



# BIO-ETHICS

## PROGRAM/CASE STUDY

CASE STUDY IV - WINTER, 1991

### THE LIVING WILL/MEDICAL DIRECTIVES

The modern march of medical technology is familiar to most of us, and, as you are aware, has raised a wide variety of questions regarding the proper end of life. Recent Supreme Court and State court decisions have raised the issue of the so-called "Living Will," to prime importance. Case IV examines a variety of approaches to this issue. Papers by Dr. Walter Jacob and Rabbi Bernard Zlotowitz outline the issue and provide us with textual foundations upon which to base further discussion. The Committee has also included statements from other branches of contemporary Judaism.

In December 1990, The Bioethics Committee met to consider a resolution on the Living Will. Written by Jerome B. Apfel, Esq., of Philadelphia, the resolution was discussed and edited by the Bioethics Committee and will be presented to the UAHC Biennial in the fall of 1991. That draft is included in this case study.

Additional sermonic and programmatic material are also included in the hope that your congregation can begin a full study of the issues relevant to the creating of what may more properly be called advanced medical directives.

The Bioethics Committee, in conjunction with the Caring Community Committee, is preparing a larger volume for personal use which will be ready by the November 1991 UAHC Convention. That volume will allow each family to list important life items (location of policies, wills, funeral requests, etc.) as well as having a section on advanced directives and durable power of attorney. It is hoped that each congregation will develop meaningful educational programming in these most important areas in order to make difficult times a little easier.

B'shalom,

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Question: What is the Jewish attitude toward a "living will"? (L. Roseman, Norcross, GA).

Answer: The "living will" provides a legal method in some thirty-seven states for terminating life support systems in the case of individuals who are dying because of serious illness or accident. The pain of family members or friends in comas over long periods of time and in a "persistent vegetative state" while attached to life preserving machinery has led to the consideration of such documents. At that juncture often no one will agree on what should be done. In some occasions the courts have intervened; in others eventually a family member or physician intervenes, but at the risk of subsequent legal action.

Those who wish to spare their family from this agonizing decision may decide on a "living will", a form frequently used with a proxy designation statement reads as follows:

Living Will Declaration

To My Family, Physician  
and Medical Facility

I,....., being of sound mind, voluntarily make known my desire that my dying shall not be artificially prolonged under the following circumstances:

If I should have an injury, disease or illness regarded by my physician as incurable and terminal, and if my physician determines that the application of life-sustaining procedures would serve only to prolong artificially the dying process, I direct that such procedures be withheld or withdrawn and that I be permitted to die. I want

treatment limited to those measures that will provide me with maximum comfort and freedom from pain. Should I become unable to participate in decisions with respect to my medical treatment, it is my intention that these directions be honored by my family and physicians) as a final expression of my legal right to refuse medical treatment, and I accept the consequences of this refusal.

Signed.....Date.....  
Witness.....Witness.....

Designation Clause (optional\*)

Should I become comatose, incompetent or otherwise mentally or physically incapable of communication, I authorize.....  
presently residing at.....  
to make treatment decisions on my behalf in accordance with my Living Will Declaration. I have discussed my wishes concerning terminal care with this person, and I trust his/her judgment on my behalf.

Signed.....Date.....  
Witness.....Witness.....

\*If I have not designated a proxy as provided above, I understand that my Living Will Declaration shall nevertheless be give effect should the appropriate circumstances arise.

The various statutes specifically exclude chronic debilitating diseases such as Alzheimers which are not life threatening and attempt to deal with other problems as well.

This approach raises many questions about traditional and modern Jewish perceptions of life and death. Is this akin to suicide or euthanasia? Suicide has always been considered a major sin (A.Z.18a; Semahot 2.2; Shulhan Arukh Yoreh Deah 345.2) and even its contemplation

was considered wrong. We have also felt that euthanasia is not consistent with our tradition (W. Jacob, ed, American Reform Responsa, #78, #79). We may see from the arguments presented in these two responsa that nothing positive may be done to encourage death, however, the "Living Will" is not euthanasia, but an instrument of antidysthanonic. Our tradition has felt that a goses (dying person) should also not be kept from dying after all hope for recovery is past, and so the Sefer Hassidim stated that if the steady rhythm of someone chopping wood is keeping a goses alive the wood chopping should be stopped (#723; Isserles to Shulhan Arukh Yoreh Deah 339.1). Earlier Biblical statements made it clear that no positive acts to abbreviate life even when there was not hope were permitted (I Samuel 31.1 ff; II Samuel 1.5ff). In a later age Solomon Eger indicated that medicine should also not be used to hinder a souls departure (Comment to Shulhan Arukh Yoreh Deah 339.1). We may then safely say that at the critical juncture of life when no hope for recovery exists the soul should be allowed to drift away peacefully. We have become even more sensitive to issues of euthanasia through our own experiences with the Holocaust.

Love of life in all its forms is very much part of our tradition. Even when conditions of life are rather doubtful and when there might have serious questions about the "quality of life" we cannot encourage euthanasia (W. Jacob, Contemporary American Reform Responsa, #83) nor can we make assumptions about "the quality of life."

The modern development of medicine has brought wonderful cures and provides additional years of life even to those in advanced years. On the other hand its technology may leave us in a permanent coma or a persistent vegetative state in which we are neither alive nor dead. Suc

individuals may be completely dependent upon life support machinery. While this is acceptable during periods of recovery, we fear a permanent coma when the mind has ceased to respond and a plateau of mere physical existence has been reached.

When the Harvard criteria of death have been satisfied, life support machinery may be removed. This state of "brain dead" has been defined by an ad hoc committee of the Harvard Medical School in 1968 (Journal of the American Medical Association, vol. 205, pp. 337ff). It recommended three tests: (1) lack of response to external stimuli or to internal need; (2) absence of movement and breathing as observed by physicians over a period of at least one hour; (3) absence of elicitable reflexes; and a fourth criterion to confirm the other three, (4) a flat or isoelectric electroencephalogram. The group also suggested that this examination be repeated after an interval of twenty-four hours. Several Orthodox authorities have accepted these criteria while others have rejected them. Moses Feinstein felt that they could be accepted along with shutting off the respirator briefly in order to see whether independent breathing was continuing (Igerot Mosheh (Yoreh De-a 11 #174). Moses Tendler has gone somewhat further and has accepted the Harvard criteria (Journal of American Medical Association, vol. 238 #15, pp. 165.1ff). David Bleich (Hapardes, Tevet 5737) and Jacob Lev (Hadarom, Nisan 5731, Tishri 5730; Noam, 5.30) have vigorously rejected these criteria as they feel that life must have ceased entirely with the heart no longer functioning, a conclusion established by Hatam Sofer in the eighteenth century (Responsa Hatam Sofer Yoreh Deah #338). We can see that although the question has not been resolved by our Orthodox colleagues, some of them have certainly accepted the recommendations

the Harvard Medical School committee. We are satisfied that these criteria comply with our concern that life has ended. Therefore, when circulation and respiration only continue through mechanical means, as established by the above-mentioned tests, then the suffering of the patient and his/her family may be permitted to cease, as no "natural independent life" functions have been sustained. We would permit a physician in good conscience to cease treatment and to remove life giving support systems. The "persistent vegetative state" is more difficult as "brain death" has not yet been reached. Such an individual would be considered a gose who is considered to be a living human being in all respects (Semahot 1.1; Yad Hil Evel 4.5; Tur; Shulhan Arukh Yoreh Deah 339.1 ff.). One may desecrate the Sabbath to help him according to Jacob Reischer (Shevut Yaakov 1:13), though others (Kenesset Hagadol) disagree.

The long discussions about a gose indicate that no positive actions to hasten death may be taken, so he is not to be moved or his eyes closed, etc. As stated above there is no prohibition against diminishing pain or increasing the person's comfort or initiating new treatment which will not change the condition of the patient. Under these circumstances a "Living Will" may be helpful although we realize that we know little of the "inner life" of people in this state; we do not wish to terminate what may still be significant to them.

It would be permissible according to this point of view to help and assist those who may need to make these kinds of judgments for us in the future through a "Living Will". This may be especially important if there is no one present who can be counted on to make an appropriate decision in keeping with our verbally expressed wishes. The document

must be worded that it deals with the "persistent vegetative state" without moving toward euthanasia. The document should be sufficiently recent to assure that it reflects the welfare of the patient.

All of us wish for a reasonable exit from this world and would also like to make that period as bearable as possible for ourselves and our surviving family. The positive outlook on life which governs Judaism prohibits any drastic steps toward death but it does not insist that life continue when the person is a goses. At that point a peaceful release is permitted. The "living will" provides one possibility; the appointment of a proxy provide another.

Walter Jacob, Chairman

Responsa Committee

March 3, 1989



## THE LIVING WILL

by Rabbi Bernard M. Zlotowitz

Though the concept of a Living Will is an outcome of advances in medical technology, the very concept of a will has ancient roots.

The most common usage of the word - will - is as a legal instrument by one which disposes of his property or a part thereof.

In Latin the word is testamentum. In Greek it is diatheke (διαθήκη). The corresponding Hebrew word for the Greek, tzawwa'ah (צוואה) which literally means "a command", is rarely used in the Talmud and the Codes. The word most often found in the Mishna and Baraita (those collections of the tannaitic texts which were not included in the Mishna) is the Greek word diatheke, transliterated into Aramaic as diatheke (דיאטהקה). For example, "one diatheke annuls another" (Baba Batra 152b). The Mishna seldom refers to wills (e.g. Baba Batra 8:5,6; 9:6,7; 113a; 130a) and with little discussion.

According to the Talmud, a will takes effect immediately upon a person's death (Baba Batra 149a) and every effort had to be made to assure that the deceased's wishes be carried out faithfully, whether written or oral (Baba Batra 156b; Gittin 15a)<sup>1</sup>. The Talmud and the Codes state that even if the written will omitted the signature of witnesses, it was nonetheless valid (Gittin 71a; Yad, Hilchot Nahalot 4:1; Shulchan Aruch, Hoshen Mishpat 250.7).

In addition to its legal value, a will carried great moral weight. Children had to respect and carry out the wishes of the deceased parent. This principle had its roots in biblical regulations concerning the Rechabites (Jehonadah, the son of Rechab laid down

certain principles that his descendants, known as Rechabites, followed: not to drink wine, not to build houses, sow no seed, plant no vineyard but to live in tents all their lives (Jer. 35:6-19) and retained its importance through the 17th century (The Jewish Encyclopedia Funk and Wagnalls, 1905, vol.12 pp. 522-523).

Another type of will originating in the Bible was the Ethical Will, an exhortation to live a moral and ethical life, generally written by a father to his children, or a teacher to his students, prior to his death. Moses left such a will to the Children of Israel when he exhorted them to walk in the ways of God (Dt. chps. 29-34). Additional examples of ancient, medieval and modern ethical wills have been cited in "Hebrew Ethical Wills", selected and edited by Israel Abrahams, the Jewish Publication Society, Philadelphia, 1926 and "Ethical Wills - a Modern Jewish Treasury," edited and annotated by Jack Riener and Nathaniel Stampfer, Schocken Books, New York, 1983.

The newest variation of the will - the Living Will - was created in response to the remarkable progress medicine has made in extending people's lives. Often, however, patients are kept alive artificially after they can no longer function meaningfully. They may be in a vegetative state, incurable, or in terrible pain. Consider, too, the astronomical medical costs that impoverish loved ones without bringing real benefit to the hopeless patient.

The Living Will allows a person of sound mind to instruct his/her physician to withhold life-sustaining procedures in the event that the person may not be competent to so instruct family or medical officials. A Living Will thereby allows a terminally ill person to die with dignity and in peace.

Not every state accepts such a will. New York does, but only if it is drafted in a clear and definitive manner. Two cases dealing with a patient refusing to undergo dialysis that were heard by the New York Appellate Court will illustrate the technical aspects of a Living Will:

In one case the court held that a patient must specify the life-sustaining measures which he or she refuses to have applied, otherwise the physician is obligated to apply them. Unless there is "clear and convincing evidence" of the patient's refusal to undergo dialysis, the doctor must order treatment. "If there is error in understanding the patient's wishes on the subject," the court ruled, "it should be on the side of life." (Matter of O'Connor, Oct. 14, 1988).<sup>2</sup>

The second case, the court went further, ruling that a competent individual has a right to refuse life-sustaining machines and the physician is under no obligation to order treatment if the patient objects. In "the Matter of Storar, 1981, Court of Appeals decision," the court held that "a competent adult has a common-law right to decline or accept medical treatments, a violation of which right results in civil liability for those who administer medical treatment without consent, despite the fact that the treatment may be beneficial or even necessary to preserve a patient's life, as the patient's right to determine the course of his own medical treatment is paramount to what might otherwise be the doctor's obligation to provide needed medical care; therefore, a doctor cannot be held to have violated

his legal or professional responsibilities when he honors the right of a competent adult patient to decline medical treatment." (Public Health Law §§ 2504, 2805-d; CPLR 4401-a).<sup>3</sup>

Justice Benjamin Cardozo was unequivocal in stating that a person is the master of his own body and has a right to determine what should be done with it. Any person "of adult years and sound mind has a right to determine what should be done with his own body." (Schloendorff v. Society, N. Y. Hospital, 211, N. Y. 125, 129-3d, 105, N. E. 92).<sup>4</sup>

Is a Living Will valid according to Jewish law? Judaism places great stress on the sanctity of life, taking precedences over almost all other values (Sanhedrin, 74a).

No active act may be taken to hasten death. The soul is a guest in the body (Lev. R34:3) and, therefore must be treated with great respect. Since God originally gave the soul (Gen.2:7; Ta'anit 22b), only God can take it back. Hence all forms of euthanasia are forbidden (Job 1:21; Avodah Zarah 18a and Tosefot; Shulchan Aruch, Yoreh De'ah 345).<sup>5</sup> Any intrusive act that hastens a person's death is tantamount to murder. In the case of a person who is terminally ill and refuses medical treatment one is not required to prolong their life by extraordinary means. Rabbi Judah ben Samuel, the Pious, states that one has a right to stop acts which would hinder the soul's departure, "... if a person is dying and someone near his house is chopping wood so that the soul cannot depart, then one should remove the (wood) chop from there..." (Gefar Chasidim [13th century] #723).

Moses Isserles (the Rama) states "... if there is anything which

hinders the departure of the soul as for example a knocking noise near the person's home because of chopping wood or there is salt on his tongue and these prevent the soul from departing it is permissible to remove them because there is no act involved at all (italics mine) only the removable hinderance." (Rama to Shulchan Aruch, Yoreh De'ah 339:1). The Talmud and the Commentaries, including the Rama himself (in another place) state that if a person is in the throes of death (goses) one should stop praying for his or her recovery or for their release (Ketubot 104a; Nedarim 40a; Rama to Shulchan Aruch, Even Ha-ezer 121:7 and Choshen Mishpat 221:2).

Rabbi Solomon Eiger goes even further in his commentary on the passage in Yoreh De'ah 339:1, when he quotes Beit Yaakov "it is forbidden to hinder the departure of the soul by the use of medicines."

Of course, in the last few instances cited we are discussing a person in the throes of death or a terminal illness, who has never expressed his/her own wishes. The decision of continued treatment is left to the rabbi and the physician. But the overwhelming and preponderant view is to discontinue and allow him/her to die in peace.

In the case of someone expressly leaving instructions to allow nature to take its course, the Living Will serves as the best guide. The Talmud emphasized that the wishes of a dying or dead person be carried out. Although the Talmud was addressing the question of

inheritance the principle may be extended to medical treatment. Hence, if an individual rejects prolonging his/her life artificially his or her wishes should be honored.

However, since we must abide by the State law on the basis of dina d'malchuta dina (the law of the land is supreme), I would suggest that a written Living Will be drafted in consultation with an attorney. Furthermore, the sanctity of life makes it advisable to involve at least three persons in the final decision-making process: a member of the family, physician and rabbi. As Scripture teaches, "(There is) a time to be born and a time to die." (Ecclesiastes 3:2).

## FOOTNOTES

1. Though the Bible lays down rules regarding inheritance ( e.g. Nu. 27 [rules of succession] or Dt. 21:17 [right of the first-born]), it is in no way a will. These are legal requirements that supercede the authority of a will. For example, in New York State a husband cannot disinherit his wife, regardless of a will's terms. The Bible laid the foundation for a will but it is the Talmud and the Codes that govern its regulations.
2. See author's article The Journal of Aging and Judaism, "Does an Elderly Patient Have the Right to Refuse Dialysis," 3(4) Summer 1989, p. 212.
3. Ibid, p. 212
4. Ibid, p. 212
5. See author's article in Bio-Ethics, "Program/Case Study, UARC Committee on Bio-Ethics," April 1989, pp.6-8.

## 2. THE LIVING WILL.

At least 17 States now have laws known as "Right To Die" or "Living Will" statutes. These statutes can be considered a legislative response to the Karen Ann Quinlan case, in which respiratory and cardiovascular functions were maintained by technological means in a patient who had lost cerebral function. The Living Will statutes recognize the right of an adult, competent person to make a written directive instructing his physician to withhold life-sustaining procedures in the event of the patient's incompetence to do so in a terminal condition.

From our standpoint, the concept of a Living Will contravenes many of the ethical axioms of our society. It allows the patient to contemplate an act of life-termination sometime in the future, and instructs the medical professional to assist him in carrying out his intent. This legally-sanctioned instruction to the physician presumes

- a) the patient's right to terminate his life by passive euthanasia under the terms of the will, and
- b) the right of the patient to impose ethical value judgments upon others who would assist him despite their own value systems.

Neither of these presumptions can be considered inalienable rights of the patient. We believe that the provisions of the Living Will contradict society's declared interest in the life and health of its citizens, and lends legal support to the State to abandon citizens no longer regarded as productive assets. From a moral standpoint, the Living Will denies the unqualified preciousness of human life, and may well weaken the will to live.

Some ethical implications of the Living Will are reflected in the following concerns:

- 1) Since it is difficult to determine whether death is imminent, the Living Will provisions may be activated prematurely.
- 2) Evaluation of medical or surgical procedures as merely

death-postponing rather than life-prolonging is often arguable. Methods considered heroic and of only temporary death-postponing value have, with the advance of medical science, proved to be life-sustaining.

- 3) During the five-year period when the Living Will is usually in effect, a patient may change his mind and yet not formally rescind the declaration, thus leaving the Will to be activated without proper informed consent.
- 4) The existence of this Will could deprive the patient of full concern by the medical team who might not otherwise pursue medical care with the greater level of care demanded by the patient's condition.
- 5) Pain appears to be the major symptom justifying the activation of the Living Will. But medical science has just begun to explore in depth the field of pain relief, as well as the special role of the hospice for the terminally ill. The Will would deflect attention and effort from forms of pain relief and encourage withholding of life-prolonging treatment.
- 6) There are no strict criteria to differentiate between a critically ill and a terminally ill patient. How terminal is terminal? Is it to be measured in days, weeks or months?
- 7) The doctor's moral conscience or religious convictions may be compromised when his actions are restricted by the terms of the Will.

Because of these, as well as other concerns, we feel that traditional Judaism does not support the use of Living Wills by patients, nor reliance on such documents by physicians.



## 'Right to die' debate could well degenerate into the 'right to kill'

By RABBI RONALD D. PRICE  
Special to the Exponent

A parent is dying. The doctor has made it clear that a feeding tube and/or respirator represent the only hope of survival. "What should we do?"

When questions like this come my way, I turn to Jewish law and tradition and to rabbinic colleagues who spend their lives studying such issues. I give advice based on what I believe Judaism has to say on the matter when one actually decides the fate of another person.

Last fall, I received a call from my wife, who was visiting her 39-year-old sister in the hospital. My sister-in-law was suffering from cancer, and the doctor had given her no more than 48 hours to live, unless she was connected to a respirator. With the device, she could live on as her life slowly and painfully ended. According

to the doctor, there was no hope of recovery other than a miracle. The dreaded question was asked: "What should we do?"

I did not want to answer. I wanted no responsibility for this decision. I felt overwhelmed and wished I had chosen a field other than the rabbinate. Who wants to live with the results of such decisions?

Today, as I look back upon our family's decision not to attach the respirator, I have my own doubts. Even though the decision was made only after consulting with rabbinic medical-ethics experts and was sound in terms of Jewish law and tradition, maybe a miracle would have happened. Did we miss that opportunity, or did we truly save her tremendous physical pain in a hopeless situation?

It makes me wonder. If I felt overwhelmed by the responsibility for this decision and, even today, sometimes question my judgment, how much worse it must be for those who make such decisions without guidance. What must it mean for a man or woman to decide the fate of a loved one and have the full weight of that decision rest only on their shoulders, forever?

The U.S. Supreme Court has rendered a decision on the "right to die." As an outgrowth of that decision, the question of artificial life support will become more dependent upon whether one has left specific instructions in advance of becoming incompetent. A "living will," which includes one's wishes and/or appoints a surrogate to make the decision, can now determine whether one lives or dies.

(Of course, the justices had the best interests of the American people in mind when they made this decision. But our courts are secular by design. Life and death are not secular matters. They are not medical matters alone. Life and death touch the deepest reaches of our spiritual being.

Doctors and scientists can only give physical evidence for life or death — heartbeat, respiration, brain activity. Legislatures may enact laws as they see fit, but they can't tell one how to make the right decision. They do not give moral guidance. Neither the scientist, nor the judge, nor the politician will be there to help one live with a life-and-death decision after it has been made.

*Our courts are secular by design. Life and death are not secular matters. They are not medical matters alone.*

We need religious guidance when we deal with maintaining life or prolonging death. That decision is one that affects not only a body, but a soul. Indeed, it touches more than one soul. It forever affects both the soul of the dying and of the one who decides his or her fate.

If I am young and healthy, I may choose to sign a document that says "no life support." Am I the same person when that day comes? A case was recently recorded of a woman who miraculously revived after life support had been removed by court order. Her sister had told the court that the woman once said she wanted no artificial life support. When asked what she would have done if consulted, the revived woman said, "Of course, I want to live!"

There seems to be a groundswell of support today for the "right to die." Unfortunately, enthusiasm for a quick solution to this exceedingly complicated problem has already begun to blur the difference between the "right to die" and

the right to kill.

Such is the case in Washington state, where signatures are now being gathered to place Initiative 119 before the voters. The proposal provides not only for the withdrawal of feeding tubes and respirators, but also allows doctors to "end the life of a person who, in the opinion of two physicians, has less than six months to live." All a person need do at the time of diagnosis is put in writing that he or she wishes to die immediately.

It is mind-numbing to discover that, according to a *New York Times*/CBS News poll, more than 50 percent of Americans agree with the recommendations of this proposal.

People don't want to become a burden to others; people don't want to have the burden of watching a loved one wither away; they don't want to face the pain and suffering of their own slow death. But where is the line between the "right to die" and what Jewish medical-ethics expert Rabbi David Feldman has called "the responsibility to die"?

As a result of the Supreme Court decision in the Cruzan case, anyone not leaving a "living will" will likely be considered irresponsible. Anyone leaving a will which asks that all available means of life support be used might be considered selfish. Will our society be far from making older people feel it is their obligation to die at a certain point, even if in good health?

While it would be possible in secular society for a suicide machine or a euthanasia proposal such as Initiative 119 to become acceptable over time, it cannot happen in traditional Judaism. Traditional Judaism tells us unequivocally that euthanasia, including suicide, is forbidden. Human beings do not give life. It is not theirs to take away.

Yet the question remains: Are we required to use all means available to artificially prolong a life so diminished in quality that it is really just prolonging death?

## 'Right to die' debate could well degenerate into the 'right to kill'

(CONTINUED)

Traditional Judaism provides pragmatic, as well as spiritual, guidance in these matters. It will consider, for instance, the diminished quality of life of a person in a persistent vegetative state. It will consider the difference between a feeding tube and a respirator. In cases with no hope of survival, the former is still required, while the latter may not be.

Jewish law also makes a distinction between a decision to connect someone to a respirator and that of turning it off after intubation. Except for the prohibition of euthanasia, these guidelines are not absolute, and no decision should be made without discussing the specifics of the case with a rabbi versed in Jewish medical ethics.

Religion and religious leaders must provide the sensitive spiritual, as well as practical, guidance that we all need when we deal with approaching death. Religious responsibility for life-and-death decisions must not be abrogated by the clergy lest life and death become cheapened matters of personal choice, and the use of "suicide machines" becomes acceptable.

My sister-in-law was never connected to a respirator. She died 24 hours after that decision was made. None of us will ever be happy about having made that decision. We are at peace with it because it was made in the context of more than 3,000 years of Jewish appreciation of the sacredness of life.

According to one study, 70 percent of those reading these words will be faced with a similar choice someday, either for themselves or for another.

When thinking of your own future, consider providing a living will like the one created by the Union for Traditional Judaism, which, while leaving the decision to a designated surrogate, also requires the decision to be made according to the standards of Jewish law and tradition. You will thereby relieve your family of at least part of this trauma.

For the sake of our humanity and your own soul, when the day comes, don't decide alone. Lean on your tradition. That is its purpose. ■

*Rabbi Ronald D. Price is executive vice president of the Union for Traditional Judaism and dean of the Institute of Traditional Judaism.*



Please review this suggested text with your personal attorney. Our intent is to provide a text which is in accordance with Jewish law and tradition. We cannot guarantee its legal acceptability in any specific state since states have varying laws regarding living wills. Please inform our office of any changes required in your state so that we can pass this information along to others.

LIVING WILL  
OF

TO MY FAMILY, DOCTOR, LAWYER AND ALL OTHERS WHOM IT MAY CONCERN:

If the time comes in the future when I can no longer take part in decisions about my health care, let this statement stand as an expression of my wishes and directions, while I am still of sound mind and capable of making decisions about my care.

If at such a time the situation should arise in which there is no reasonable expectation of my recovery from extreme physical or mental disability, when I can no longer relate to and interact with friends and loved ones, I direct that the decision to let me die, or to administer medications, artificial life support or "heroic measures," including but not limited to the use of antibiotics, respirators, dialysis, artificial nutrition and hydration, and resuscitation, be made in a manner consistent with Jewish law and tradition and in consultation with a rabbi, competent in Jewish law and the field of Jewish medical ethics, to be chosen by \_\_\_\_\_  
(spouse, children, family, friend...)

In addition, if death is impending and imminent, I direct that a decision on the matter of the transplanting of my healthy and appropriate organs upon my death be made in the same manner.

I ask that medication be mercifully administered to me to alleviate suffering, including but not limited to pain and feelings associated with suffocation and all other types of extreme discomfort.

THOSE SO INCLINED MAY INCLUDE THE FOLLOWING PARAGRAPH:

(I would like to live out my last days at home or in a hospice rather than in a hospital. If it does not jeopardize the chance of my recovery and does not impose an untenable burden on my family.)

I am making this statement after careful consideration and in accordance with my strong convictions and beliefs. I want the

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261 East Lincoln Avenue, Mount Vernon, New York 10552

(914) 667-1007

wishes and direction here expressed carried out to the maximum extent permitted by law. Insofar as they are not legally enforceable, I hope that those to whom this document is addressed will regard themselves as morally and legally bound by these provisions.

I understand the full meaning of this instrument and sign it voluntarily and willfully. I may revoke this instrument at any time, provided that I am capable of making decisions about my care.

Dated: \_\_\_\_\_

\_\_\_\_\_  
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Draft 12/17/90  
Jerome B. Apfel, Esquire  
1200 Four Penn Center Plaza  
Philadelphia, PA 19103  
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UNION OF AMERICAN HEBREW CONGREGATIONS

RESOLUTION PROPOSED BY BIO-ETHICS COMMITTEE

WHEREAS, Jewish tradition affirms the sanctity of life, as well as the precept that every means must be undertaken to preserve life, and also affirms that when there is no hope for a patient and death is certain the patient being "goses" - that is, terminally ill where death is irreversible - impediments to death may be removed enabling a patient to be permitted to die in dignity and in peace, and

WHEREAS, Recent scientific developments now make it possible to artificially prolong the lives of people whose deaths would be imminent unless they receive certain medical treatment and procedures, and

WHEREAS, The application of such treatment and procedures has resulted in many thousands of patients being kept alive with a minimum quality of life after they have become (1) incompetent, and are (2) either terminally ill or in a persistent vegetative state, with no chance of recovery, and

WHEREAS, Such patients, when competent, have neither expressed their views nor had the opportunity to express their views on issues of death and dying, and

WHEREAS, Such artificial treatment and procedures have taken and continue to take an enormous toll upon the spiritual, emotional

and economic resources of such patients, family and friends, some having been exposed to protracted litigation through Court systems, and

WHEREAS, Clergy, physicians and other health care providers are often confronted with a variety of irreconcilable or unresolvable moral and ethical conflicts when patients have not expressed their views as to death and dying issues, and

WHEREAS, The United States Supreme Court in the 1990 landmark decision of Cruzan V. Director, Missouri Department of Health, affirmed that a competent person has a constitutional liberty interest under the Due Process clause of the United States Constitution to refuse unwanted medical treatment, that such liberty interest survives incompetency and should be protected when a decision to refuse treatment is clearly expressed with specificity when competent, such as through the execution of an advance health care directive (living will) and/or a durable health care power of attorney.

RESOLVED:

1. The UAHC reaffirms the ethical, moral and legal right of each individual in accordance with Reform tradition to make his or her own health care decisions, and that such right survives incompetency;
2. The UAHC and its member congregations should develop and promote educational programs to inform each member of the existence of death and dying related decision making issues, to urge members to contemplate such issues with their family,

friends, physicians and Rabbi, and, in so doing, to then clearly express their personal preferences to either receive or reject artificial life sustaining medical treatment and procedures in the event of incompetency when combined with either a terminal illness or a persistent vegetative state, with no chance of recovery;

3. The UAHC and its member congregations should encourage its members to use advance health care directives and/or other legally acceptable and binding writings, such as durable health care powers of attorney, for the purpose of memorializing their respective decisions; and

4. The UAHC and its member congregations should promote and support the enactment of national, state and provincial legislation, preferably of a uniform nature, designed to facilitate the decision making process set forth above, which when enacted and individually implemented would take into account each individuals personal perception of quality of life and, among other things, would, if ever needed, afford guidance to family, friends, clergy, physicians and other health care providers and would also, in general, minimize traumatic and costly treatment and litigation involving death and dying issues.

CHOOSE LIFE...UNLESS IT IS A MACHINE!

Every day we make decisions and rarely think about life and death, but on Yom Kippur we spend the entire day reflecting about the gossamer threads that intertwine life and death. No one ever believes that one day they will have to make the ultimate decision of life and death for someone they love. When it happens, the scene is so wrenching--so intimate--so agonizing in its intensity that it cannot really be described. Questions of life and death are always basically the same. Regardless of age, gender or circumstance, they differ only in name and details. Someone you love is critically ill--cancer--or there has been an emergency--heart attack or stroke--diagnoses may differ, but the end is always the same. Then suddenly, without any warning, extensive medical technologies and the vast array of lights--plugs--tubes--whizzing and whirring sounds, the incredible health care team effort saves a life--someone you love. A life has been sustained, but only on machines, and all too often the quality of that life has been diminished beyond recognition! In the aftermath there is confusion--shock--fear, anger all mixed with hope and sadness. About this time, someone calls the rabbi. For all those involved: spouses, siblings, children, parents, grandchildren, friends. The preciousness of life has been illuminated and everyone has been chastened. During the rabbi's visit--someone meekly asks the question--as if merely uttering the words is an act of bad faith--"what should I do?" Our sense of innocence has been destroyed. We begin to consider the burdensome reality of the critical, nearly fatal impairment--"rabbi, what should I do?" What if they ask about the machines--"Should I turn them off? Doesn't our religion teach us to choose life?"

This is no time for a glib rabbinic answer--no time for a trite theology--no time for a canned recitation of Jewish tradition on medical ethics. Someone lies in a bed with the singular gift of life being sustained by a vast array of modern medical technology. No one I've ever met can be objective about the question, or what they want to hear as the answer.

I have already had too many opportunities in my rabbinate to face that scene--too many pleading voices, waiting for the wisdom, I have so desperately wanted to provide. Every answer I give is for that moment only--to that person uniquely--I have no other answer! But over the past year I have had some experiences which have led me to different possible answers and hopefully, wiser insights.

Now when such human drama is played out and someone turns and asks me--"doesn't our religion teach us to choose life?--I will answer : "yes"--every single aspect of our faith--our observance--our people and its destiny affirms choose life...But now I will add..."unless it is a machine!"

The question: "rabbi, what should I do?" In reference to the removal of life sustaining treatment is not a theological question or a medical ethics dilemma--it is a horrifying human plea for a legitimizing religious credential to an answer that



should never be asked of anyone. We are all going to die--it is a certainty humans have confronted from the beginning of their very consciousness. The only questions remain--"how" and "when?" If we were capable or willing to engage in medieval providential reflection, one might also ask "why", but most of us have long ago abandoned such reflections. The "how" and "when" of death both motivates and impairs our days of living. As medical technology has increasingly provided us with the means of delaying death, the answers to the questions are now increasingly legal interpretations. More and more it is the law, not theology nor medicine who is answering "how" and "when we will die. And it is this reality which stimulates my response--"choose life...Unless it is a machine."

In April, 1989 Rudi Linares held the medical staff at Rush-Presbyterian St. Lukes Medical Center at gunpoint while he removed the respirator and held his son, Sammy in his arms until he died. The desperate agony of this father illuminated only one of thousands of cases in which persons are in persistent vegetative states and yet remain alive without any qualitative context of life. The Linares case stimulated the Cook County State's Attorney, Cecil Partee, to establish a special task force on the foregoing of life sustaining treatment. The task force was called together to provide the county and the state with an interdisciplinary review of the questions, terms, limits, guidelines and possible legislation. The group was drawn from every element of the community--health care, legal, medicine and clergy, ethics, academics--I was honored and humbled to be one of the task force members--and it was during my learning, listening, discussing and reflecting on its work when I decided that I was obligated to preach this sermon.

Remembering Moses' dramatic oration in Deuteronomy--"see I have put before you today the blessing and the curse--life and death--therefore choose life that you and your progeny should live". I realized that the complex realities of contemporary medical technologies do not apply. I am convinced that had Moses any notion of what we have created to delay death indefinitely, he too would warn everyone--"choose life...Unless it is a machine!"

The task force concluded that patients within a decisional capacity do have the right to refuse the "initiation or continuation of medical treatment--including life sustaining treatment." The autonomy of the patient was understood as almost sacrosanct. Yet, the task force in no way was prepared to endorse active euthanasia, or a physician assisted suicide. There is a need for advance planning by patients and health care workers regarding life sustaining treatment--either its initiation or continuation. The recent U.S. Supreme Court decision in the Cruzan case underscores this and makes it even more important for everyone--absolutely everyone--to fill out Living Wills and Durable Powers of Attorney for Health Care. This is particularly essential when a patient loses their decisional capacity. When a surrogate can and should be permitted to make such decisions on behalf of the patient. There was no clear consensus on the removal of nutrition and hydration especially when the patient lacks decisional capacity or their i

no Durable Power of Attorney for Health Care as in the case of Nancy Cruzan or Sidney Greenspan, who is 82 and has been in a persistent vegetative state for 6 years. There needs to be an operative policy and process for hospitals and health care workers to behave in the best interest of all parties.

The report is extensive in its depth as well as offering a piece of model legislation. The report offers a key glossary of oft used and little understood idioms like "terminal"; "imminent"; "extraordinary burdensomeness" and "permanent unconsciousness" or "persistent vegetative state". I want to praise the vision of Cecil Partee, the State's Attorney for drawing together the Task Force--the first of its kind anywhere. I am proud of the work of the Task Force members and especially of the Chief Executive Officer of the State's Attorney's Office, Robert Portman, who is Director of the Task Force. And even though the initial attempts at legislation failed, I am sure some measure will pass--if we as the public demand it--because the absence of any legislation only makes the possibility of another Rudi Linares greater--or the agony of Sidney Greenspan's family more certain.

The most pressing conclusion with which I came away was my moral obligation to raise these issues within my congregation. I realized that a one day shabbat study session this past spring was not enough--nor will it be enough to raise these issues during our seminar on sundays program this December when Dr. David Orntlicher, a lawyer with the A.M.A. will give a lecture, as will I. I needed to challenge you--all of you--each of you--today--on Yom Kippur, when we read from the torah vacharta b'chevin--"therefore, choose life!"

The English translation of this Hebrew phrase hides an essential part of the imperative. The word "vacharta" is second person singular. "You choose life!" Each of us is commanded to choose life--not you, the community as a whole. Hence, each of us has a responsibility to choose for ourselves what we mean by living life. This is not an imperative given only to the sick or to the elderly--it is given to each of us--all of us. Today I understand this imperative to mean that each of us is required to fill out a Durable Power of Attorney for Health Care. The Durable Power of Attorney for Health Care, rather than "a Living Will" is what we must fill out. Living wills are only applicable in cases of terminal illness and will not allow someone else to make a decision on behalf of the patient about life sustaining treatment. In other cases--for example, in the case of an auto accident, or Sidney Greenspan, who had a stroke after having Alzheimer's Disease. We usually assume it is only the elderly, the ill and the frail who should have such documents. Yet time after time, it is the young person who unexpectedly is injured or incapacitated without decisional capacity. When we cannot speak or express ourselves, we force others to make decisions which they cannot make without desperate agony. Even if we have orally articulated our desires, without a document in which each of us has individually chosen life - and when it should end, someone who loves us will choose. Love should never be so powerful. Without the protection of a Durable Power of Attorney for Health Care, we are forfeiting our choice of life and we are passing the

burden to those we love. Even worse, we might be left like Sidney Greenspan and Nancy Cruzan. In the case of someone whose circumstances are defined as a "persistent vegetative state"--as permanent coma, this means an indefinite life...on a machine. Only a Durable Power of Attorney for Health Care provides surrogates with the decisional capacity to remove such life sustaining treatment. In the case of "persistent vegetative state"--"life sustaining" is really "death delaying". This critical differentiation makes the Durable Power of Attorney the ultimate statement of one's choosing one's own dignity. U'vacharta bahaim - you- individually, choose life. The supreme court in the Cruzan case has made it clear that each state can dictate for itself the nuances of how and when someone can die-- unless the patient has made it clear and his/her surrogates are empowered to act on their behalf.

On Yom Kippur we are confronted with the fragility of life and death. Our prayers and reflections today reaffirm that life is singularly precious--and that each of us is responsible individually for the command: choose life! Thus, each of us can and must spare those we love from the agony of choosing life or death for us. We must sit with our spouses, children, parents, siblings, life partners, close friends, and review the issues. The issues that pertain to the right to die are volatile. Sitting down and filling out a Durable Power of Attorney for Health Care Will and should provoke conversation about how much we--individually will choose to assert our autonomy as a patient. These are harrowing individual decisions--each individual must scrutinize his/her own sense of burdensomeness to themselves, as well as to others. We are duty bound to fill out the forms and sign them. I feel so strongly about this that I have acquired 1000 such Durable Powers of Attorney for Health Care through the Chicago Medical Society. They will be available on tables as you leave. There is also a medical directive form now being used experimentally through the A.M.A., which goes into even greater detail, which can be appended to the Durable Power of Attorney. Don't put this on your desk in the pile of important papers or put it away for when you want to discuss these very difficult subjects. U'vacharta bahayim--therefore choose life--does not mean when its convenient or comfortable--but now!

I have come to realize during these past several months that not only does each of us have our own individual discomfort and confusion about life and death--but society as a whole has lost its basic understanding of "life" and "death". Consider for a moment the irony, if not the paradox of our time that we have no consensus on what the ideas of "life" and "death" mean. In our century, we have experienced both the problem of uncontrolled over-population and countless victims of genocide.

Right-to-die questions are already overlapping right-to-life/pro-choice issues. The Supreme Court has decided in "Webster" that life begins at conception, yet in "Cruzan", death cannot begin unless a feeding tube can be removed -- which is illegal. "Life" and "death" have been defined within narrow and contested areas by the Supreme Court, yet many, if not most of us here today neither believe nor accept their definitions. Can we be any less confused as individuals? The last seven years our

society has been forced to re-evaluate the link between "death" and the source of life...Sexuality! The pandemic of AIDS has made all of us rethink more than our moral standards. AIDS has shattered our innocence about celebrating life without fear of death. It is not coincidental that right-to-die issues open us up to a virtual flood of over-stimulating crises in our midst! AIDS, pro-life/pro-choice, aging and health-care are all intertwined in the delicate and complex web which links life and death in our daily lives.

The failure of the courts and legislatures to solve the problem of those in persistent vegetative states cannot go unmentioned. It is estimated that there are 10,000 persons in the United States in persistent vegetative states--a chronic wakefulness without any awareness. This is one of the cruel legal catch 22's of our time. Can anyone imagine the pain of Rudi Linares or Nancy Cruzan's parents or Sidney Greenspan's wife of 56 years? What is more unimaginable is our society's inability to solve the problem of what life and death mean for such people. This legal limbo is even more grotesque when one thinks about the violence we have come to accept in our society. It is projected this year that 23,000 persons will die in the U.S. from hand guns. Given this projection, do you realize that it will be easier and more certain for an African American teenager to be shot and killed over a pair of basketball shoes than for one of the 10,000 persons, like Sidney Greenspan, in persistent vegetative states to die peacefully with dignity? There is something morally misdirected about a society that cannot protect those who choose life from dying cruel and unnecessary deaths, nor can it protect those who would otherwise choose quiet death from cruel and unnecessary living.

We must demand that those we respect from the various intellectual disciplines, help us as a society toward a recovery of the meaning of the ideas, life and death, because unless we truly understand what we mean by life and death, we cannot possibly choose life and appreciate the gift and the responsibility of what we have chosen. The complexity of our time pushes us to the very edge.

"I put before you today--the blessing and the curse--life and death--therefore, choose life'. The words are powerful and dramatic, but the responsibility of making that choice requires much more than power and drama. We live longer today than in any other time in history, but we do not live forever. All of us will die one day. Our Jewish devotion to living is not diminished by our honest recognition of the human condition. Our society has created medical technologies which have preempted our reflective conclusions. Those of us here and those of our dear ones who are not present this morning can still make their own choice for life. Let us each choose for ourselves and save others from an unnecessary and agonizing dilemma. As I challenge each of you to fill out the durable powers of attorney for health care, I also want to challenge the Jewish community's institutions to do the same for individuals. The Council for Jewish Elderly and the Federation supported homes, like the Lieberman, the Northwest and Self-Help, as examples. The torah commands us to "choose life" so the Jewish community should live

by its values and educate and facilitate people in filling out Durable Powers of Attorney for Health Care, especially for those people who have decisional capacity and want to become residents of Federation supported facilities.

Let us put the biblical drama of u'vacharta bahayim aside and confront the sobering reality that our challenge is more aptly stated--"choose life--unless it is a machine!"

Rabbi Joseph A. Edelheit  
Emanuel Congregation  
Chicago, IL

## THE MEDICAL DIRECTIVE: AN INTRODUCTION

As part of a person's right to self determination every adult has the freedom to accept or refuse any recommended medical treatment. This is relatively easy when people are well and can communicate. Unfortunately, during severe illness, people are often unable to communicate their wishes at the very time that many critical decisions about medical interventions need to be made.

The Medical Directive states a person's wishes for or against types of medical interventions in several key situations, so that the person's wishes can be respected even when he or she cannot communicate.

A Medical Directive only comes into effect if a person becomes incompetent, or unable to make decisions or to express his or her wishes. It can be changed at any time up until then. Decisions not involving incompetence should be discussed directly with the physician.

The Medical Directive also allows for appointing someone to make medical decisions for a person should he or she become unable to make his or her own: this is a proxy or durable power of attorney. The Medical Directive also allows for a statement of wishes concerning organ donation.

A copy of the completed Medical Directive should be given to a person's regular physician and to his or her family or friend to ensure that it is available when necessary.

Medical Directives should be seen not only as legal protection for personal rights but also as guide to a person's physician. Discussion of Medical Directives with the physician can help in making plans for health care that suit a person's values.

\* \* \*

A person's wishes usually reflect personal, philosophical, and religious views, so people may wish to discuss the issues with his or her family, friends, and religious mentor as well.

Before recording a personal statement in the Medical Directive it may be helpful to consider the following question. What kind of medical condition, if any, would make life hard enough that attempts to prolong life would be undesirable? Some may say none. For others the answer may be intractable pain. For other people the limit may be permanent dependence on others, irreversible mental damage, or inability to exchange affection.

Under such circumstances as these the goal of medical treatment may be to secure comfort only, or it may be to use ordinary treatments while avoiding heroic ones, or to use treatments that offer improved function (palliation), or to use all appropriate interventions to prolong independent of quality. These points may help to clarify a person's thoughts and wishes.

**MY MEDICAL DIRECTIVE**

This Medical Directive expresses, and shall stand for, my wishes regarding medical treatments in the event that illness should make me unable to communicate them directly. I make this Directive, being 18 years or more of age, of sound mind and appreciating the consequences of my decisions.

**SITUATION (A)**

If I am in a coma or in a persistent vegetative state, and in the opinion of my physician and several consultants have no known hope of regaining awareness and higher mental functions no matter what is done, then my wishes regarding use of the following, if considered medically reasonable, would be:

**SITUATION (B)**

If I am in a coma, and in the opinion of my physician and several consultants have a small likelihood of recovering fully, a slightly larger likelihood of surviving with permanent brain damage, and a much larger likelihood of dying, then my wishes regarding the use of the following, if considered medically reasonable, would be:

**SITUATION (C)**

If I have brain damage or some brain disease which in the opinion of my physician and several consultants cannot be reversed and which makes me unable to recognize people, or to speak understandably, and I also have a terminal illness, such as incurable cancer which will likely be the cause of my death, then my wishes regarding use of the following, if considered medically reasonable, would be:

**SITUATION (D)**

If I have brain damage or some brain disease which in the opinion of my physician and several consultants cannot be reversed and which makes me unable to recognize people, or to speak understandably, but I have no terminal illness, and I can live in this condition for a long time, then my wishes regarding use of the following, if considered medically reasonable, would be:

	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION
	WANT	WANT	WANT
1) CARDIOPULMONARY RESUSCITATION— if on the point of dying the use of drugs and electric shock to start the heart beating, and artificial breathing.			X
2) MECHANICAL BREATHING— breathing by a machine.			
3) ARTIFICIAL NUTRITION AND HYDRATION— nutrition and fluid given through a tube in the vein, nose, or stomach.			X
4) MAJOR SURGERY— such as removing the gall bladder or part of the intestines.			
5) KIDNEY DIALYSIS— cleaning the blood by machine or by fluid passed through the belly.			
6) CHEMOTHERAPY— drugs to fight cancer.			X
7) MINOR SURGERY— such as removing some tissue from an infected toe.			X
8) INVASIVE DIAGNOSTIC TESTS— such as using a flexible tube to look into the stomach.			X
9) BLOOD OR BLOOD PRODUCTS—			
10) ANTIINFECTIVES— drugs to fight infection.			X
11) SIMPLE DIAGNOSTIC TESTS— such as blood tests or x-rays.			X
12) PAIN MEDICATIONS, EVEN IF THEY DEPRESS CONSCIOUSNESS AND INDIRECTLY SHORTEN MY LIFE—			X

	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION
	WANT	WANT	WANT
			X
			X
			X
			X
			X
			X

	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION
	WANT	WANT	WANT
			X
			X
			X
			X
			X

	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION	I WANT A TRIAL TO SEE IF I CAN IMPROVE MY SITUATION
	WANT	WANT	WANT
			X
			X
			X
			X
			X

**DURABLE POWER OF ATTORNEY** (Consult family attorney)

I understand that my wishes expressed in these four cases may not cover all possible aspects of my care if I become incompetent. I also may be undecided about whether I want a particular treatment or not. Consequently there may be a need for someone to accept or refuse medical interventions for me in consultation with my physicians. I authorize:

\_\_\_\_\_

\_\_\_\_\_

as my proxy(s) to make the decision for me whenever my wishes expressed in this document are insufficient or undecided.

Should there be any disagreement between the wishes I have indicated in this document and the decisions favored by my above named proxy(s). I wish my proxy(s) to have authority over my medical directive /I wish my medical directive to have authority over my proxy(s). (Please delete as necessary.)

Should there be any disagreement between the wishes of my proxies,

\_\_\_\_\_

shall have final authority.

**ORGAN DONATION**

I hereby make this anatomical gift to take effect upon my death.

I give: \_\_\_\_\_ my body; \_\_\_\_\_ any needed organs or parts; \_\_\_\_\_ the following organs or parts \_\_\_\_\_

to the following person or institution; \_\_\_\_\_ the physician in attendance at my death; \_\_\_\_\_ the hospital in which I die; \_\_\_\_\_ the following named physician, hospital, storage bank or other medical institution \_\_\_\_\_;

for the following purposes: \_\_\_\_\_ any purpose authorized by law; \_\_\_\_\_ transplantation; \_\_\_\_\_ therapy; \_\_\_\_\_ research; \_\_\_\_\_ medical education.

**MY PERSONAL STATEMENT** (use another page if necessary.)

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

Signed \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_

Witness \_\_\_\_\_ Date \_\_\_\_\_



# Filling the Gap Where a Living Will Won't Do

By ELISABETH ROSENTHAL

Several years ago Lily Stone signed a document called a "living will," rejecting in advance any heroic medical treatment in the event she became hopelessly ill and unable to speak for herself.

But when she suffered a major heart attack last year, the 76-year-old Westchester woman spent 23 days comatose in an intensive care unit on a respirator before she died. It was treatment her husband knew she would not have wanted, but could not prevent.

"I waived the living will form and asked the doctors to disconnect the respirator and they said, 'Sorry, that doesn't apply,'" her husband, Ted, said recently. "She suffered no pain, but each day was heart-rending, like 23 funerals. And it could have been 23 weeks or 23 months."

Though many people have drawn up living wills as a means to guide medical decisions as the end of life nears, patients who fill them out often find themselves derailed from paths they thought carefully planned, often by doctors who say the instructions are unclear or who are hesitant to withhold life-prolonging treatment on the strength of a piece of paper.

Today, many health care experts say that goal is often better achieved by a newer document, a health care proxy, in which patients designate a surrogate who has legal authority to make medical decisions if they are too sick to offer an opinion. Others recommend that the living will and health care proxy be combined in some way.

## Living Will Limitations

Living wills have been around for 25 years and they haven't done the job," said George Annas, professor of law at the Boston University Medical School. Although proxies are new and it is difficult to predict if unforeseen problems will arise, "there is a major trend towards proxies, and they are likely to take over the field," Professor Annas said.

In the last few years 22 states, including New York, have passed laws allowing for health care proxies, often to compensate for the shortcomings of legislation regarding living wills. New York's proxy statute, which has been widely praised, takes effect tomorrow.

Before these statutes, in many states even a next-of-kin could not compel doctors to withdraw life-sustaining treatments, like use of a respirator, although he could make some less critical treatment decisions. Surrogates designated by proxies are found to make decisions based on the patient's known wishes or, if these are not known, based on his or her best interest.

"The consensus now is that in states where the law allows, you should use a proxy and appoint a person to make health care decisions for you," said Fenella Rouse, director of Concern for Dying-Society for the Right to Die. New York and California are such states.

The relative power of health care proxies and living wills vary from state to state. All states have laws, called durable power of attorney statutes, which allow a person to delegate responsibility for his affairs to a proxy. But the concept has only recently been applied to health care decisions, and some states have not explicitly acknowledged the concept of a health care proxy in their laws.

In New Jersey the society recommends both a living will and health care proxy; proposals on such documents are pending in the State Legislature, but both concepts have been upheld in the state's courts. In states like Pennsylvania and Ohio, where durable power of attorney laws cannot be used to withdraw medical treatment, the society still endorses living wills.

## Federal Law on Patients

The Federal Patient Self-Determination Act, which takes effect this October, will require hospitals and nursing homes to advise patients of state laws on living wills and health care proxies when they are admitted.

The major flaw of living wills is that most, like Mrs. Stone's, are simple statements indicating that the bearer does not want heroic measures in the case of terminal illness.

(more)



## Proxies' Legal Status

Not all states have statutes specifically relating to health care proxies; some may fall into more than one category.

Jurisdictions with durable power of attorney statutes that permit agents to make medical decisions specifically including decisions to withdraw or withhold life support: California, Florida, Georgia, Illinois, Kansas, Kentucky, Maine, Massachusetts, Michigan, Mississippi, Nevada, New York, Ohio, Oregon, Rhode Island, South Carolina, South Dakota, Tennessee, Texas, Vermont, West Virginia, Wisconsin, District of Columbia.

States with durable power of attorney statutes that positively authorize consent to medical treatment, but do not

specifically authorize withdrawal or withholding of life support:

Alaska, Colorado, Connecticut, Louisiana, New Mexico, North Carolina, Pennsylvania, Washington.

States with durable power of attorney statutes that have been interpreted, through court decisions, attorney general's opinions or other statutes, to permit agents to make medical decisions, including those to withhold or withdraw life support:

Arizona, Colorado, Hawaii, Iowa, Maryland, New Jersey, New York, Virginia.

States that authorize proxy appointment through their "living will" or "natural death" acts, with proxies permitted to make decisions authorized by the act when the patient is in a medical condition covered by the act, usually "terminal" as defined by the act:

Arkansas, Delaware, Florida, Idaho, Indiana, Louisiana, Maine, Minnesota, Texas, Utah, Virginia, Wyoming.

States with general power of attorney statutes that make no mention of medical decisions:

Alabama, Missouri, Montana, Nebraska, New Hampshire, North Dakota, Oklahoma.

Source: Society for the Right to Die, 250 West 57th Street, New York, N.Y. 10107

## The health care proxy, a valuable document for the terminally ill.

But such directions do not speak to specific circumstances, and are subject to interpretation. Doctors as well as hospital lawyers have been reluctant to rely on simple dictums to direct a complex, messy process like modern hospital death.

In a landmark case in New York State, Tom Wirth, a New York City man with AIDS, was hospitalized after he became incoherent from a brain infection called toxoplasmosis, one of the many infections that plague AIDS patients. The man had signed a living will, saying that if his condition was irreversible, he did not want extraordinary treatment. Over his companion's objection, the doctors gave him antibiotics.

They argued that the patient's wishes were unclear with regard to toxoplasmosis, since the serious brain infection was potentially reversible and curable, although his AIDS was not. The courts upheld the doctors' judgment. Mr. Wirth died of the infection despite the treatment.

"Living wills require patients to forecast in advance what their medical conditions will be and what treatments will be available," said Tracy E. Miller, executive director of the New York State Task Force on Life and the Law, which proposed that New York adopt a proxy, rather than a living will statute.

"It's very rare that living wills have one specific interpretation," said Professor Annas. "Many use vague terms like 'extraordinary' and 'no hope.' When is there ever no hope? So if a doctor doesn't want to follow a living will, it's easy to find an excuse not to."

In addition, most living will laws stipulate that the documents take effect when a patient is permanently unconscious or "terminal," generally meaning that death is imminent. Consequently, they do not cover people with Alzheimer's disease or stroke victims who linger incompetent for months before they die.

### Optimism on Use of Proxies

Health care experts predict that doctors who have shied away from living wills may find health proxies more palatable. "Many health care workers are uncomfortable relying on a document to make a life-and-death decision," said Professor Annas. "It can't speak. It can't listen to treatment alternatives now."

Another advantage of proxy laws is that patients can select a close friend or companion rather than a relative as a representative, an attractive option for gay patients, whose biological relatives legally take precedence over lifelong partners.

At a time when health care has become increasingly complex, designating a health proxy is generally logistically simple. Under the New York statute, which experts expect to be a

national model, the declaration must include the patient's name; the name address and telephone number of the proxy; optional information on an alternate proxy and the signatures of two witnesses over the age of 18.

Some states require the signatures to be notarized or restrict who may serve as a witness. Many proxy documents include a space where the patient may issue specific health care instructions to his surrogate or may limit his power. In New York, no official form is needed, although a sample is available.

"There is absolutely no reason to get a lawyer involved," said Ms. Miller of the state task force.

Many health experts say that the best strategy is to designate a health care surrogate through a proxy and complete a living will as well. The instructions of the living will can then serve as a guide for the surrogate.

But others worry that presenting both forms to the doctor leaves the door open for legal battles if a surrogate and a doctor disagree over the interpretation of a patient's instructions. They recommend that the living will only be addressed to the designated surrogate.

"He can keep it in a drawer and pull it out if it supports his case," said Professor Annas.

### Limitations of Proxy Laws

Even the most comprehensive health care proxy laws have limitations, usually relating to tube feeding and hydration. In New York, the surrogate can only reject these options if he can claim specific knowledge of the patient's wishes on the subject, through a living will, written statement or prior conversations. In Kentucky and Tennessee, surrogates cannot reject these options for patients in persistent comas, but can step in once the patient is "terminal," meaning that death is imminent.

Although the New York State Task Force had recommended that all medical decisions be similarly treated under the proxy law, lobbying by Roman Catholic groups led to a bill requiring special requirements for withholding food or water.

Health experts recommend that people pick surrogates carefully, inform the designated person and spend time discussing their wishes.

Dr. Joseph d'Oronzio, a medical ethicist at Overlook Hospital in Summit, N.J., told of an aunt who asked him to serve as her proxy, feeling that her own children were too young to handle the responsibility.

He said yes, but insisted on a meeting first. "I found she had six or seven very specific scenarios about dying and very clear wishes about what she wanted done," he said. "One problem with the proxy notion is that the people may not have sat down and gotten down and dirty."

Whatever route is chosen, health experts say, the documents must be readily available. Stories are legion of elderly people resuscitated in emergency rooms while forms that would have rejected the treatments sit in safety deposit boxes or in a child's bedside table.

"These sorts of documents should be close to the surface," said Dr. D'Oronzio. "If possible, wear it as a talisman."

FILLING THE GAP WHERE A LIVING WILL  
WON'T DO

(continued)

## Sample Health Care Proxy

Legal forms vary from state to state. This is adapted from the form developed by New York State.

1. I, \_\_\_\_\_ (name) \_\_\_\_\_, hereby appoint \_\_\_\_\_ (name, home address and telephone number) \_\_\_\_\_ as my health care agent to make any and all health care decisions for me, except to the extent that I state otherwise. This proxy shall take effect when and if I become unable to make my own health care decisions.

2. Optional instructions: I direct my agent to make health care decisions in accord with my wishes and limitations as stated below or as he or she otherwise knows. \_\_\_\_\_

(Example: I have discussed with my agent my wishes about artificial nutrition and hydration and I want my agent to make all decisions about these measures.)

3. Name of substitute or fill-in agent if the person I appoint above is unable, unwilling or unavailable to act as my health care agent. \_\_\_\_\_ (name, home address and telephone number) \_\_\_\_\_

4. Unless I revoke it, this proxy shall remain in effect indefinitely, and until the date or conditions stated here: \_\_\_\_\_

5. Signature, address and date: \_\_\_\_\_

Statement by two witnesses, other than the proxy; both must be 18 or older.

To obtain a printed copy of the New York State form, with instructions, send a self-addressed stamped envelope to Proxy, Post Office Box 1634, New York, N.Y. 10116-1634.

# Why have to die with dignity?

Phila.  
Inquirer  
10/8/90

By FELICIA ACKERMAN

Several years ago. The New Yorker ran a Lorenz cartoon of a street scene showing men weeping into large handkerchiefs. One sobbing man clung to a pole. Another sat at the curb. Others were walking down the street. And a woman was saying to another, "Sometimes I miss the old days, when men were ashamed to cry in public."

Well, sometimes I miss the old days when death was a taboo subject. Nowadays the subject is so fashionable that it would be hard for a fatally ill person to escape knowing what he is supposed to say: "I do not fear death. I fear only pain, suffering and being a burden to my loved ones. And I fear the loss of dignity. I want to die with dignity." This sort of line has become practically *de rigueur* for the terminally ill. Nearly every month, someone earnestly proclaims it in a newspaper or magazine.

So it seems high time to examine what the line really amounts to and whose interests the social pressure in its favor really serves.

"I do not fear death." Well, why not? For people who value their lives and don't believe in the hereafter, doesn't fearing death make perfect sense? "Confronting my own mortality has made me value life so much I no longer fear death?" — that's a popular variant. But it seems even more paradoxical.

We would be skeptical of people who claimed to value their marriages so much they wouldn't mind getting divorced, or value their jobs so much they wouldn't mind getting fired. Why, then, should those who value life be expected to face its loss with equanimity?

"I fear being a burden to my loved ones." This idea is so entrenched in contemporary culture that any in-

*The notion that the terminally ill should accept death with serenity doesn't help.*

vidual who questions it risks being instantly condemned as selfish. But I think the real question should be why we would call a desperately ill person selfish if he ranks his life ahead of his family's convenience, rather than calling his family selfish if they rank their convenience ahead of his life.

It is cruel to pretend the greatest burden of illness falls on anyone but the patient. And it is downright brutal to promote the view that the terminally ill should sacrifice what is left of their lives in order to make things easier on their loved ones — whose love can hardly be worthy of the name if they find such a sacrifice appalling.

"I want to die with dignity." Personally, I've always considered dignified people stuffed shirts. So I doubt that a fatal disease would make me find

dignity more precious than life.

To put the matter less flippantly, I think we need to re-examine the idea that people severely disabled by terminal illness have less human dignity than those who are able-bodied and healthy, an idea often connected with the view that it is somehow degrading to be "dependent on machines."

But who isn't? I depend on telephones, cars and computers. Why should this give me more dignity than people who are conscious but who depend on respirators, catheters and feeding tubes? Surely, terminally ill people are not uplifted by the suggestion that their infirmities rob them of dignity and worth. Wouldn't it be more humane to encourage people not to be ashamed of the body's inevitable decline or of the need for mechanical aids?

The notion that the terminally ill should be paragons of serene acceptance, ready to bow out as soon as they become burdensome, hardly serves their interests. It serves the interests of those who want sick people to be as little trouble and expense as possible. But a country that has spent as much as we have on weapons can hardly claim inability to afford to support human life, including the lives of the ill and helpless.

The phrase "kept alive on machines" calls up images of comatose people whose bodily functions are provided artificially. An obvious question is, "What's the point?" None, I would say, for those who have signed living wills. But choosing not to sign one also makes sense. People sometimes emerge from supposedly irreversible comas — and of course, not all people kept alive on machines are in comas at all. Some are conscious, but simply cannot eat or breathe unassisted.

Without pressure for any particular line on dying, some terminally ill people probably will be serene, selfless and eager to bow out quickly. But others will not, and such people should not be criticized for denying that being a "burden" is a fate worse than death or that human dignity requires the body of a teenage jogger.

The slogan "Whose life is it, anyway?" applies as much to terminally ill people who want to live as long as possible as to those who are ready to die.

Felicia Ackerman is an associate professor of philosophy at Brown University in Providence, R.I.

*I was appalled by the audacity of these outsiders to presume to know what was best for the patient. None of them could look at things from my husband's perspective. His decision . . . was not a frivolous choice.*

Janet P. Zinzeleta

'No one can estimate the power of the human will'

BALTIMORE  
EVENING SUN  
10/4/90

## There's also a right to live

**T**HE SUPREME COURT'S ruling that the parents of 22-year-old Nancy Cruzan have no right to remove the feeding tube that is keeping her alive cannot be forgotten: It seemed a cruel decision. It forced her parents to watch their child linger, perhaps for years, in her irreversible, unconscious, vegetative state.

Janet P.  
Zinzeleta

The hearts of the nation have gone out to this family in their tragedy, which centers around the highly publicized and controversial right to die.

But there is another thing to consider when discussing the complex issue of patients' rights. That is the need for understanding and encouragement when a patient decides to fight to live.

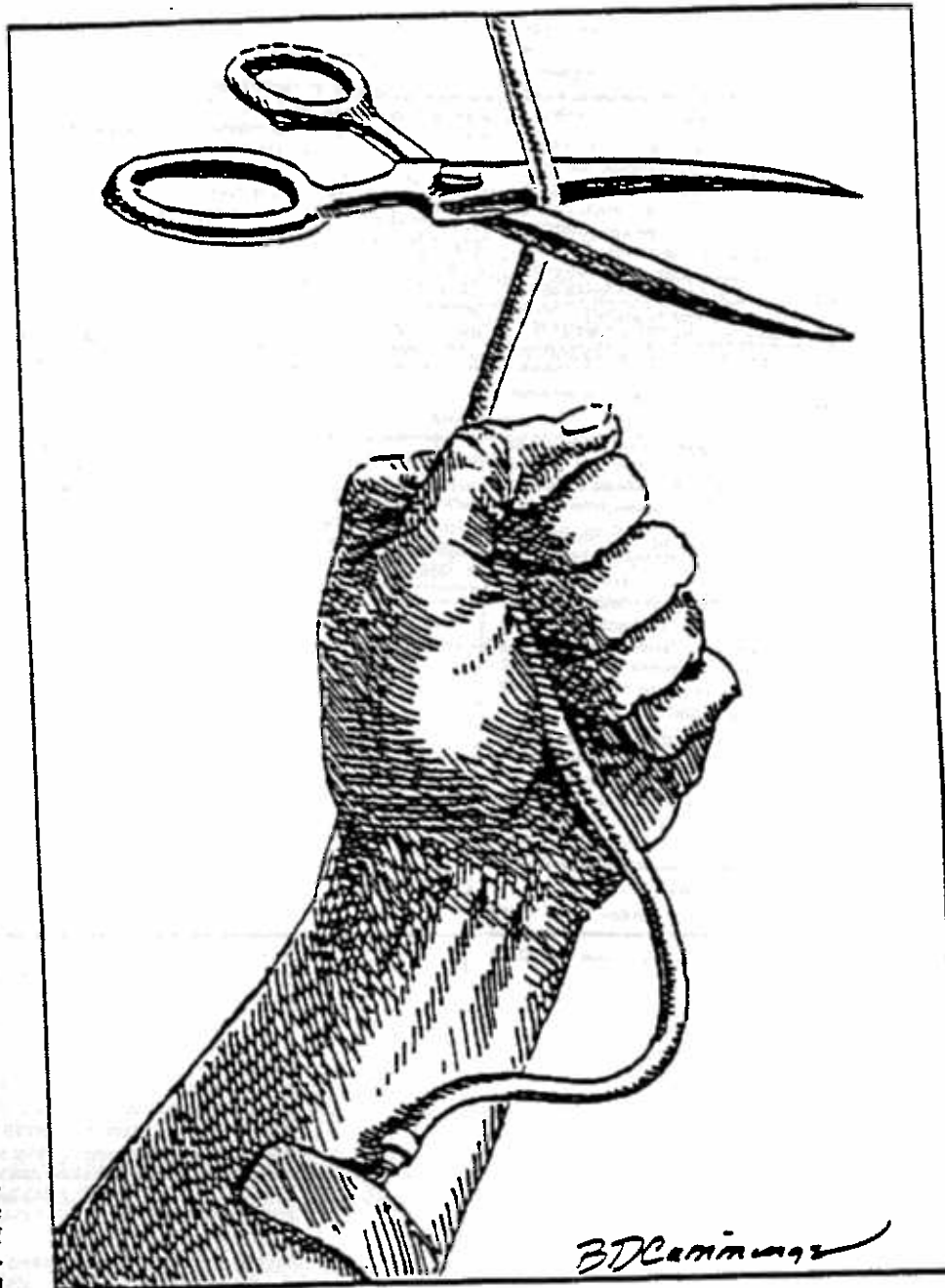
When I arrived at the hospital during my husband's second treatment of chemotherapy for acute monocytic leukemia, he said, "I hope you'll understand, but I'll never go through this again. I'd rather die."

Yet each time he relapsed and was told that without more treatment he would have about three weeks to live, he chose to enter again into what seemed a living hell: fevers spiking to 106 degrees, shaking chills, vomiting, hallucinations — and all without the possibility of a cure.

In a period of over three years, he endured seven treatments of chemotherapy, as well as three other hospitalizations for complications. He suffered from pneumonia, dehydration, spinal meningitis contracted from a contaminated transfusion, an operation for embolisms, nerve damage in his hands and feet, vertigo and hearing loss caused by the chemicals he received. He did not realize himself how strong his will to live was until he was confronted with the alternative.

We were fortunate in having a supportive, caring doctor who, with each relapse, offered the best treatment available for the situation. Yet three of the nurses who attended him expressed their opinions that he should take no further treatment. One of these well-meaning young women suggested, very gently, that other patients had chosen instead to spend their last days at home with their families and implied that he should do likewise.

Another nurse embarrassed him by sarcastically commenting on his being back in the hospital again for more chemotherapy.



A third told me that she and other nurses had discussed how they "felt like shaking" patients who put themselves and their families through such torture by continuing to take treatment.

I was appalled by the audacity of the outsiders to presume to know what was best for the patient. None of them could look things from my husband's perspective. I decided to continue fighting as long as I

# There's also a right to live

(continued)

treatment was available was not a frivolous choice. He wanted to live — it was that simple. He had only one chance at life; when that was over there would be no second opportunity. He wanted to get every drop he could from his cup of life.

As dying patients often do, my husband established goals: to see a daughter graduate from high school, another get her doctorate, a son return to college after having discontinued his education. Each event he lived to see gave a new dimension to his existence and to ours. Each sharing of a major happening involved him a little longer in our lives and in our memories. We have the consolation of knowing that he did all in his power to stay with us.

There are many cases when a patient decides that he or she wants to leave the pain and misery, he or she chooses to forgo further treatment. This decision should be honored when it is ascertained that it is the patient's wish. But not all patients want to shorten life, and when this is the case, the person's desire to struggle should be honored. We frequently hear of people living beyond all medical predictions, for no one can estimate the power of the human will. Nor can anyone, even the closest relative, presume to know another's wishes.

The case of Nancy Cruzan is tragic. In all likelihood, if she could be given the opportunity, she would choose to die. The Supreme Court's decision has resulted in many Americans preparing a durable power of attorney to provide a way for others to avoid such a tragic situation.

Appointing a guardian who knows one's wishes and has the legal standing to decide medical treatment if one is unable to decide can provide peace of mind. Most of us think such a document only appropriate for the elderly. The Cruzan case shows that it is not.

But those patients who are still able to express their wishes should receive all the help and support their courageous decisions deserve. If that decision is to forgo further treatment, there are places, such as hospices, to help them through their final days. If that decision is to pursue every avenue available until the end, those who minister to them do them an injustice if they do not make every effort to encourage them in that decision.

*Janet P. Zinzeleta writes from Elliott City.*

## A Few Definitions

- **Advance directive** - If you want your wishes to guide those responsible for your care you have to plan for what you want in advance. Generally such planning is more likely to be effective if it's done in writing. So, by an "advance directive" we mean any written directions you prepare in advance to say what kind of medical care you want in the event you become unable to make decisions for yourself.

There are three kinds of advance directives.

1. **Proxy directives** - One way to have a say in your future medical care is to designate a person (a proxy) you trust and give that person the legal authority to decide for you if you are unable to make decisions for yourself. Your chosen proxy (known as a health care representative) serves as your substitute, "standing in" for you in discussions with your physician and others responsible for your care.

So, by a proxy directive we mean written directions that name a "proxy" to act for you. Another term some people use for a proxy directive is a "durable power of attorney for health care".

2. **Instruction directives** - Another way to have a say in your future medical care is to provide those responsible for your care with a statement of your medical treatment preferences. By "instruction directive" we mean written directions that spell out in advance what medical treatments you wish to accept or refuse and the circumstances in which you want your wishes implemented. These instructions then serve as a guide to those responsible for your care. Another term some people use for an instruction directive is a "living will".

3. **Combined directives** - A third way combines features of both the proxy and the instruction directive. You may prefer to give both written instructions, and to designate a health care representative or proxy to see that your instructions are carried out. So, by a "combined directive" we mean a single document in which you select a health care representative and provide them with a statement of your medical treatment preferences.

Whichever form you choose, it is important to remember to discuss your health care preferences with others. In order to help you choose the kind of directive which best suits your circumstances, the following pages answer some frequently asked questions about advance directives.

## 2. Questions and Answers

Why should I consider writing an advance directive?

Serious injury, illness or mental incapacity may make it impossible for you to make health care decisions for yourself. In these situations, those responsible for your care will have to make decisions for you. Advance directives are legal documents which can provide information about your treatment preferences to those caring for you, helping to insure that your wishes are respected even when you can't make decisions yourself. A clearly written directive helps prevent disagreements among those close to you and alleviates some of the burdens of decisionmaking which are often experienced by family members, friends and health care providers.

When does my advance directive take effect?

Your directive takes effect when you no longer have the ability to make decisions about your health care. This judgment is normally made by your attending physician, and any additional physician who may be required by law to examine you. If there is any doubt about your ability to make such decisions, your doctor will consult with another doctor with training and experience in this area. Together they will decide if you are unable to make your own health care decisions.

What happens if I regain the ability to make my own decisions?

If you regain your ability to make decisions, you resume making your own decisions directly. Your directive is in effect only as long as you are unable to make your own decisions.

What is the advantage of having a health care representative, isn't it enough to have an instruction directive?

Your doctor and other health care professionals are legally obligated to consider your expressed wishes as stated in your instruction directive or "living will". However, instances may arise in which treatments are proposed that you may not have thought about when you wrote your directive. If this happens your health care representative has the authority to participate in discussions with your health care providers and make treatment decisions for you in accordance with what he or she knows of your wishes. Your health care representative will also be able to make decisions as your medical condition changes in accordance with your wishes and best interests.

If I decide to appoint a health care representative, who should I trust with this task?

The person you choose to be your health care representative has the legal right to accept or refuse medical treatment (including life-sustaining measures) on your behalf and to assure that your wishes concerning your medical treatment are carried out. You should choose a person who knows you well, and who is familiar with your feelings about different types of medical treatment and the conditions under which you would choose to accept or refuse either a specific treatment or all treatment.

A health care representative must understand that his or her responsibility is to implement your wishes even if your representative or others might disagree with them. So it is important to select someone in whose judgment you have confidence. People that you might consider asking to be your health care representative include:

- a member of your family or a very close friend,
- your priest, rabbi, or minister, or
- a trusted health care provider, but your attending physician cannot serve as both your physician and your health care representative.

Should I discuss my wishes with my health care representative and others?

Absolutely! Your health care representative is the person who speaks for you when you can't speak for yourself. It is very important that he or she has a clear sense of your feelings, attitudes and health care preferences. You should also discuss your wishes with your physician, family members and others who will be involved in caring for you.

Does my health care representative have the authority to make all health care decisions for me?

It is up to you to say what your health care representative can and cannot decide. You may wish to give him or her broad authority to make all treatment decisions including decisions to forego life-sustaining measures. On the other hand, you may wish to restrict the authority to specific treatments or circumstances. Your representative has to respect these limitations.

Is my doctor obligated to talk to my health care representative?

Yes. Your health care representative has the legal authority to make medical decisions on your behalf, in consultation with your doctor. Your doctor is legally obligated to consult with your chosen representative and to consider his or her decision as if it were your decision.

Is my health care representative the only person who can speak for me, or can other friends or family members participate in making treatment decisions?

It is generally a good idea for your health care representative to consult with family members or others in making decisions, and if you wish you can direct that he or she do so. It should be understood by everyone, however, that your health care representative is the only person with the legal authority to make decisions about your health care even if others disagree.

If I want to give specific instructions about my medical care, what should I say?

If you have any special concerns about particular treatments you should clearly express them in your directive. If you feel there are medical conditions which would lead you to decide to forego all medical treatment, including life-sustaining measures, and accept an earlier death, this should be clearly indicated in your directive.

Are there particular treatments I should specifically mention in my directive?

It is a good idea to indicate your preferences concerning two specific kinds of life-sustaining measures: artificially provided fluids and nutrition and cardiopulmonary resuscitation. Stating your preferences clearly concerning these two treatments will be of considerable help in avoiding uncertainty, disagreements or confusion about your wishes. The enclosed forms provide a space for you to provide specific directions concerning your wishes with respect to these two forms of treatment.

Can I request all measures be taken to sustain my life?

Yes. You should make this choice clear in your instruction directive. Remember, an instruction directive can be used to request medical treatments as well as to refuse unwanted ones.

Does my doctor have to carry out my wishes as stated in my instruction directive?

If your treatment preferences are clear your doctor is legally obligated to implement your wishes, unless doing this would violate his or her conscience or accepted medical practice. If your doctor is unwilling to honor your wishes he or she must assist in transferring you to the care of another doctor.

Can I make changes in my directive?

Yes. An advance directive can be updated or modified, in whole or in part, at any time, by a legally competent individual. You should update your directive whenever you feel it no longer accurately reflects your wishes. It is a good idea to review your directive on a regular basis, perhaps every 5 years. Each time you review the directive, indicate the date on the form itself and have someone witness the changes you make. If you make a lot of changes, you may want to write a new directive. Remember to notify all those important to you of any changes you make.

Can I revoke my directive at any time?

Yes. You can revoke your directive at any time, regardless of your physical or mental condition. This can be done in writing, orally, or by any action which indicates that you no longer want the directive to be in effect.

Who should have copies of my advance directive?

A copy should be given to the person that you have named as your health care representative, as well as to your family, your doctor, and others who are important to you. If you enter a hospital, nursing home, or hospice, a copy of your advance directive should be provided so that it can be made part of your medical records.

Can I be required to sign an advance directive?

No. An advance directive is not required for admission to a hospital, nursing home, or other health care facility. You cannot be refused admission to a hospital, nursing home, or other health care facility because you do not have an advance directive.



Will another state honor my advance directive?

It is likely that your advance directive will be honored in another state, but this is not guaranteed.

What if I already have a living will?

While you may want to review your existing living will or advance directive and make sure it reflects your wishes, there is no legal requirement that you do so.

Do I need an attorney or a doctor to write one?

You should consult with anyone you think can be helpful, but it is not necessary. This booklet and the forms which are included are designed to enable you to complete your advance directive without the need for legal or medical advice. If the medical terminology is unclear to you, most health care professionals will be able to help you understand it.

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### Terms you should understand

**1. Artificially provided fluids and nutrition:** The provision of food and water to seriously ill patients who are unable or unwilling to eat. Depending on the method used and the condition of the patient, techniques may involve minor surgery, continuous supervision by medical (and sometimes surgical) personnel, risk of injury or infection, and side effects.

**2. Cardiopulmonary Resuscitation (CPR):** A treatment administered by health care professionals when a person's heartbeat and breathing stops. CPR may restore functioning if administered properly and in a timely fashion and may include the use of drugs and/or mechanical devices.

**3. Life-sustaining measures:** The use of any medical procedure, device, drugs, surgery, or therapy that uses mechanical or other artificial means to sustain, restore or replace a vital bodily function, thereby prolonging the life of a patient.

**4. Decisionmaking capacity:** A patient's ability to understand the benefits and risks of a proposed medical treatment and its alternatives and to reach an informed decision.

**5. Health care representative or health care proxy:** In the event an individual loses decisionmaking capacity, a health care representative or proxy is a person who has been legally designated to make decisions on his or her behalf. A health care representative is appointed through the execution of a proxy directive (a durable power of attorney for health care).

**6. Terminal condition:** The terminal stage of an irreversibly fatal illness, disease, or condition. While determination of a specific "life expectancy" is not required for a diagnosis of a "terminal condition", a prognosis of a life expectancy of one year or less, with or without the provision of life-sustaining treatment, is generally considered terminal.

**7. Permanent unconsciousness:** A medical condition defined as total and irreversible loss of consciousness. The term "permanently unconscious" includes the conditions persistent vegetative state and irreversible coma. Patients in this condition cannot interact with their surroundings or others in any way and do not experience pleasure or pain.

**8. Persistent vegetative state:** A condition of permanent unconsciousness in which the patient loses all capacity for interaction with their environment or other people. It is usually caused by an injury to the brain. It is normally not regarded as a terminal condition and with the aid of medical care and artificial feeding and hydration patients can survive for many years.

**9. Incurable and irreversible chronic diseases:** Disabling diseases such as Alzheimer's disease or ALS or "Lou Gehrig's disease," which get worse over time eventually resulting in death. Depending on the disease, the patient may also experience partial or complete loss of physical and mental abilities. Because the rate at which these diseases advance may be slow, such diseases are not considered terminal in their early stages.

**10. Attending physician:** The doctor directly responsible for your medical treatment. He or she may or may not be your regular family physician. Depending on your health care needs the attending physician may consult with others in order to diagnose and treat your medical condition, but she remains directly responsible for your care.

## PROGRAMMATIC SUGGESTIONS

1. Create a congregational forum on the status of advanced directives in your area. What is the law? Are statutes pending?

Many congregations have created panels with physicians, the congregational rabbi and legal representatives to discuss the application of their particular disciplines to the creation of advanced directives.

2. Sponsor an educational evening with the above to "walk through" the filling out of the directive. Have enough forms available so that copies may be filed at the synagogue if so desired.
3. Create within the congregation an individual who would be willing to be available to members when questions concerning the directives emerge.
4. Compare the documents from Dr. Jacob and Rabbi Zlotowitz and those of the more traditional communities (the Compendium and the Union of Traditional Judaism). How do we approach the subject of individual autonomy (see Bioethics Committee Case II: The Right to Refuse Treatment).
5. Draw on excellent material from American Association of Retired Persons (AARP). See: Tomorrow's Choices  
Preparing Now for Future Legal,  
Financial, and Health Care  
Decisions.  
AARP  
1909 K. Street, NW  
Washington, DC 20049
6. Does the writing and implementation of an advanced medical directive allow for the removal of artificial impediments or give passive allowance for euthanasia?
7. How do we justify that all life comes from God with our wish to involve ourselves in what some would call "God's Will?"
8. In light of current discussions regarding the so-called "right to die"...how do we as Jews react to the following comment: "The quantity of man's life is in the hands of God, the quality of his life is in man's hands only."  
(Max Arzt in "The Rosh Hoshonah Anthology, p. 95).

(more)

PROGRAMMATIC SUGGESTIONS

9. We are compelled to do everything to give/save life. Yet we are living in a time of limited resources. How do we allocate the economic/human resources so that the greatest good is achieved? Who decides who gets what?  
See: American Reform Responsa #75  
"Choosing Which Patient to Save"  
Modern Medicine and Jewish Ethics  
Fred Rosner  
"Allocation of Scarce Medical Resources," p. 339
  
10. Compare the articles from the Philadelphia Inquirer and Baltimore Sun with attitudes of Dr. Walter Jacob and Rabbi Bernard M. Zlotowitz.