initialed statement 2, on the following page please initial each of the statements (a, b, c) with which you agree:

a. _____ I realize that there may come a time when I am diagnosed as having an incurable and irreversible illness, disease, or condition. If this occurs, and my attending physician and at least one additional physician who has personally examined me determine that my condition is **terminal**, I direct that life-sustaining measures which would serve only to artificially prolong my dying be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to make me comfortable and to relieve pain.

In the space provided, write in the bracketed phrase with which you agree:

To me, terminal condition means that my physicians have determined that:

_____

[I will die within a few days] [I will die within a few weeks]
[I have a life expectancy of approximately or less *(enter 6 months, or 1 year)*]

b. _____ If there should come a time when I become **permanently unconscious**, and it is determined by my attending physician and at least one additional physician with appropriate expertise who has personally examined me, that I have totally and irreversibly lost consciousness and my capacity for interaction with other people and my surroundings, I direct that life-sustaining measures be withheld or discontinued. I understand that I will not experience pain or discomfort in this condition, and I direct that I be given all medically appropriate care necessary to provide for my personal hygiene and dignity.

c. _____ I realize that there may come a time when I am diagnosed as having an **incurable and irreversible** illness, disease, or condition which may not be terminal. My condition may cause me to experience severe and progressive physical or mental deterioration and/or a permanent loss of capacities and faculties I value highly. If, in the course of my medical care, the burdens of continued life with treatment become greater than the benefits I experience, I direct that life-sustaining measures be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to make me comfortable and to relieve pain.

(Paragraph **c.** *covers a wide range of possible situations in which you may have experienced partial or complete loss of certain mental and physical capacities you value highly. If you wish, in the space provided below you may specify in more detail the conditions in which you would choose to forego life-sustaining measures. You might include a description of the faculties or capacities, which, if irretrievably lost, would lead you to accept death rather than continue living. You may want to express any special concerns you have about particular medical conditions or treatments, or any other considerations which would provide further guidance to those who may become responsible for your care. If necessary, you may attach a separate statement to this document or use* **Section E** *to provide additional instructions.)*

Examples of conditions which I find unacceptable are:

_____

_____

_____

_____

D) SPECIFIC INSTRUCTIONS: Artificially Provided Fluids and Nutrition; Cardiopulmonary Resuscitation (CPR). *On page 3 you provided general instructions regarding life-sustaining measures. Here you are asked to give specific instructions regarding two types of life-sustaining measures—artificially provided fluids and nutrition and cardiopulmonary resuscitation.*

In the space provided, write in the bracketed phrase with which you agree:

1. In the circumstances I initialled on page 3, I also direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion,

_____

[be withheld or withdrawn and that I be allowed to die]
[be provided to the extent medically appropriate]

2. In the circumstances I initialled on page 3, if I should suffer a cardiac arrest, I also direct that cardiopulmonary resuscitation (CPR)

_____

[not be provided and that I be allowed to die]
[be provided to preserve my life, unless medically inappropriate or futile]

3. If neither of the above statements adequately expresses your wishes concerning artificially provided fluids and nutrition or CPR, please explain your wishes below.

_____

_____

_____

E) ADDITIONAL INSTRUCTIONS: *(You should provide any additional information about your health care preferences which is important to you and which may help those concerned with your care to implement your wishes. You may wish to direct your health care representative, family members, or your health care providers to consult with others, or you may wish to direct that your care be provided by a particular physician, hospital, nursing home, or at home. If you are or believe you may become pregnant, you may wish to state specific instructions. If you need more space than is provided here you may attach an additional statement to this directive.)*

_____

_____

_____

F) BRAIN DEATH: *(The State of New Jersey recognizes the irreversible cessation of all functions of the entire brain, including the brain stem (also known as whole brain death), as a legal standard for the declaration of death. However, individuals who cannot accept this standard because of their personal religious beliefs may request that it not be applied in determining their death.)*

Initial the following statement only if it applies to you:

_____ To declare my death on the basis of the whole brain death standard would violate my personal religious beliefs. I therefore wish my death to be declared solely on the basis of the traditional criteria of irreversible cessation of cardiopulmonary (heartbeat and breathing) function.

G) AFTER DEATH—ANATOMICAL GIFTS: *(It is now possible to transplant human organs and tissue in order to save and improve the lives of others. Organs, tissues and other body parts are also used for therapy, medical research and education. This section allows you to indicate your desire to make an anatomical gift and if so, to provide instructions for any limitations or special uses.)*

Initial the statements which express your wishes:

1. _____ **I wish** to make the following anatomical gift to take effect upon my death:

   A. _____ any needed organs or body parts

   B. _____ only the following organs or parts

   _____

for the purposes of transplantation, therapy, medical research or education, or

   C. _____ my body for anatomical study, if needed.

   D. _____ special limitations, if any:

   _____

If you wish to provide additional instructions, such as indicating your preference that your organs be given to a specific person or institution, or be used for a specific purpose, please do so in the space provided below.

_____

_____

_____

2. _____ **I do not wish** to make an anatomical gift upon my death.

Part Three: Signature and Witnesses

H) COPIES: The original or a copy of this document has been given to the following people *(NOTE: If you have chosen to designate a health care representative, it is important that you provide him or her with a copy of your directive.)*:

1. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

2. *name* _____
   address _____
   city _____ *state* _____
   telephone _____

I) SIGNATURE: By writing this advance directive, I inform those who may become entrusted with my health care of my wishes and intend to ease the burdens of decisionmaking which this responsibility may impose. I have discussed the terms of this designation with my health care representative and he or she has willingly agreed to accept the responsibility for acting on my behalf in accordance with this directive. I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this _____ day of _____, 19____.

signature _____

address _____

city _____ *state* _____

J) WITNESSES: I declare that the person who signed this document, or asked another to sign this document on his or her behalf, did so in my presence, that he or she is personally known to me, and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, and am not designated by this or any other document as the person's health care representative, nor as an alternate health care representative.

1. *witness* _____
   address _____
   city _____ *state* _____
   signature _____
   date _____

2. *witness* _____
   address _____
   city _____ *state* _____
   signature _____
   date _____

New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care (The New Jersey Bioethics Commission) March 1991

The New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care

INSTRUCTION DIRECTIVE

I understand that as a competent adult I have the right to make decisions about my health care. There may come a time when I am unable, due to physical or mental incapacity, to make my own health care decisions. In these circumstances, those caring for me will need direction concerning my care and they will require information about my values and health care wishes. In order to provide the guidance and authority needed to make decisions on my behalf:

A) I,_____, hereby declare and make known to my family, physician, and others, my instructions and wishes for my future health care. I direct that all health care decisions, including decisions to accept or refuse any treatment, service or procedure used to diagnose, treat or care for my physical or mental condition and decisions to provide, withhold or withdraw life-sustaining measures, be made in accordance with my wishes as expressed in this document. This instruction directive shall take effect in the event I become unable to make my own health care decisions, as determined by the physician who has primary responsibility for my care, and any necessary confirming determinations. I direct that this document become part of my permanent medical records.

Part One: Statement of My Wishes Concerning My Future Health Care

In ***Part One,*** *you are asked to provide instructions concerning your future health care. This will require making important and perhaps difficult choices. Before completing your directive, you should discuss these matters with your doctor, family members or others who may become responsible for your care.*

In **Sections B and C,** *you may state the circumstances in which various forms of medical treatment, including life-sustaining measures, should be provided, withheld or discontinued. If the options and choices below do not fully express your wishes, you should use* **Section D,** *and/or attach a statement to this document which would provide those responsible for your care with additional information you think would help them in making decisions about your medical treatment.* **Please familiarize yourself with all sections of Part One before completing your directive.**

B) GENERAL INSTRUCTIONS. To inform those responsible for my care of my specific wishes, I make the following statement of personal views regarding my health care:

Initial ONE of the following two statements with which you agree:

1. _____ I direct that all medically appropriate measures be provided to sustain my life, regardless of my physical or mental condition.

2. _____ There are circumstances in which I would not want my life to be prolonged by further medical treatment. In these circumstances, life-sustaining measures should not be initiated and if they have been, they should be discontinued. I recognize that this is likely to hasten my death. In the following, I specify the circumstances in which I would choose to forego life-sustaining measures.

If you have initialed statement 2 on page 1, please initial each of the statements (a, b, c) with which you agree:

a. _____ I realize that there may come a time when I am diagnosed as having an incurable and irreversible illness, disease, or condition. If this occurs, and my attending physician and at least one additional physician who has personally examined me determine that my condition is **terminal**, I direct that life-sustaining measures which would serve only to artificially prolong my dying be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to make me comfortable and to relieve pain.

In the space provided, write in the bracketed phrase with which you agree:

To me, terminal condition means that my physicians have determined that:

_____

[I will die within a few days] **[I will die within a few weeks]**
[I have a life expectancy of approximately **or less** *(enter 6 months, or 1 year)*]

b. _____ If there should come a time when I become **permanently unconscious**, and it is determined by my attending physician and at least one additional physician with appropriate expertise who has personally examined me, that I have totally and irreversibly lost consciousness and my capacity for interaction with other people and my surroundings, I direct that life-sustaining measures be withheld or discontinued. I understand that I will not experience pain or discomfort in this condition, and I direct that I be given all medically appropriate care necessary to provide for my personal hygiene and dignity.

c. _____ I realize that there may come a time when I am diagnosed as having an **incurable and irreversible** illness, disease, or condition which may not be terminal. My condition may cause me to experience severe and progressive physical or mental deterioration and/or a permanent loss of capacities and faculties I value highly. If, in the course of my medical care, the burdens of continued life with treatment become greater than the benefits I experience, I direct that life-sustaining measures be withheld or discontinued. I also direct that I be given all medically appropriate care necessary to make me comfortable and to relieve pain.

*(Paragraph **c.** covers a wide range of possible situations in which you may have experienced partial or complete loss of certain mental and physical capacities you value highly. If you wish, in the space provided below you may specify in more detail the conditions in which you would choose to forego life-sustaining measures. You might include a description of the faculties or capacities, which, if irretrievably lost, would lead you to accept death rather than continue living. You may want to express any special concerns you have about particular medical conditions or treatments, or any other considerations which would provide further guidance to those who may become responsible for your care. If necessary, you may attach a separate statement to this document or use **Section D** to provide additional instructions.)*

Examples of conditions which I find unacceptable are:

_____

_____

_____

_____

C) SPECIFIC INSTRUCTIONS: Artificially Provided Fluids and Nutrition; Cardiopulmonary Resuscitation (CPR). *On page 2 you provided general instructions regarding life-sustaining measures. Here you are asked to give specific instructions regarding two types of life-sustaining measures—artificially provided fluids and nutrition and cardiopulmonary resuscitation.*

In the space provided, write in the bracketed phrase with which you agree:

1. In the circumstances I initialled on page 2, I also direct that artificially provided fluids and nutrition, such as by feeding tube or intravenous infusion,

_____

[be withheld or withdrawn and that I be allowed to die]
[be provided to the extent medically appropriate]

2. In the circumstances I initialled on page 2, if I should suffer a cardiac arrest, I also direct that cardiopulmonary resuscitation (CPR)

_____

[not be provided and that I be allowed to die]
[be provided to preserve my life, unless medically inappropriate or futile]

3. If neither of the above statements adequately expresses your wishes concerning artificially provided fluids and nutrition or CPR, please explain your wishes below.

_____

_____

_____

D) ADDITIONAL INSTRUCTIONS: *(You should provide any additional information about your health care preferences which is important to you and which may help those concerned with your care to implement your wishes. You may wish to direct family members or your health care providers to consult with others, or you may wish to direct that your care be provided by a particular physician, hospital, nursing home, or at home. If you are or believe you may become pregnant, you may wish to state specific instructions. If you need more space than is provided here you may attach an additional statement to this directive.)*

_____

_____

_____

E) BRAIN DEATH: *(The State of New Jersey recognizes the irreversible cessation of all functions of the entire brain, including the brain stem (also known as whole brain death), as a legal standard for the declaration of death. However, individuals who cannot accept this standard because of their personal religious beliefs may request that it not be applied in determining their death.)*

Initial the following statement only if it applies to you:

_____ To declare my death on the basis of the whole brain death standard would violate my personal religious beliefs. I therefore wish my death to be declared solely on the basis of the traditional criteria of irreversible cessation of cardiopulmonary (heartbeat and breathing) function.

F) AFTER DEATH—ANATOMICAL GIFTS: *(It is now possible to transplant human organs and tissue in order to save and improve the lives of others. Organs, tissues and other body parts are also used for therapy, medical research and education. This section allows you to indicate your desire to make an anatomical gift and if so, to provide instructions for any limitations or special uses.)*

Initial the statements which express your wishes:

1. _____ **I wish** to make the following anatomical gift to take effect upon my death:

   A. _____ any needed organs or body parts

   B. _____ only the following organs or parts

_____

for the purposes of transplantation, therapy, medical research or education, or

   C. _____ my body for anatomical study, if needed.

   D. _____ special limitations, if any:

_____

If you wish to provide additional instructions, such as indicating your preference that your organs be given to a specific person or institution, or be used for a specific purpose, please do so in the space provided below.

_____

_____

_____

2. _____ **I do not wish** to make an anatomical gift upon my death.

Part Two: Signature and Witnesses

G) COPIES: The original or a copy of this document has been given to the following people *(NOTE: It is important that you provide a family member, friend or your physician with a copy of your directive.):*

1. *name* _____

   address _____

   city _____ *state* _____

   telephone _____

2. *name* _____

   address _____

   city _____ *state* _____

   telephone _____

H) SIGNATURE: By writing this instruction directive, I inform those who may become entrusted with my health care of my wishes and intend to ease the burdens of decisionmaking which this responsibility may impose. I understand the purpose and effect of this document and sign it knowingly, voluntarily and after careful deliberation.

Signed this _____ day of _____, 19____.

signature _____

address _____

city _____ *state* _____

I) WITNESSES: I declare that the person who signed this document, or asked another to sign this document on his or her behalf, did so in my presence, that he or she is personally known to me, and that he or she appears to be of sound mind and free of duress or undue influence. I am 18 years of age or older, and am not designated by this or any other document as the person's health care representative, nor as an alternate health care representative.

1. *witness* _____
   address _____
   city _____ *state* _____
   signature _____
   date _____

2. *witness* _____
   address _____
   city _____ *state* _____
   signature _____
   date _____

Death and the Brain Damaged Patient

prepared for the New Jersey Commission on Legal and Ethical Problems in the Delivery of Health Care by Jerry M. Belsh, M.D., Robert Wood Johnson Medical School

Most of us have heard the term brain death. And, unfortunately, some of us have known relatives or friends who have been declared brain-dead. However, the meaning of the term and its relationship to our traditional understanding of death may be unclear. The purpose of this pamphlet is to explain in lay terms the concept of brain death and how this concept influences the activities of physicians in treating severely brain-damaged patients and declaring death.

Since earliest times, death was determined when a patient's breathing and heartbeat permanently stopped. And, in the era prior to mechanical ventilators and other life-support systems, death was usually quite clear to doctor and family. If a person stopped breathing or his heart stopped beating it was certain that his entire cardiac, respiratory and brain functions would come to a halt. When these organs stopped functioning, the entire body would begin a process of disintegration and decay, thus reassuring physicians that the person was indeed dead.

In today's modern hospital, technological advances in life-support systems have become commonplace, resulting in advances in patient care unheard of just a short time ago. Mechanical ventilators, cardiac pacemakers, medication to support circulation and heart function, and mechanical or transplanted organs have all contributed to our ability to prolong life. However, the use of this same technology has resulted in situations where patients have lost major signs of life (such as brain function), while other presumed signs of life (heartbeat and breathing) are being artificially maintained. Patients may suffer total and irreversible loss of all brain functions as a result of hemorrhage, trauma, tumor, or lack of oxygen related to cardio-pulmonary arrest. Yet, emergency and intensive care personnel can often maintain or re-establish heartbeat and breathing with the help of technological support despite the absence of brain functions. In cases like these, physicians realized that the determination of death was not as clear-cut as it had been in the years prior to mechanical ventilators. Such cases caused the medical, legal and religious communities to re-evaluate and more precisely define how death is determined.

Over the last 25 years the dilemma of how to deal with these unfortunate cases has largely been resolved. Beginning with the report on brain death by a distinguished Harvard Medical School committee (1968) and proceeding with the guidelines on determination of death issued by the consultants to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behaviorial Research (1981), widespread national

agreement has evolved among medical and legal experts concerning determination of death in the brain-damaged patient. These experts agree that the total and irreversible absence of all functions of the entire brain means death of the individual, even if mechanical support systems can sustain the heart and lungs.

Questions & Answers About Brain Death

1. What is brain death?

The term brain death, first used in 1968, means that a human's brain has permanently stopped functioning while the heart is kept beating with the aid of machines and drugs. It is used to describe the death of a patient due to total and irreversible destruction of all functions of the entire brain. Death is determined this way only when a patient's respiratory and circulatory systems are being artificially maintained in an intensive care unit. For such a patient the brain death standard is used to determine death.

2. Is the death in the term "brain death" the same as traditional cardiopulmonary death (*i.e.*, death when heartbeat and breathing stop?)

Yes. Death is generally considered an event where functioning of the human being or "organism as a whole" has permanently ceased. Once death occurs an individual can no longer integrate the various organ systems of the body nor respond to his or her internal or external environment. These functions are controlled by the brain, the critical organ which, unlike the heart or lungs, can never be replaced. For these reasons death is the same whether it is determined by neurological testing of brain function (as with brain-damaged patients on ventilators) or by bedside testing of cardiopulmonary function (as with all other patients). Once the cardiopulmonary system--whether artificially supported or not--has permanently ceased to function, the brain no longer receives oxygenated blood and likewise ceases to function. In both situations (cessation of brain functioning despite heartbeat and the more common cessation of cardiopulmonary functioning), the result is death of the human organism. When death is declared according to neurological criteria all life-support measures are ordinarily discontinued. (*But see* questions 9 & 10.)

3. What functions of the brain cease with brain death?

All functions of the brain have permanently ceased when the patient is determined dead. This includes functions of both the cerebral hemispheres ("upper brain") and of the diencephalon and brainstem ("lower brain"). Functions of the upper brain include cognition, memory, voluntary control of movement, and capacity for experiencing emotions and pain. Functions of the

lower brain include breathing, circulation, temperature control, and integration of organ systems. The brainstem also controls eye and facial movements, chewing, yawning, swallowing, and several other "brainstem reflex" movements. Consciousness is controlled by the interaction of the cerebral hemispheres with the diencephalon and brainstem.

4. What tests are utilized to determine if a patient is brain dead?

Prior to testing a patient for brain death potentially reversible medical conditions such as drug intoxication, low blood pressure, or extremely low body temperature must be searched for and either treated or ruled out. Once these conditions have been eliminated, testing for brain death is then appropriate. Over the years, a set of tests has been developed which reliably determines that all brain functions have irreversibly ceased. Although there may be some minor variations among hospitals and physicians, all testing requires demonstration of the following: (1) the patient must be completely and persistently unresponsive; (2) brainstem reflexes (*e.g.*, eye response to light, gag response to tracheal suctioning) must be absent; and (3) there must be no spontaneous breathing. These sets of tests must be administered twice. The period of time between testing varies depending on the suspected cause of the injury and other factors.

In addition, in some cases laboratory tests to confirm the absence of brain functions may be necessary. This lab test is usually either an electro-encephalogram (EEG) or a cerebral blood flow study. The EEG records brain activity on paper when the brain is functioning; the EEG is essentially flat when the brain is not functioning. The cerebral blood flow test measures blood flow to the brain and will record essentially no flow when the brain has ceased functioning.

5. How reliable are these tests?

Based on extensive medical experience over nearly 20 years, these tests have proven to be totally reliable in identifying the brain-dead patient and only the brain-dead patient. In the words of one expert, "the validity of the criteria [*i.e.*, brain death tests] must be considered to be established with as much certainty as is possible in biology or medicine."

6. What is coma?

Coma is a state where the patient appears to be sleeping but cannot be aroused to open the eyes or perform any purposeful movements. Coma is usually caused by a severe abnormality of the brain caused by disease or injury. Depending on the extent and severity of brain damage, the patient may or may never recover or "wake up". Because individuals determined to be brain dead according to the tests described above have permanently lost all functions of the entire brain, they cannot wake up. These individuals are not in a coma but, in fact, are dead.

7. What is persistent vegetative state?

The term persistent vegetative state ("PVS") describes the condition of a patient who has lost all functions of the cerebral hemispheres or upper brain (*e.g.*, cognition, memory, ability to experience pain and emotion) but maintains all or some functions of the brainstem (*e.g.*, breathing, eye opening, chewing). Such patients may appear to be awake, but they are not aware of and do not interact in any meaningful way with their environment. Although prognosis for any recovery of cognition is excluded by this diagnosis, these patients exhibit some signs of brain functioning and are certainly not dead. With the help of excellent nursing and medical care, patients can be sustained in this condition for many years.

8. Are there laws concerning brain death?

As of April 1991, all 50 states recognize by law that a patient may be determined dead based on neurological testing for brain death. Brain death standards have been widely accepted by the medical community across the nation for many years. Guidelines for brain death determination in New Jersey are established by regulations issued by the Board of Medical Examiners and the Department of Health. These guidelines are based on those published in 1981 by the distinguished President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behaviorial Research.

9. What is the stance of the major religions regarding brain death?

Most religious traditions recognize that irreversible cessation of total brain functioning (*i.e.*, brain death) indicates death of the human being. Some traditions do not recognize brain death criteria and continue to rely on the traditional criteria of cessation of heartbeat and breathing in determining death. Family members are encouraged to discuss religious aspects of death determination with the patient's physician, a member of the clergy or hospital chaplain.

10. What happens if the patient's religious beliefs do not recognize brain death?

New Jersey law recognizes an exemption from the application of the brain death standard if a declaration of death on this basis would violate the patient's personal religious beliefs. In these circumstances life-support mechanisms should be continued until death is determined according to the traditional standard of permanent cessation of hearthbeat and breathing. Individuals, or the family members and friends of patients who for religious reasons do not accept brain death, should clearly communicate this fact to the attending physician or other health care provider. A person may also wish to document his or her religious

beliefs regarding brain death in an advance directive for health care which can then be attached to the patient's medical records when entering the hospital.

11. How are the topics of brain death and organ transplantation related?

Transplantation of a viable heart, kidney, lung, liver, or pancreas into a sick patient is often the only way of providing a renewed and healthy life to that patient. The major and sometimes only source of such transplantable organs are patients who are determined dead by neurological testing, although not all brain dead patients are suitable organ donors. It should be absolutely clear that no organs can be removed from such a patient unless (1) the patient meets all accepted medical criteria for brain death; and (2) the patient indicated a desire when living to make an organ donation upon his or her death such as by completing an organ donor form, *or*, in the absence of patient consent, there is informed consent by the family. If the patient's prior oral or written expressions indicate an objection to donating his or her organs, then no organs can be removed. Further information on organ donation can be obtained from your local hospital or the State Department of Health.

Commission Publications

Single copies of the following publications are available for the cost of postage and handling. For information on obtaining multiple copies please write to the Commission.

- *The New Jersey Advance Directives for Health Care and Declaration of Death Acts: Statutes, Commentaries and Analyses*. November 1991. $3.00 per copy.
- *Advance Directives for Health Care: Planning Ahead for Important Health Care Decisions*. March 1991. For a single copy send a 9 X 12 inch self-addressed stamped envelope with $1.00 postage.
- *Problems and Approaches in Health Care Decisionmaking: The New Jersey Experience*. May 1990. $5.00 per copy, single copies only.
- *The New Jersey Advance Directives for Health Care Act: A Guidebook for Health Care Professionals*. Available January 1992. $2.00 per copy.

Please send a check or money order payable to the Treasurer, State of New Jersey to:

The New Jersey Bioethics Commission
CN-061
Trenton, New Jersey 08625

Declaration of Death Acts

The New Jersey Commission
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in the Delivery of Health Care

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