



often dissipate, especially when the worth of their lives is vindicated through meaningful employment or by families, friends and faith communities who appreciate their gifts. Yet 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 state that the patients' "quality of life" is low. Families may make disabled members feel guilty about the burden of care the family must bear. Disabled people may elect to forgo life-support in a living will under the misguided notion that they are acting selflessly.

Advocates claim that the control over end-of-life care is valuable for disabled people because they are often the victims of dependence. By forgoing life support, 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. This does not empower disabled people; it constitutes a final surrender to helplessness.

Giving designees broad discretion to make on-the-spot treatment decisions is also an imperfect solution. They may not respect the lives and wishes of the disabled people they represent. They may think the disabled life is not worth continuing or seek some pecuniary gain by the person's death.

Perhaps a better approach is for both disabled and able-bodied people to complete advance directives that presume in favor of life support while permitting proxies to forgo such treatment should it become fruitless. That is, 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.

The PCBE 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." Disabled people should never accede to a vision of health care planning that disparages the lives they have lived. Any advance directive should clearly display a presumption in favor of a will for living.

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The full-length version of this article is posted at <http://www.usccb.org/prolife/programs/rlp/mikochik.pdf>.



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# A WILL FOR LIVING

*by Stephen L. Mikochik*

*Hope and Trust in Life!*  
**RESPECT LIFE**

In 2005, the President's Council on Bioethics (PCBE) issued a report critical of living wills in advance care planning. It questioned whether patients could knowingly elect to forgo life support in advance of a hypothetical future in which they might become incapacitated. 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.

Absent from the PCBE's 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. Those concerns are unique and some comment about the use of living wills by such people is warranted. 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. Through written “instruction directives” or “living wills,”



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 life-sustaining techniques, people became worried that such interventions would merely prolong their dying in an undignified fashion that could drain their families' financial resources. The “living will” was advanced during the 1960's to address these concerns.

Advocates for living wills argue that they promote autonomy by enabling patients to avoid overtreatment and costly procedures that could drain resources they want to leave for family and friends. Living wills also keep decision-making on the patient's shoulders, relieving family members of the stress and discord that could result if decisions to forgo treatment were theirs.

The PCBE, however, contended that living wills could not meet the goals their advocates set for them. They may not accurately reflect a person's preferences since individuals are asked to predict their reactions to a host of maladies they cannot anticipate and medical interventions they may not understand. Treatment choices often change over time, yet individuals may neglect to alter their living wills to reflect such

change. Finally, there is evidence that incompetent patients often receive care inconsistent with their instructions.

The PCBE concluded that living wills could not ensure genuinely informed consent because that requires a grasp of facts no one can truly know in advance.

The PCBE thus 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 by means of proxy directives. Such directives take seriously patients' desires to shape their future treatment by enabling the family or friends they select to make such choices, while “emphasiz[ing] less the importance of selfdetermination and correspondingly more the importance of solidarity and interdependence.”

But 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