



A WILL FOR LIVING

by Stephen L. Mikochik

In 2005, the President's Council on Bioethics (PCBE) issued a report critical of the heavy reliance experts placed on living wills in advance care planning.¹ It specifically questioned whether patients could knowingly elect to forgo life-support in advance of a hypothetical future in which they might become incapacitated. Its thoughtful analysis concluded that living wills neither achieved the ends advocates set for them nor could do so because they were premised on an illusory notion that patients could maintain autonomy in making treatment decisions after becoming incompetent and dependent. Instead it called for greater use of proxy directives (appointing family members or friends to make medical decisions for incapacitated patients) as they offered the best hope for accommodating the known wishes and best interests of such people.

The PCBE analyzed living wills from the perspective of able-bodied persons, contemplating a time when they might become incapacitated. Absent from its report, however, was any discussion of the questions living wills raised for people already disabled, especially whether their wills should include instructions to forgo life-support. Because those concerns are unique, some comment about the use of living wills by such people is warranted to make the PCBE report complete. Before taking up that task, I will first explain some key terms and then outline the analysis the PCBE put forward.

“Advance directives” are declarations by which individuals provide directions for their future medical care in the event they become incompetent.² The term includes both instruction and proxy directives. “Instruction directives” or “living wills” are written instruments in which

individuals set forth their preferences for or against certain therapeutic treatments and the considerations that should govern provision of their future medical care. Living wills can be quite specific, particularly concerning the provision or withdrawal of medically assisted food and hydration, CPR, mechanical ventilation, kidney dialysis and other life-sustaining procedures. “Proxy directives” or “health care powers of attorney” are documents in which individuals designate an agent to make treatment decisions for them if they become incapacitated.

With the advent of more effective life-sustaining techniques after World War II, people became worried that such interventions would merely prolong their dying in an undignified fashion that could drain their families' financial resources.³ The idea of a “living will” was originally advanced during the 1960's to address these concerns. In 1976, California became the first state to give living wills legal effect in its Natural Death Act.⁴ Today, all states have laws authorizing individuals to execute some form of advance directive. In 1990, Congress passed the Patient Self Determination Act that required hospitals and other health care providers receiving Medicare and Medicaid funds to provide patients an opportunity to complete an advance directive upon admission.⁵

Several high-profile cases have raised public interest in living wills. In a 1976 ruling, for example, the New Jersey Supreme Court held that the parents of a young woman in a “persistent vegetative state” who had never completed a living will could have her respirator removed if their best judgment were that she would have agreed if competent.⁶ In a later case involving similar facts, the U.S. Supreme Court decided that States would

not violate the Fourteenth Amendment by requiring clear and convincing evidence of incompetent patients' past wishes before guardians could have their food and hydration discontinued.⁷ And in the recent debate surrounding Terri Schiavo, allegedly in a "persistent vegetative state" as well, some argued that, if only she had executed a living will, the litigation over withdrawal of her food and hydration could have been avoided.

Advocates for living wills argue that they promote autonomy by enabling patients to avoid overtreatment, as well as costly procedures that could drain resources they want to leave for family and friends, at a time when their incapacity prevents them from objecting.⁸ Living wills also keep decision-making on the patient's shoulders, relieving family members of the stress and discord that would result if decisions to forgo treatment were theirs. Further, completing a living will facilitates rational planning before the onset of critical ailments and can foster communication among patients, families and physicians over the care patients would prefer at the end of life.

The PCBE, however, contended that living wills could not meet the goals their advocates set for them.⁹ First, most Americans have never executed a living will. When they do, it may not accurately reflect their preferences since individuals are asked to predict their reactions to a host of maladies they cannot anticipate and medical interventions they may not understand. Even when living wills address specific scenarios, they may provide little guidance if other ailments are actually contracted. Further, since treatment choices often change over time, individuals may neglect to alter their living wills to reflect such change. Finally, living wills frequently are not transmitted to those making medical decisions; and, when they are, there is evidence that incompetent patients often receive care inconsistent with their instructions.

The PCBE concluded that, at bottom, the premise that living wills would further patient autonomy was flawed since they could not insure genuinely informed consent.¹⁰ Simply put, informed consent to treatment decisions requires a grasp of facts no one can truly know in advance. For example, patients "do not and cannot know in advance

whether the experience of old age with dementia will still seem valuable to a future self, even though it is not the life they would freely choose. Can individuals really know in advance that such a life would be worse than death?"¹¹ Though not suggesting that health providers wholly disregard the instructions patients set forth in their living wills, the PCBE nonetheless claimed that giving them trumping effect would ignore the fact that patients' wishes could change over time and adapt to new circumstances.

Ultimately, the PCBE concluded that living wills were a failed attempt to maintain autonomy in the face of dependence. It thus determined that the prospect of incapacity called for patients to place their trust in another's judgment to make the best treatment decisions for them, taking both their prior wishes and present circumstances into account.¹² It accordingly saw proxy directives as a superior avenue for advance care planning. Such directives take seriously patients' desires to shape their future treatment by enabling the family or friends they select to make such choices, while "[a]t the same time, ... emphasis[ing] less the importance of self-determination and correspondingly more the importance of solidarity and interdependence."¹³

The PCBE, however, did not consider whether people already disabled were in any better position to give genuinely informed consent.¹⁴ After all, such people know their own conditions and can judge for themselves whether their lives are worth continuing. Why should they not have the option to decline resuscitation or other forms of life-support in order to end burdens they no longer wish to bear? Yet we should not be quick to conclude that such consent is truly informed since it may only expose our own fears about living with disability.

Admittedly, disabled people can internalize society's negative attitudes about their conditions and consequently choose in living wills to forgo life-support. This is most evident at the onset of a traumatic injury when individuals first experience the loss of capacity. With pain management and rehabilitation, however, these feelings often dissipate over time. This is true especially when the worth of their lives is vindicated through

meaningful employment or by families, friends and faith communities who appreciate their gifts. Of course, they would never experience that positive change if their instructions to forgo life-support became effective first. And such directives can lie around like loaded guns ready to discharge even after that change has occurred.

Even people with long-standing disabilities may remain vulnerable to the suggestions of others that their lives are not worth living. Physicians may subtly communicate the message that such patients' "quality of life" is low or that strained health care resources can be better spent elsewhere. Families may share in these negative attitudes and make disabled members feel guilty about the burden of care the family must bear. As a result, disabled people may elect to forgo life-support in a living will under the misguided notion that they are acting selflessly or that God is offering them an "out" even when, on the contrary, rejecting such care may constitute suicide by omission.

Advocates further claim that the control over end-of-life care that living wills provide is particularly valuable for disabled people because they are often the victims of enforced dependence. By forgoing life-support, it is said, such individuals act autonomously and thus affirm their human worth. Yet it is a curious kind of autonomy that liberates only by having people make themselves dead. Rather than empowering disabled people to take charge of their lives, it constitutes a final surrender to helplessness. "This is, of course, part of the pro euthanasia philosophy that sick and disabled people want and need 'death with dignity,' strongly implying that we are 'dignified' only in death."¹⁵

Weighing these concerns, it is tempting to reply that disabled people should execute living wills that forbid health providers ever to terminate their life-support. Such documents, however, offer no assurance of treatment if they are unavailable or disregarded when patients are unable to speak for themselves. Moreover, if strictly followed, such instructions could undercut patients' own best interests since treatment that merely prolonged dying would have to continue.

Notwithstanding the PCBE's preference for proxy directives, giving designees broad discretion to make on-the-spot treatment decisions is also an imperfect solution. Not all proxies know and respect the lives and wishes of the disabled people they represent, and it would be rash not to take account of the chance that proxies may choose to forgo life-support to end patients' lives they think not worth continuing or to obtain for themselves some pecuniary gain.

Perhaps a better approach is for disabled people (and, for that matter, able-bodied people as well) to complete advance directives that presume in favor of life-support while permitting proxies to forgo such treatment should it become fruitless. Put another way, proxies should discontinue life-sustaining measures only if death is inevitable and imminent, the measures cause intractable suffering, or the financial burden the treatment imposes on families is truly excessive in light of its limited benefit for sustaining patients' lives. This approach may help avoid decisions based on "quality of life" rather than quality of treatment and provide some measure for judging the propriety of choices made on patients' behalf.

The PCBE stated a durable truth when it observed: "We should not too readily acquiesce in a vision that isolates us in the time of our dependency, or a vision that rests on the false notion that individuals can precisely determine and manage every facet of their lives until the very end."¹⁶ To this insight, I would add that disabled people should never accede to a vision of health care planning that disparages the lives they have lived. Accordingly, any living will or other advance directive they choose to complete should clearly display a presumption in favor of a will for living.

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¹ See President's Council on Bioethics, *Taking Care: Ethical Caregiving in Our Aging Society*, "Chapter 2: The Limited Wisdom of Advance Directives" (Sept., 2005).

² See *ibid.*, at 56-58. See also U.S. Dept. of Health and Human Services, *Literature Review on Advance Directives*, 3-6 (June, 2007). The PCBE would include oral instructions within advance directives. The HHS Reviewers, however, contend that, as commonly used in the medical literature, the term is limited to written instruments.

³ See *Taking Care*, at 58-67. See also *Literature Review*, at 7-8.

⁴ See *Taking Care*, at 91 n.2.

⁵ See *ibid.*, at 91 n.5.

⁶ See *In re Quinlan*, 355 A.2d 647 (N.J. 1976).

⁷ See *Cruzan v. Director, Mo. Dept. of Health*, 497 U.S. 261 (1990).

⁸ See *Taking Care*, at 67-70.

⁹ See *ibid.*, at 70-79; Perkins, Henry S., "Controlling Death: The False Promise of Advance Directives," *Annals of Internal Medicine*, Vol. 100, Iss. 1, 51 (July 3, 2007).

¹⁰ See *Taking Care*, at 80-88.

¹¹ *Ibid.*, at 83-84.

¹² See *ibid.*, at 89-90.

¹³ *Ibid.*, at 89.

¹⁴ See generally, Stith, Marah, "The Semblance of Autonomy: Treatment of Persons with Disabilities under the Uniform Health-Decisions Act," 22 *Issues L. & Med.* 39 (Summer, 2006); Ouellette, Alicia, "Disability and the End of Life," 85 *Oreg. L. Rev.* 123 (2006). Cf. N.Y. State Task Force on Life & the Law, "When Death is Sought: Assisted Suicide and Euthanasia in the Medical Context," 120-125 & 146-148 (May, 1994).

¹⁵ Davis, Alison, "The Mental Capacity Act: A Disability Perspective" (unpublished presentation at Oxford University) (2005).

¹⁶ *Taking Care*, at 90.

Resources

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www.healthinaging.org/public_education/pain (American Geriatrics Society Foundation for Health in Aging)

www.iaetf.org (International Task Force on Euthanasia and Assisted Suicide)

www.kofc.org/faith/cis/028/sacredlife.cfm (Knights of Columbus Catholic Information Service)

www.ncbcenter.org (Nat'l Catholic Bioethics Center)

www.ncpd.org (Nat'l Catholic Partnership on Disability)

www.nrlc.org (Nat'l Right to Life Committee)

www.nursesforlife.org (Nat'l Assn. of Pro-Life Nurses)

www.seniorhealthcare.org (Senior Health Care Organization)

www.usccb.org/prolife/issues/euthanas/index.shtml#1 (USCCB Secretariat of Pro-Life Activities)

www.vegetativestate.org (papers presented at the International Congress on Life-Sustaining Treatments and Vegetative State)