

# 8 ADVANCE DIRECTIVES AND THE PHYSICIAN: TALKING WITH HEALTHY PATIENTS ABOUT DYING

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If at some time in the future I am admitted to a nursing home, and *in the absence of my ability to give directions concerning my care*, it is my intention that this directive shall be honored by my family and physician(s) as the final expression of my legal right to refuse medical and surgical treatment and accept the consequences of such refusal.

I consent only to nursing care, pain medication, and needed sedation. **NOTHING ELSE!**

*All other medicines* of any type are **STRICTLY FORBIDDEN!**

I prohibit any type of medical or surgical treatment **UNDER ANY CIRCUMSTANCES!**

If I sustain a fracture or any other injury, I will allow sedation, *ample* and frequent pain medicine, immobilization, and **ABSOLUTELY NOTHING ELSE!**

Diagnostic tests, except the required chest x-ray, **ARE NOT PERMITTED!**

I may be assisted to drink, food may be offered, **BUT SPOONFEEDING IS FORBIDDEN!**

—Dr. Louis Shattuck Baer, Clinical Professor of Medicine Emeritus,  
Stanford University[1]

There is no consensus about death and dying in our culture. Most of us have some idea of—possibly even strong convictions about—the kind of death we hope for and the kind we dread. But one person's hope is another's dread. We have no consensus about the best way to die, the

best place to die, the best time to die. Nor is any consensus to be expected in a pluralistic culture, for death and dying are metaphysical and existential, focusing and also challenging basic beliefs about who we are, how we have lived, and what life is about.

Most of us will die in some kind of health care facility, in the care of a physician or a team of physicians. And the kind of medical treatment persons then receive often plays an important role in determining whether or not they get the kind of death they want. But because there is no consensus about death and dying, there can be no consensus about terminal medical care: the kind of treatment that one person desperately wants would strike another as pointless, degrading, horrible.

The moral and legal rights of patients to make decisions concerning their own medical treatments is well-established [2]. And because there is no consensus on death, dying, and terminal medical care, preserving the right becomes, if anything, even *more* important for hopelessly and terminally ill patients. But such decisions cannot be made in a meaningful way if one does not know what one's condition is and what alternative treatments are possible. So, hopelessly and terminally ill patients, especially, should be informed about their conditions and their options in the face of these conditions.

This position is supported by the President's Commission on medical ethics [3]. It is in line with the results of recent surveys that indicate that both well and seriously ill patients want to be informed about their conditions and to participate in decisions about their treatments [4]. Fears that such discussions would prove harmful to seriously or terminally ill patients have not been substantiated [5]. Most physicians also accept, in theory, at least, the conclusion that patients should participate in decisions concerning their terminal care [6].

However, medical practice apparently lags behind this theoretical consensus. A 1981 study by S. E. Bedell and T. L. Delbanco that focused on decisions about cardiopulmonary resuscitation (CPR) in the hospital indicates that even those physicians who believe that patients should participate in such decisions rarely discuss them with their patients [7]. Why not? According to Bedell and Delbanco, physicians believe that they already know what their patients want, that patients usually "tell you in other ways besides words that they do (or do not) want to be resuscitated" [8, p. 1091]. But Bedell and Delbanco show that this reliance on nonverbal communication is not nearly accurate enough: the physicians in their study seriously overestimated the number of their patients who wanted CPR.

If nonverbal communication is not accurate enough and patients have a right to make important medical decisions about their own treatments, then physicians have an obligation to discuss with their patients the kinds of treatment they want and think they will want. (And if hopelessly

and terminally ill patients' treatments are the most open to question, physicians then have a *special* obligation to conduct such discussions.) In an editorial in the *New England Journal*, M. Angell makes this point forcefully, concluding that "nothing should be taken for granted. What does the patient want? Ask him" [9].

But *when* should the patient be asked? Too often, there seems to be no appropriate time. Discussions of death, dying, and terminal care are widely thought by both physicians and patients to be irrelevant (because the patient is not yet dying) until it is too late, until the patient's ability to have discussions has been undermined by illness, drugs, shock, and anxiety—by the process of dying. And even if early discussions *are* regarded as relevant, the inability to find a suitable time for them is another important reason for their not taking place.

In this essay I will argue that physicians and patients pay too high a price for avoiding discussions of terminal care and dying; there would be important benefits for both from such discussions. I will also urge that the answer to the question of when physicians and patients should discuss death, dying, and terminal care is—the sooner the better. Others have made similar suggestions in passing [10]. But these points are worth investigating and emphasizing because they are so much at odds with standard medical practice.

## THE RATIONALE FOR EARLY DISCUSSION

I propose that physicians should actively help patients plan for their dying process; discussions of death and dying with all competent, adult patients should be a standard part of good medical practice and records. These discussions should focus on the kind of terminal care and death the patient wishes to have (and also on the kind of terminal care the physician is inclined to offer, given his or her own principles and preferences). Some patients will want to know what the prognosis is; others will not, preferring words of encouragement and hope. Some will want their physicians to "do everything possible," no matter how expensive or invasive the procedure; others will see heroic measures and at some point even ordinary measures as pointless, wasteful, even degrading. Different patients will have radically different assessments of the points at which the quality of their lives would be so low as to be no longer worth preserving, and radically different ideas about how quickly they want to get through the process of dying. Some patients will want to retain whatever clarity of consciousness is possible, even at the expense of great pain; others will prefer to be made comfortable. And some will want to be made comfortable even at the expense of substantial risks of a shortened life; others will not. Some will want to be organ donors; to others this idea is abhorrent. Some will want the safety and security of

dying in a hospital; many will prefer the more personal death of a hospice or their own homes. People rarely wish to die alone, but the wishes of the few who do should be known and respected. And finally, there are the questions of postmortems, of the disposal of the remains, and of the kind of funeral or memorial service, if any, that is desired (though this last question is arguably beyond the scope of a physician's care).

These discussions should begin while individuals are still young and healthy, before there is any question of serious illness, much less of whether or not the individuals are dying. Decisions should be reviewed every three or four years, reminding the patients that, although they can change their directives for terminal care at any time, their directives, if any, will govern the kind of terminal care they will receive, should they be unable to speak for themselves. Patients should be encouraged and helped to formalize the conclusion of these discussions in some kind of advance directive, for a written advance directive is more likely to be carried out than one that is merely verbal. (Remember that one kind of advance directive says, in effect, "Keep me alive as long as you can.")

The advance directive and a summary of the discussion leading to it should be a standard part of the patient's medical record, so that it would be readily available to specialists and hospital staff. But the patient should also be encouraged to talk about the discussion and advance directive with family and friends so that they will know about his or her wishes.

Such discussion is never academic and never premature. Although thoughts of death and dying may be far from a young and healthy person's mind, a person of any age may be admitted to the intensive care unit (following an automobile accident, for example) with no time or ability to voice concerns about the course of treatment. And the need for discussion with healthy patients becomes even more pressing as patients age; every physician knows that many patients who are admitted to nursing homes and hospitals for terminal care are not sufficiently lucid to give genuinely informed consent, even if still technically competent.

Even if there is sufficient time and lucidity for reflecting about one's terminal care after it has begun, the emotions generated by impending death and the foreign hospital setting may make it difficult to figure out what one wants. The ambivalence and waffling by patients about the kinds of terminal care they wish to receive are no doubt due in part to not having thought about the issues before [11]. Family members also appear on the scene when death is imminent, each with their own, often unacknowledged, agenda of fear, remorse, and guilt, and the wishes of these relatives may further obscure or even come to replace the patient's preferences.

Many observers have pointed out that the main obstacle to a patient's

effective participation in decision making is lack of competence [12]. But lack of competence from illness, drugs, and debilitation, together with shock, fright, acute anxiety, a lack of time for reflection, an alien environment, and outside pressures—all work against the patient's making a rational decision about treatment. And these are all present in various combinations in a terminal illness—*particularly* when such decisions have not been thought through and discussed in advance.

## ADVANTAGES FOR PATIENTS AND PHYSICIANS

We get clearer about what we want by talking about it; discussion breeds autonomy. And it is the enhancement and preservation of autonomy—in this context, of getting the kind of terminal care and death we seek—that generates the patient's main interest in discussing death, dying, and terminal care. Diminished or destroyed autonomy, due to compromised capacity for informed and sustained reflection, seems an almost inescapable feature of illness; and even if the seriously ill person remains lucid enough to make informed decisions, he or she has a severely restricted ability to carry them out. But if we are confident that others will carry out our wishes when we can no longer do so, another kind of autonomy can be preserved and increased—one that relies on trust. For we are autonomous, not only when we can and do carry out our decisions but also when we know that others will do so for us.

Thus, trust in others also enhances autonomy, and sensitive, open discussion normally breeds trust. However, as Angell points out, there are significant barriers to a patient's initiating discussion of terminal care and dying: "Not only must [patients] somehow know when to speak and what is at stake . . . but they must be certain that they won't offend their physicians by asking questions" [13]. Consequently, physicians find that only their most assertive patients will initiate discussion of terminal care and dying. But physicians need not simply follow the lead of their most assertive patients; they can initiate discussion of such matters, knowing that these discussions will increase patients' trust that their physician will carry out their will. The patient's trust is obviously good for the physician, as well as the patient.

Discussions of death and dying offer other important advantages for physicians. Preserving and enhancing patient autonomy are goals of most physicians and should be goals of all physicians. Indeed, patient autonomy—not preservation of life, health, or ability to function—can be argued to be *the* goal of medicine [14]. It is not, therefore, in the interest of physicians to remain uninformed about what kinds of terminal care their patients want to receive, nor to be reduced to relying on their own hunches about what their patients "would have wanted" when formulating plans of terminal care. It is also not in the interest of physicians

to have their adherence to a basic principle of medical ethics—that of pursuing the individual patient's well-being—threatened, clouded, or undermined by the strong wishes of possibly distraught family members.

Thus, for physicians, perhaps the greatest advantage of such discussions would be to reduce or eliminate pressure to practice inappropriate kinds of medicine. One of my colleagues speaks movingly about how demoralizing and degrading it is to try to shock a few more beats into the heart of a dying patient or to order yet another invasive, dehumanizing, and expensive procedure in an effort to briefly forestall an inevitable death. He asks, despairingly, "Why is it that when a plan of terminal care is discussed, those who are in favor of doing most, always win?" Thus, many physicians find themselves giving or ordering tests, procedures, and treatments that their best ethical and medical judgments question.

One of the main reasons physicians often feel forced to throw the whole arsenal of medical technology into a questionable effort is that patients' wishes about their own death are not known. "Presumed consent" is a slender reed to support a decision substituting palliative care for aggressive treatment. Thus, many physicians feel forced to presume that their patients "would have wanted" life prolongation, regardless of physical condition or emotional and spiritual cost. This may not, in fact, be the patient's wish; but in the absence of discussion how is the physician to tell?

Reflective, informed, explicit, and reiterated consent provides a much more solid basis, both ethically and legally, for any plan of terminal care than does presumed consent or the questionable consent of a very ill patient. Consequently, the physician is in a much better position to justify a plan of terminal care if death and dying have been discussed with the patient. And the physician would be in the best possible position if he or she could say to the family, to the other members of the hospital staff, and even to a court of law: "For over twenty years I have been discussing with this patient the kind of terminal care and death he wants. We discussed it again after I told him about his present illness, and when he was admitted to the hospital yesterday, he said that nothing had changed. I am giving him precisely the kind of care he has always said he wanted."

#### HOW AND WHEN TO BEGIN DISCUSSION

If patients and their physicians would both benefit from discussing terminal care and dying before the dying process has begun, these discussions ought to be instituted. But how? At the very least physicians could begin by discussing with patients whether they want to be in-

formed about all important medical findings, including terminal illness, and whether they want to be consulted on all important medical decisions; or whether they would like to designate a friend or family member to be informed and to act as a proxy<sup>[15]</sup>. This would, no doubt, often lead naturally into discussions of the kind of terminal care the patient wishes to receive. Alternatively, the physician might begin these discussions by asking the patient whether he or she wants to sign a living will.

There would be significant benefits to both physicians and patients even if the discussion of dying and terminal care got no further than the patient's designating a specific family member to give proxy consent, for the physician would then be spared the agonies of trying to discover which family member speaks most faithfully for the patient, and the patient would gain assurance that the family member most trusted would direct the terminal care if he or she were unable to do so.

When should such discussions take place? One of my colleagues suggests that they would be an appropriate part of the physician's initial interview with a new patient, when the physician is trying to find out who the patient is; and the patient, what kind of practice he or she can expect from this physician; and when neither yet has any reason to believe that the patient is seriously ill. If the physician has strong convictions or principles that dictate the kinds of terminal care he or she is willing to provide, the patient should know what they are from the beginning. If, however, it seems better to wait until a relationship with the patient has been established, this discussion could be initiated *before* a routine physical.

Angell suggests that the discussion process should be repeated on each admission to a hospital. I would disagree with the idea that hospital admission would be the best time to initiate such discussion, because of the patient's anxiety and fear, including fear—often justified—that the physician has not told the whole truth about the patient's illness and the options for treatment. Moreover, discussion upon admission to a hospital often comes too late, not only for the reasons of competence and family pressures discussed above but also because some dying patients ought not to be admitted to a hospital at all, given their preference for dying at home. However, discussion of dying and terminal care upon discharge from the hospital might be a good idea: "You pulled through; you're going to get better. But if you're not so fortunate next time, what kind of care do you want?"

Thus, there are difficult questions about how and when these discussions are best conducted. But I would urge that it is better not to wait until the patient becomes old, for death and dying are not the exclusive preserve of the aged. Moreover, if discussion is begun while the patient is still young and healthy, periodically reviewed, and for-

mulated in a written directive, the long-term stability of the patient's wishes could be a matter of record. Family and friends who will likely bear the burden of witnessing the death would also have had time to become more comfortable with the patient's wishes about his or her terminal care. Finally, although older patients may have thought more about death and dying, they rightfully resent the impression that all they have left to do is die.

### PROBLEMS WITH EARLY DISCUSSION

Objections to the idea of the physician as death counselor can be raised, but they do not seem *prima facie* decisive. Granted, many patients will not have firm convictions about many of the issues. That is one reason to think about and discuss them. And if after reflection the patient still is unsure of what he or she wants, that in itself may be important information for the physician, since a different plan of terminal care may be appropriate for one who is unsure. Granted also, some patients' convictions will be unstable. That is why the discussion needs to be periodically reviewed and renewed. And granted, a patient's preferences may be based on lack of information about what the various choices entail and on unreal expectations about what dying will be like. Physicians should do what they can to clear up misconceptions; this is a crucial aspect of patient education. In sum, the patient's statements about his or her preferred kind of terminal care and death may not always be reliable, but they are almost certainly more reliable than a "facit understanding" of what the patient "would have wanted."

Extremely delicate ethical issues about how physicians should handle the reluctance of some patients to discuss death and dying will also have to be resolved. To what extent should physicians insist on discussing death with patients who seem opposed to such discussion? Is their opposition merely an initial resistance that eventually they will be glad they worked through, or is it symptomatic of a deeper inability to face their own death? If the latter, might these discussions, in the absence of extensive counseling or even therapy, seriously compromise the quality of these patients' individual lives, because of a stultifying preoccupation with death?

Some physicians would no doubt find that they, too, would need to work through their attitudes toward death and dying in order to discuss these matters comfortably, for such discussions bring into focus the fact that both patient and physician will die. Perhaps medical schools and continuing medical education programs should provide training in how best to discuss death and dying with patients.

### CONCLUSION

Even though we all seek to ignore death, and even though our thoughts on our own deaths may not be fully reliable, most of us do care very much about how our lives will end. And thinking about our own deaths is not completely foreign to us: insurance salesmen and lawyers have managed to persuade us to think about these things long enough, at least, to buy life insurance policies and to make out our wills. Physicians similarly should be able to convince us that the disposition of our final days or months is an important matter for reflection, discussion, and then making our wishes known.

I suspect, then, that discussions about death and dying with one's physician would turn out to be much like any other visit to the doctor: you don't want to go, you don't want to even think about the possibilities that make you go—disease, illness, declining vitality, and death. But afterward you're glad you did it.

### NOTES

1. L. S. Baer, *Let the Patient Decide: A Doctor's Advice to Older Persons* (Philadelphia: Westminster Press, 1978), 150.
2. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Summing Up* (Washington D.C.: Government Printing Office, 1983); President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions* (Washington D.C.: Government Printing Office, 1982), 193–251; R. M. Veatch, *Death, Dying, and the Biological Revolution: Our Last Quest for Responsibility* (New Haven, Conn.: Yale University Press, 1976) 204–248.
3. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Deciding to Forego Life-sustaining Treatment* (Washington D.C.: Government Printing Office, 1983) pp. 236–239.
4. *Ibid.*; Veatch, *Last Quest for Responsibility*. N. H. Cassem, R. S. Stewart, "Management and Care of the Dying Patient," *Int. J. Psychiatry Med.* 6 (1975), 293–304; D. Oken, "What to Tell Cancer Patients," *JAMA* 175 (1961), 1120–1128.
5. R. J. Alford, "Informed Consent: A Study of Patient Reaction," *JAMA* 216 (1971), 1325–1329; S. H. Imbus and B. E. Zawacki, "Autonomy for Burned Patients When Survival Is Unprecedented," *N. Engl. J. Med.* (1977), 308–311.
6. S. E. Bedell and T. L. Delbanco, "Choices about Cardiopulmonary Resuscitation in the Hospital: When Do Physicians Talk with Patients?" *N. Engl. J. Med.* (1984), 1089–1093; D. H. Novack et al., "Changes in Physician's Attitudes toward Telling the Cancer Patient" *JAMA* 241 (1979), 897–900.
7. Bedell and Delbanco, "Choices about Cardiopulmonary Resuscitation."
8. *Ibid.*
9. M. Angell, "Respecting the Autonomy of Competent Patients" *N. Engl. J. Med.* 310 (1984), 1116.
10. B. Lo and A. Jonsen, "Clinical Decisions to Limit Treatment" *Ann. Intern.*

*Med.* 93 (1980), 764-768; S. H. Wanzer et al., "The Physician's Responsibility toward Hopelessly Ill Patients," *N. Engl. J. Med.* 310 (1984), 955-959.

11. D. L. Jackson and S. Younger, "Patient Autonomy and 'Death with Dignity,'" *N. Engl. J. Med.* 310 (1979), 404-408.

12. President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, *Making Health Care Decisions* (Washington D.C.: Government Printing Office, 1982); L. H. Roth, A Meisel, and C. W. Lidz, "Tests of Competency to Consent to Treatment," *Am. J. Psychiatry* 134 (1977), 279-283; Wanzer, "The Physician's Responsibility"; Lo and Jansen, "Clinical Decisions."

13. Angell, "Respecting the Autonomy."

14. E. Cassell, "What is the Function of Medicine?" in McMulin E., ed. *Death and Decision* (Boulder, Colo.: Westview Press, 1978), 35-44.

15. Angell, "Respecting the Autonomy."