

# LIVING WILLS

Casey Frank, 1998

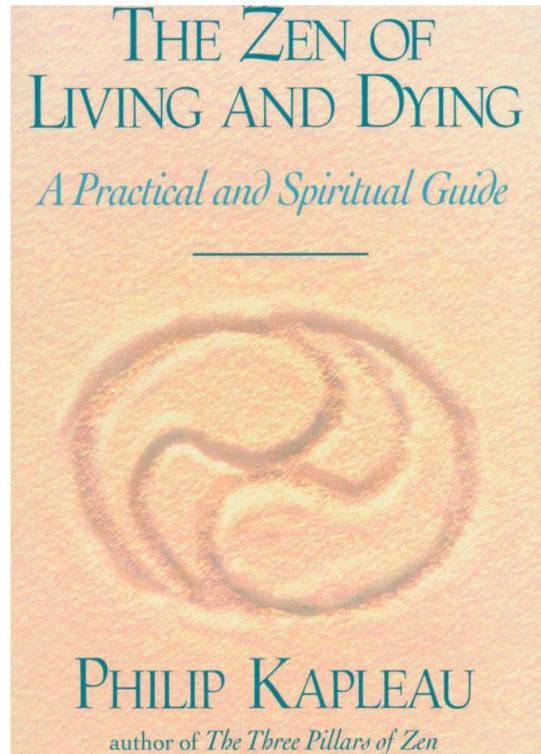
**W**e live in a world of ever-expanding medical treatment options, where more decisions are the responsibility of patients than ever before.[1] Some of the most important medical decisions we will ever make arise as we near the end of our lives. By preparing adequately for death we not only reduce the decision-making burden on our families, we also engender greater clarity in ourselves. The best way to plan for death is to: (1) create advance medical directives, setting forth in writing our wishes as best we can; (2) appoint a health care agent to deal with the unexpected circumstances that are sure to arise; and (3) find out what kinds of end-of-life assistance are available from our physician.

## Living with Technology

In the developed world, life has become inextricably integrated with technology. We are born, live and die in an engineered realm. Eighty percent of us die in hospital beds.[2] It is said that "Nature never failed the heart that loved her," but for most of us, that love is one-sided. We are but half-hearted naturalists. We welcome the joy of natural good health, but we fight against the equally natural ills to which we are also susceptible.

Through medicine we reduce pain and disability and improve the quality and length of life. We explicitly choose when to do much that in the past would simply have happened to us. We control reproduction, extend life, and have an increasing number of options around how we die. End-of-life choices evoke profound concerns and anxieties, both because they are unfamiliar to us and because they are of ultimate

consequence. However, they are the ineluctable extension of a world where autonomy has become paramount.



*In The Zen of Living and Dying*

Roshi Philip Kapleau

(Boston: Shambhala, 1998), 209

## The Rise of Patient Autonomy

Historically, physician beneficence toward patients was the controlling principle of medical practice. More recently, patient autonomy has become the ascendant ethic.[3] Autonomy is usually seen as the right to refuse treatment. This right became rooted in law following a landmark case where it was ruled that: "Every human being of adult years and sound mind has a right to determine what shall be done with his own body." [4] Patient autonomy has also expanded to encompass the right of surrogates to refuse treatment on behalf of patients [5] and a patient's limited right to die. [6] A difficulty arises when we cannot make or communicate our wish to receive treatment -- or to be left alone.

This determination of when we are actually unable to make and communicate our own medical treatment decisions is usually made by the treating physician, who tests whether we lack the capacity to give informed consent. Informed consent requires that we understand the risks and benefits of any medical decision. It is limited to that issue alone.

Our treatment decisions must be voluntary and informed -- that is, based on adequate information supplied to us by our physician. Properly, physicians look to see that we: (1) express treatment choices; (2) understand and retain sufficient medical information over time; (3) are able to articulate relevant issues; and (4) can do a simple risk-benefit analysis.

Next, we must be able to communicate our choices clearly. If we are unconscious, delirious, or paralyzed, this is obviously impossible and makes informed consent unrealizable. It is, in effect, the same as mental incapacity. Thus, it is vital that we plan ahead while we have the time and faculties. The best way to do this is by creating written advance directives. Everyone who is not a minor should do this. Some of the most famous and contentious situations regarding patient autonomy have involved people who were in their twenties and good health before they became incapacitated, like Karen Quinlan and Nancy Cruzan.

### **Advance Directives**

Advance directives allow a patient not only to refuse unwanted treatment but also to request it as desired. The purpose of advance directives is to predict our future treatment decisions and provide guidance to caregivers and family members. These directives usually come into play only when a patient is unable to give informed consent directly, as discussed above. If a patient doesn't provide guidance for future decisions, then families and physicians must

make these decisions in an atmosphere of urgency and uncertainty. Directives give voice to a patient's views when they cannot be voiced directly. They do not deprive a person of personal autonomy but preserve and extend it into the future.

These advance directives have become more popular since they were used by President Nixon and Jackie Kennedy. President Bill Clinton and Hillary Clinton have also announced their intention to provide advance directives for their own care and treatment.[7] All federally funded hospitals must provide written guidance for creating directives upon the admission of a patient (although they cannot require their creation).[8]

What if you become incapacitated before creating an advance directive? If you have no close relative, a guardian may need to be appointed. The power of a guardian is based on a court order issued after a formal hearing. A guardian must act in the best interests of the incapacitated person.[9] A court-appointed guardian is less subject to challenge than a health care agent. The procedure of appointing a guardian is more expensive and time-consuming than that of creating advance directives and thus is utilized only as a last resort. As a practical matter, as long as there are written directives or, alternately, if there is someone to speak for the patient and there is no conflict among family members, a guardian should not be necessary.[10]

### **Health-Care Agents**

The most important advance directive appoints a health care agent, also known as a surrogate, or proxy, who can make decisions on behalf of a patient. The majority of health care decisions that need to be made involve day-to-day care and treatment or placement options -- not just "pulling-the-plug." Because there is no way to

address every medical possibility in advance, it is essential to have an agent who can respond to the unforeseeable.

An in-depth discussion of your options with your physician is essential to clarify your own wishes. You must then communicate your decisions and your sensibilities to your agent. Though the directive appointing the agent should be in writing, nothing can replace face-to-face communication in helping an agent understand your views. You should also discuss these issues with your family, to avoid surprises and reduce the possibility of dissension later on.

The legality of withholding food and water is a special case in many states. Often food and water cannot be withdrawn unless all treatment has also been withheld. Further, the presumption that a patient wants them is stronger than for less "essential" treatments. Thus, you should express your wishes explicitly in writing if you wish to have food and water withheld, and you should clarify under what circumstances this measure should be implemented.

### **Living Wills**

The best known advance directives are living wills, written to prohibit the excessive prolonging of the dying process. Living wills are valid only if a patient is in a terminal medical condition from which there is no reasonable expectation of recovery. Living wills are limited to refusal of treatment. Because they are limited in what they cover, they are no substitute for the appointment of an agent. Another limitation of living wills with no agent is that they may be ignored by your physician unless you have an agent to interpret and facilitate them.[11] However, if your state legally allows it, a combined directive, which both appoints an agent and gives specific instructions though a living will, is ideal. Further, if you have no

one to act as your agent, a living will will afford the best opportunity for expressing your wishes.

Remember, advance directives on the whole are not limited to mere refusal of treatment. They are also your opportunity to communicate the level of treatment you desire. For example, your advance directive can specify the desired level of pain relievers you wish to receive and in what circumstances food and water should be withheld. Advance directives give us the opportunity to share our personal decisions about these issues.

### **Some Troublesome Issues**

One makes a directive while still somewhat distant from the events that it addresses. Usually people who have chosen to forego life-sustaining treatments do not later change their minds.[12] The very process of creating an advance directive helps you to think through and stabilize your treatment choices. But there have been cases where people have recovered from an unconscious condition thought to be irreversible[13] and this, understandably, raises a disturbing question about the wisdom of withholding life-sustaining treatments. However, these are rare exceptions. Very few persons rendered unconscious by trauma for months ever return to functional lives.[14]

Another emerging risk of advance directives is the possibility that they may leave a patient at the mercy of a financially frugal HMO or an unscrupulous nursing home administrator, who might want to save money by withholding treatment prematurely, inadvertently hastening a patient's death. This problem can be mitigated by having a health care agent.

### **Resources**

Forms to guide the creation of advance directives are available from Choice in Dying, 200

Varick Street, New York, NY 10014, Tel: (800) 989-9455; website: [www.choices.org](http://www.choices.org); email: [cid@choices.org](mailto:cid@choices.org). In Europe, contact the World Federation of Right-to-Die Societies, 61 Minterne Avenue, Norwood Green, Southall, Middlesex, England UB2 4HP; Tel: (44)181-574-3775.

You may wish to have your lawyer draw up your advance directives. It is advisable to use the form accepted in your state, although you can customize it to suit your choices. Using your state's accepted form ensures that it will be legally enforceable and familiar to your health care provider. Have your directives witnessed by two adults and notarized. And it is essential to give copies to your doctor, your lawyer, close family members, and anyone else who might be in a position to make -- or contest -- a decision about your medical treatment. Keep a copy of the directives in a very convenient place readily available in an emergency.

### **Physician Assistance for the Dying**

So-called physician-assisted suicide has polarized public opinion in the United States. Adherent opponents liken it to Nazi eugenics; adamant supporters cast it as a simple question of personal freedom. "Physician assistance for the dying" is really a better way to describe this process, as a patient's quest for a dignified death and a physician's assistance at the end of life involve much more than the solitary issue of assisted suicide. Pain relief, other palliative or comfort care, mutual communication, respect for the autonomy of the patient, and respect for the judgment of the physician are all important. We need to explore these issues with our physicians while we are lucid, so we can understand what kind of help might be provided to us.

Many see a physician's role to be that of a collaborator with his patients -- one that continues until death itself. This goes beyond the mere prolongation of life and could even include helping someone to die.[15] Certainly most physicians strive to help their patients heal without wanting to consider the final option. However, some incurably ill patients suffer mightily in spite of the best efforts of their physicians.[16] Although physician assistance in dying invokes legitimate concerns, it would be overly partisan to reject it out of hand.[17] Following is a discussion of several key issues in this debate.

### **Untreated Mental Illness**

Physician assistance in dying should only follow the patient's competent, settled decision to die. Mental states where we cannot grasp the consequences of our decision, treatable clinical depression, or temporary feelings of despair may make death seem desirable.[18] In these circumstances, physician-assisted suicide cannot be justified. The consequences of an intentional death are so great that they must be reflected upon with deliberate seriousness, as discussed earlier in the section "Suicide and Euthanasia."

### **Untreated Physical Symptoms**

The wish to die is often related to unrelieved or under-treated physical pain. For this reason, all options to relieve a patient's physical pain should be thoroughly explored before physician-assisted suicide is considered. A much-needed emphasis on palliative care, including pain-relief, is gaining support in many states. Hospice physicians and oncologists are among the most skilled in adequate pain relief.[19]

### **Vulnerability of the Disenfranchised**

Members of minorities, the disabled, the elderly, and the poor are especially vulnerable to the inherent biases that characterize society.

Consequentially, these groups fear that, since they are disenfranchised, they may be more likely to be encouraged to die. Surveys appear to show that this is why a clear majority of the poor, the elderly and blacks oppose legalization of physician-assisted suicide, even though an overall majority of Americans support it.[20]

### **Physicians' Objections**

Even if we accept that patient autonomy has become paramount, physicians should not be required to sacrifice their own moral integrity to meet the patient's wishes.[21] Many physicians make a clear distinction between their duty to "first do no harm" and assisting a patient to intentionally end his or her life. They are concerned that such assistance will dilute the mission of the profession. Physicians with good-faith conscientious objections could simply excuse themselves from participation. The recently proposed laws that would legalize physician assistance in dying would also protect physicians' right to do so.[22]

### **The Law**

In 1991, Dr. Timothy Quill published an explicit account of his efforts to assist a severely ill patient to die.[23] Although the actions described were widely practiced and ages-old, they had usually been performed sub-rosa.[24] Indeed, one of Dr. Quill's aims was to stimulate an open discussion of these practices and to end their secretive application.[25]

Two legal cases, including one in which Dr. Quill was the defendant, were combined and

recently decided by the U.S. Supreme Court. The Court ruled that the right to die can be limited by states to the patient's refusal of treatment. Thus, no patient currently has a right to affirmative assistance in dying under the U.S. Constitution.[26] In some states such assisted suicide still constitutes manslaughter.[27] Until states give physicians license to act freely in concert with their patients at the end of life, patients are limited to explicitly refusing treatment and to receiving treatments that are classified as having a "double effect." For example, the administering of opiates to reduce pain can have the added effect of suppressing respiration and shortening life. The intended effect is pain relief; the unintended but unavoidable -- and thus permitted -- effect can be death.

### **Conclusion**

According to a recent study, 53 percent of physicians treating AIDS victims have assisted a patient in dying.[28] Is it better to accept this reality or hold fast to an older view of a doctor's role? The American Medical Association opposes physician-assisted suicide and submits that better care will eliminate the need.[29] Others have suggested criteria for the direct regulation of physician assistance in dying.[30] Clinical criteria, guidelines, and the necessary forms are available from some physician groups, in spite of the fact that the process is currently illegal.[31] Resolution of this momentous issue is nowhere near consensus, so it must be resolved by each of us as best we can.

## Endnotes

1. Elisabeth Rosenthal, "Hardest Medical Choices Shift to Patients," *The New York Times* (January 27, 1994), A1.
2. Sherwin B. Nuland, *How We Die : Reflections on Life's Final Chapter* (New York: Knopf, 1994).
3. Beauchamp & Childress, *Principles of Bio-medical Ethics* (New York: Oxford Univ. Press, 1989), 67.
4. *Schloendorff v. Society of New York Hospital*, 105 N.E. 92, 129-130 (N.Y. 1914).
5. *Matter of Quinlan*, 355 A.2d 647 (N.J. 1976).
6. *Cruzan by Cruzan v. Director, Missouri Dept. of Health*, 497 U.S. 261, 271 (1990).
7. Michael Kramer, "Pulling the Plug," *Time Magazine*, (October 3, 1993).
8. 42 U.S.C. § 1395cc(f).
9. See, e.g., C.R.S. § 15-14-311(2).
10. Intra-family conflicts are not uncommon. In the case of *In re Martin*, 517 N.W.2d 749 (1994), the spouse's interpretation of the comatose patient's wishes was flatly contradicted by his sister and mother, placing the controversy before a court.
11. Susan Gilbert, "Doctors Often Fail to Heed Wishes of the Dying Patient," *The New York Times* (November 22, 1995), A1.
12. Marion Danis, MD, et al, "Stability of Choices about Life-Sustaining Treatments," *Annals of Internal Medicine* (April 1, 1994), 567.
13. Bill Inman was brain damaged from an auto accident, in a coma for a year, and was not expected to recover. Four years later he was living at home, speaking, able to feed and dress himself, and was learning to walk. David McQuay, "A One in a Million Miracle," *The Denver Post* (July 21, 1985).
14. The Multi-Society Task Force on PVS, "Prognosis for Recovery," *N.E.J.M.* (June 2, 1994), 1572.
15. Timothy E. Quill, MD, *Death and Dignity* (New York: Norton 1993), 51-52.
16. *Ibid.*, 156.
17. For a fuller discussion of objections to physician-assisted suicide, see: "When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context" (New York: New York State Task Force on Life and the Law, April, 1997).
18. Jane E. Brody, "Depression May Lead Dying Patients to Seek Suicide," *The New York Times* (June 18, 1997), B10.
19. *Death and Dignity*, op. cit., 79-80.
20. David E. Rosenbaum, "Americans Want a Right to Die. Or So They Think," *The New York Times* (June 8, 1997), E3.
21. "The American College of Physicians Ethics Manual," *Annals of Internal Medicine* (1992), 117: 948.
22. See, for example, *The Oregon Death with Dignity Act*, Or. Rev. Stat. § 127.800 (1994).
23. "A Case of Individualized Decision Making," *N.E.J.M.* (March 7, 1991), 691-694.
24. D.A. Asch, "The role of critical care nurses in euthanasia and assisted suicide," *N.E.J.M.* (1996), 334(21): 1374-1380.
25. *Death and Dignity*, op. cit., 175. Even if we accept that patient autonomy has become paramount, physicians should not be required to sacrifice their own moral integrity to meet the patient's wishes.[21] Many physicians make a clear distinction between their duty to "first do no harm" and assisting a patient to intentionally end his or her life. They are concerned that such assistance will dilute the mission of the profession. Physicians with good-faith conscientious objections could simply excuse themselves from participation. The recently proposed laws that would legalize physician assistance in dying would also protect physicians' right to do so.[22]
26. *Vacco v. Quill*, 117 S.Ct. 2293 (1997).
27. C.R.S. § 18-3-104(1)(b) (1987 and Supp. 1997).
28. Lee R. Slome, Ph.D., et al, "Physician-Assisted Suicide and Patients with Human Immunodeficiency Virus Disease," *N.E.J.M.* (February 6, 1997), 417.
29. "Doctors Design Rules on Care for the Dying" *The New York Times* (June 23, 1997), A12.
30. *Death and Dignity*, op. cit., 161-165.
31. "Physician-Hastened Death: Advisory Guidelines for the San Francisco Bay Area," are available from: Steve Heilig, Bay Area Network of Ethics Committees, c/o San Francisco Medical Society, 1409 Sutter Street, San Francisco, CA 941098.