ADVANCE DIRECTIVES PRESERVE AUTONOMY DESPITE INCAPACITY

A principle topic of worry for older adults is how decisions about their health would be handled if they suddenly were to become incapacitated, whether for several months or for the remainder of their lives. Attorneys and social workers can offer assistance in planning for care before incapacitating illness or injury strikes. Advance directives, a catchall for documents such as living wills and durable powers of attorney, provide individuals with a sound and realistic role in decisions that must be reached by others after the onset of incapacity. These documents merely do not shift decision making to others. Appropriately used, they allow the principal (or maker of the document) to effect decisions in specific appropriate situations. At other times, the agent (or proxy) is authorized to resolve a matter.

Some individuals fear that the existence of advance directives beckons illness and therefore must be avoided. Nonetheless, for some individuals, such documents never will need to be activated. Preparation of the documents by communication with one’s family and physician is a precaution that often results in greater peace of mind for all concerned. In cases where a person’s loss of capacity is predictable, such as Alzheimer’s disease, careful, early planning is essential.

Although financial management, personal care, and health care decisions are all themes for planning, personal care and health care decisions are most important because, in long-term care, they are not separated so easily. Health care decisions become extensions of personal care. How one is to live when one is frail will affect health care through the decision-making process. Personal care matters include arranging for spiritual and religious needs, receiving mail, purchasing clothing and appliances, taking custody of valuable papers, caring for pets, and arranging for travel. Health care matters include making decisions about surgery and the use of medications, the use of life-sustaining technologies, and seeking any medical treatment.

The way in which an individual could bring about control of decision making was illustrated in March 1983, when the President’s Commission for the Study of Ethical Problems in Medicine and Biomedicine and Behavioral Research submitted the extensive report *Deciding to Forgo Life-Sustaining Treatment* in which the use of durable powers of attorney to appoint people who are authorized to make personal and medical decisions is encouraged.\(^1\) While controversy exists in some states about whether their general durable powers laws can include health

\(^1\) *Deciding to Forgo Life-Sustaining Treatment* (Washington, D.C.: President’s Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, 1983).
orders. The Joint Commission on Accreditation of Healthcare Organizations (formerly the Joint Commission on Accreditation of Hospitals) now requires hospitals to have in place protocols for how “Do Not Resuscitate” orders will be handled. All of these efforts contribute to discussions about the ways in which substitute decision making can be made for the range of health care situations.

Maintaining autonomy through personal and surrogate decision making is an important step for everyone, especially those people who are aware of progressive illnesses such as Alzheimer’s disease. Legal instruments, such as durable powers of attorney, are a beneficial method for assuring a balance of autonomy and protection.

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RESERVATIONS ABOUT ADVANCE DIRECTIVES

Advance directives, the documented indication of one’s wishes about medical and personal care made in advance of incapacitating illness or injury, is a subject of increasing interest to health care consumers and providers. Some consumers, especially older persons, view advance directives as absolute assurance that unwanted or burdensome treatment will not be used to prolong their dying. Their concern about such treatment is prompted by personal experiences with family members or friends and by media reports of court cases in which life-sustaining treatment was continued in violation of individual or family wishes. Health care providers, in general, regard written documents such as a living will, the appointment of a proxy decision maker, or both, as information necessary to decision making.

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2Guidelines on the Termination of Life-Sustaining Treatment and the Case of the Dying (Briarcliff Manor, N.Y.: Hastings Center, 1987).
What, then, are some of the concerns about advance directives? The reservations about advance directives are not based on the argument made by some opponents that advance directives, legislative recognition of them, or both, represent a move toward state-sanctioned euthanasia. Instead, one concern is that a misplaced confidence in the absolute prohibition of a specific treatment or of all treatments may exist, or that "everything" will be done, if so requested. If a living will is viewed as having the same power as a regular will—or is used as a substitute for communication about one's wishes—confusion, conflict, and harm may result. This is not an insurmountable objection, but it means that public education is necessary to promote understanding of the purpose and limits of an advance directive.

Can a person give information consent to medical treatment in advance of a specific situation or about a certain treatment modality? Even aside from the issue of what constitutes informed consent in most treatment decisions, an advance directive should not be viewed as informed consent or refusal, nor as binding on proxy and providers in any and all situations that may arise. Rather, it should be regarded as a statement of a person's wishes and beliefs to guide the decision makers in making decisions as the person would have made. The decision makers are obligated to do what is best for the person. Morally, the advance directive serves as a useful guide—a means for maintaining autonomy. Autonomy—self-determination—is not only a basic moral and legal right, but also an instrumental good. Each person is better able to determine what is in his or her own best interest, given his or her values, beliefs, and circumstances, than is someone else. Situations may arise in which it may not be in the best interest of a person to follow a specific directive, particularly in the short term. Reasonable medical judgment may indicate that a certain treatment modality is needed for a person's comfort or that additional time is required for better assessment of long-term prognosis. For example, it may be appropriate to treat despite a nontreatment directive in situations in which medically provided hydration may be necessary for comfort, tube feeding is needed to improve poor nutritional status, resuscitation is required for an emergency such as choking, or intubation for anesthesia for a surgical procedure is necessary for comfort. Note that the nature and intent of such interventions are primarily for temporary relief or to provide additional time for assessment of prognosis. These interventions should not be continued if they provide no long-term benefit and if the person had indicated that he or she wanted to avoid prolonged provision of life-sustaining treatment.

Other important concerns about advance directives relate to the potential for their abuse, such as coercion or fraud, that they might be used for cost-containment reasons or that they might become a universal medical standard. For example, vulnerable persons may be coerced into signing advance directives as conditions of care, or to receive health insurance or fraudulent advance directives may be prepared to prevent or to force treatment. These concerns are not unique to advance directives, but are inherent in many aspects of care. Therefore, awareness by health care providers, advocates, and family members of the potential for abuse and continued advocacy for vulnerable persons will be required. A nontreatment directive might be used to reduce the personal burden of care on the family or for the monetary benefit of family or other proxy, or health care institution for cost containment reasons.

What if advance directives should come to be considered as the norm rather than as additional information to be considered when making treatment decisions? What this portends, at the least, is short-term confusion. Providers already are experiencing confusion because some states do not have legislation on advance directives. Laws that do exist vary. A nationwide Uniform Rights of the Terminally Ill Act has been proposed, which might be interpreted as a national standard for decision making.¹ Such a uniform norm that originally was intended to enhance individual autonomy might become a universal requirement or be regarded as one. Some individuals may not

¹Uniform Rights of the Terminally Ill Act, drafted and approved by the National Conference of Commissioners on Uniform State Laws, Chicago, Ill., August 1985.
want to engage in prospective planning for medical treatment when they become incapacitated. Will their autonomy be respected as well?

The concern about justice is perhaps more speculative. Fairness dictates that all persons be treated similarly, or at least have similar access to care of equal quality. Is an advance directive a claim for a certain quality of care? If so, what about the nonclaimants? Will they be provided with disproportionately burdensome treatment because they have not claimed or declared their right to refuse treatment? Is it conceivable that the reverse could occur and advance directives would become primarily a claim for treatment? Then what of the nonclaimants?

These concerns are a reminder that the topic of advance directives, as with so many issues in medical ethics, becomes more complex as they are pondered. Advance directives must be approached thoughtfully and cautiously, recognizing that they are neither as good nor as bad, as right nor as wrong, as their proponents and opponents claim. Thoughtful discussion, application, and vigilance are needed, as in all areas of health care.

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