Enough: The Failure of the Living Will

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Enough

THE FAILURE OF THE LIVING WILL

By Angela Fagerlin and Carl E. Schneider

In pursuit of the dream that patients’ exercise of autonomy could extend beyond their span of competence, living wills have passed from controversy to conventional wisdom, to widely promoted policy. But the policy has not produced results, and should be abandoned.

By their fruits ye shall know them.

Enough. The living will has failed, and it is time to say so.

We should have known it would fail: A notable but neglected psychological literature always provided arresting reasons to expect the policy of living wills to misfire. Given their alluring potential, perhaps they were worth trying. But a crescendoing empirical literature and persistent clinical disappointments reveal that the rewards of the campaign to promote living wills do not justify its costs. Nor can any degree of tinkering ever make the living will an effective instrument of social policy.

As the evidence of failure has mounted, living wills have lost some of their friends. We offer systematic support for their change of heart. But living wills are still widely and confidently urged on patients, and they retain the allegiance of many bioethicists, doctors, nurses, social workers, and patients. For these loyal advocates, we offer systematic proof that such persistence in error is but the triumph of dogma over inquiry and hope over experience.

A note about the scope of our contentions: First, we reject only living wills, not durable powers of attorney. Second, there are excellent reasons to be skeptical of living wills on principle. For example, perhaps former selves should not be able to bind latter selves in the ways living wills contemplate. And many people do and perhaps should reject the view of patients, their families, and their communities that informs living wills. But we accept for the sake of argument that living wills desirably serve a strong version of patients’ autonomy. We contend, nevertheless, that living wills do not and cannot achieve that goal.

And a stipulation: We do not propose the elimination of living wills. We can imagine recommending them to patients whose medical situation is plain, whose crisis is imminent, whose preferences...
are specific, strong, and delineable, and who have special reasons to prescribe their care. We argue on the level of public policy: In an attempt to extend patients’ exercise of autonomy beyond their span of competence, resources have been lavished to make living wills routine and even universal. This policy has not produced results that recompense its costs, and it should therefore be renounced.

Living wills are a bioethical idea that has passed from controversy to conventional wisdom, from the counsel of academic journals to the conventions of law books, from professors’ proposals to professional practice. Advance directives generally are embodied in federal policy by the Patient Self-Determination Act, which requires medical institutions to give patients information about their state’s advance directives. In turn, the law of every state provides for advance directives, almost all states provide for living wills, and most states “have at least two statutes, one establishing a living will type directive, the other establishing a proxy or durable power of attorney for health care.” Not only are all these statutes very much in effect, but new legislative activity is constant. Senators Rockefeller, Collins, and Specter have introduced bills to “strengthen” the PSDA and living wills, and state legislatures continue to amend living will statutes and to enact new ones.

Courts and administrative agencies too have become advocates of living wills. The Veterans Administration has proposed a rule to encourage the use of advance directives, including living wills. Where legislatures have not granted living wills legal status, some courts have done so as a matter of common law, and where legislatures have granted them legal status, courts have cooperated with eager enthusiasm. Living wills have assumed special importance in states that prohibit terminating treatment in the absence of strong evidence of the patient’s wishes. One supreme court summarized a common theme: “[A] written directive would provide the most concrete evidence of the patient’s decisions, and we strongly urge all persons to create such a directive.”

Not only do legislatures, courts, administrative agencies, and professional associations promote the living will, but other groups unite with them. The Web abounds in sites advocating the living will to patients. The web site for our university’s hospital plugs advance directives and suggests that it “is probably better to have written instructions because then everyone can read them and understand your wishes.”

Our own experience in presenting this paper is that its thesis provokes some bioethicists to disbelief and inertia.

If after so much propaganda so few of us have living wills, do we really want them, or are we just saying what we think we ought to think and what investigators want to hear?

The grandees of law and medicine also give their benediction to the living will. The AMAs Council on Ethical and Judicial Affairs proclaims: “Physicians should encourage their patients to document their treatment preferences or to appoint a health care proxy with whom they can discuss their values regarding health care and treatment.” The elite National Conference of Commissioners on Uniform State Laws continues to promulgate the Uniform Health-Care Decisions Act, a prestigious model statute that has been put into law in a still-growing number of states. Medical journals regularly admonish doctors and nurses to see that patients have advance directives, including living wills. Bar journals regularly admonish lawyers that their clients—all their clients—need advance directives, including living wills. Researchers demonstrate their conviction that living wills are important by the persistence of their studies of patients’ attitudes toward living wills and ways of inveigling patients to sign them.

Dignation. It is as though they simply cannot bear to believe that living wills might not work. How can anything so intuitively right be proved so infuriatingly wrong? And indeed, bioethicists continue to investigate ways the living will might be extended (to deal with problems of the mentally ill and of minors, for example) and developed for other countries.

Although some sophisticated observers have long doubted the wisdom of living wills, proponents have tended to respond in one of three ways, all of which preserve an important role for living wills. First, proponents have supposed that the principal problem with living wills is that people just won’t sign them. These proponents have persevered in the struggle to find ways of getting more people to sign up.

Second, proponents have reasserted the usefulness of the living will. For example, Norman Cantor, distinguished advocate of living wills, acknowledges that “some commentators doubt the utility or efficacy of advance directives,” (by which he
means the living will), but he con-cludes that “these objections don’t ob-viate the importance of advance di-recitives.” Other proponents are daunted by the criticisms of living wills but offer new justifications for them. Linda Emanuel, another emi-nent exponent of living wills, writes that “living wills can help doctors and patients talk about dying” and can thereby “open the door to a positive, caring approach to death.”¹⁷

Third, some proponents concede the weaknesses of the living will and the advantages of the durable power of attorney and then propose a durable power of attorney that incor-porates a living will. That is, the forms they propose for establishing a durable power of attorney invite their authors to provide the kinds of in-structions formerly confined to living wills.¹⁸

None of these responses fully grapples with the whole range of difficul-ties that confound the policy promot-ing living wills. In fairness, this is partly because the case against that policy has been made piecemeal and not in a full-fledged and full-throated analysis of the empirical literature on living wills.

In sum, the law has embraced the principle of living wills and cheerfully continues to this moment to expound and expand that principle. Doctors, nurses, hospitals, and lawyers are daily urged to convince their patients and clients to adopt living wills, and patients hear their virtues from many other sources besides. Some advocates of living wills have shifted the grounds for their support of living wills, but they persist in believing that they are useful. The time has come to investi-gate those policies and those hopes systematically. That is what this article attempts.

We ask an obvious but unasked question: What would it take for a regime of living wills to function as their advocates hope? First, people must have living wills. Second, they must decide what treatment they would want if incompetent. Third, they must accurately and lucidly state that preference. Fourth, their living wills must be available to people making decisions for a patient. Fifth, those people must grasp and heed the living will’s instructions. These condi-tions are unmet and largely un-meetable.

Do People Have Living Wills?

At the level of principle, living wills have triumphed among the public as among the princes of medi-cine. People widely say they want a living will, and living wills have so much become conventional medical wisdom “that involvement in the process is being portrayed as a duty to physicians and others.”¹⁹ Despite this, and despite decades of urging, most Americans lack them.²⁰ While most of us who need one have a property will, roughly 18 percent have living wills.²¹ The chronically or terminally ill are likelier to prepare living wills than the healthy, but even they do so fitfully.²² In one study of dialysis pa-tients, for instance, only 35 percent had a living will, even though all of them thought living wills a “good idea.”²³

Why do people flout the conven-tional wisdom? The flouters advance many explanations.²⁴ They don’t know enough about living wills,²⁵ they think living wills hard to exe-cute,²⁶ they procrastinate,²⁷ they hesi-tate to broach the topic to their doc-tors (as their doctors likewise hesi-tate),²⁸ Some patients doubt they need a living will. Some think living wills are for the elderly or infirm and count themselves in neither group.²⁹ Others suspect that living wills do not change the treatment people receive; 91 percent of the veterans in one study shared that suspicion.³⁰ Many patients are content or even anxious to delegate decisions to their fami-lieties,³¹ often because they care less what decisions are made than that they are made by people they trust. Some patients find living wills incom-patible with their cultural traditions.³²

Thus in the large SUPPORT and HELP studies, most patients pre-ferred to leave final resuscitation deci-sions to their family and physician in stead of having their own preferences expressly followed (70.8% in HELP and 78.0% in SUPPORT). “This result is so striking that it is worth re-stating: not even a third of the HELP patients and hardly more than a fifth of the SUPPORT patients “would want their own preferences fol-lowed.”³³

If people lacked living wills only because of ignorance, living wills might proliferate with education. But studies seem not to “support the specu-lations found in the literature that the low level of advance directives use is due primarily to a lack of informa-tion and encouragement from health care professionals and family members.”³⁴ Rather, there is considerable evi-dence “that the elderly’s action of delaying execution of advance direc-tives and deferring to others is a delib-erate, if not an explicit, refusal to par-ticipate in the advance directives process.”³⁵

The federal government has sought to propagate living wills through the Patient Self-Determina-tion Act,³⁶ which essentially requires medical institutions to inform pa-tients about advance directives. How-ever, “empirical studies demonstrate that: the PSDA has generally failed to foster a significant increase in advance directives use; it is being implemented by medical institutions and their per-sonnel in a passive manner; and the involvement of physicians in its im-plmentation is lacking.”³⁷ One com-mentator even thinks “the PSDA’s legal requirements have become a ceiling instead of a floor.”³⁸

In short, people have reasons, often substantial and estimable rea-sons, for eschewing living wills, rea-sons unlikely to be overcome by persua-sion. Indeed, persuasion seems quickly to find its limits. Numerous studies indicate that without consid-erable intervention, approximately 20 percent of us complete living wills, but programs to propagate wills have mixed results.³⁹ Some have achieved significant if still limited increases in
the completion of living wills, while others have quite failed to do so.

Thus we must ask: If after so much propaganda so few of us have living wills, do we really want them, or are we just saying what we think we ought to think and what investigators want to hear?

**Do People Know What They Will Want?**

Suppose, counterfactually, that people executed living wills. For those documents to work, people would have to predict their preferences accurately. This is an ambitious demand. Even patients making contemporary decisions about contemporary illnesses are regularly daunted by the decisions’ difficulty. They are human. We humans falter in gathering information, misunderstand and ignore what we gather, lack well-considered preferences to guide decisions, and rush headlong to choice. How much harder, then, is it to conjure up preferences for an unspecifiable future confronted with unidentifiable maladies with unpredictable treatments?

For example, people often misapprehend crucial background facts about their medical choices. Oregon has made medical policy in fresh and controversial ways, has recently had two referenda on assisted suicide, and alone has legalized it. Presumably, then, its citizens are especially knowledgeable. But only 46 percent of them knew that patients may legally withdraw life-sustaining treatment. Not only do people regularly know too little when they sign a living will, but often (again, we’re human) they analyze their choices only superficially before placing them in the time capsule. An ocean of evidence affirms that answers are shaped by the way questions are asked. Preferences about treatments are influenced by factors like whether success or failure rates are used, the level of detail employed, and whether long- or short-term consequences are explained first. Thus in one study, “201 elderly subjects opted for the intervention 12% of the time when it was presented negatively, 18% of the time when it was phrased as an advance directive already in use, and 30% of the time when it was phrased positively. Seventy-seven percent of the subjects changed their minds at least once when given the same case scenario but a different description of the intervention.”

If patients have trouble with contemporaneous decisions, how much more trouble must they have with prospective ones. For such decisions to be “true,” patients’ preferences must be reasonably stable. Surprisingly often, they are not. A famous study of eighteen women in a “natural childbirth” class found that preferences about anesthesia and avoiding pain were relatively stable before childbirth, but at “the beginning of active labor (4-5 cm dilation) there was a shift in the preference toward avoiding labor pains... During the transition phase of labor (8-10cm)
the values remained relatively stable, but then . . . the mothers’ preferences shifted again at postpartum toward avoiding the use of anesthesia during the delivery of her next child.”52 And not only are preferences surprisingly labile, but people have trouble recognizing that their views have changed.53 This makes it less likely they will amend their living wills as their opinions develop and more likely that their living wills will trea-sonously misrepresent their wishes.

Instability matters. The healthy may incautiously prefer death to dis-arbility. Once stricken, competent pa-tients can test and reject that prefer-ence. They often do.4 Thus Wilfrid Sheed “quickly learned [that] cancer, even more than polio, has a disarran-ging way of bargaining downward, begin-ning with your whole estate and then letting you keep the game war-den’s cottage or badminton court; and by the time it has tried to fright-en you to death and threatened to take away your very existence, you’d be amazed at how little you’re willing to settle for.”55

At least sixteen studies have inves-tigated the stability of people’s prefer-ences for life-sustaining treatment.54 A meta-analysis of eleven of these studies found that the stability of pa-tients’ preferences was 71 percent (the range was 57 percent to 89 per-cent).57 Although stability depended on numerous factors (including the illness, the treatment, and demo-graphic variables), the bottom line is that, over periods as short as two years, almost one-third of preferences for life-sustaining medical treatment changed. More particularly, illness and hospitalization change people’s preferences for life-sustaining treatments.58 In a prospective study, the desire for life-sustaining treatment declined significantly after hospital-ization but returned almost to its original level three to six months later.59 Another study concluded that the “will to live is highly unstable among terminally ill cancer pa-tients.”60 The authors thought their findings “perhaps not surprising, given that only 10-14% of individu-als who survive a suicide attempt commit suicide during the next 10 years, which suggests that a desire to die is inherently changeable.”

The consistent finding that inter est in life-sustaining treatment shifts over time and across contexts coin-cides tellingly with research charting people’s struggles to predict their own tastes, behavior, and emotions even over short periods and under familiar circumstances.61 People mispredict what poster they will like,62 how much they will buy at the grocery store,63 how sublimely they will enjoy an ice cream,64 and how they will ad-just to tenure decisions.65 And people “miswant” for numerous reasons.66 They imagine a different event from the one that actually occurs, nurture inaccurate theories about what gives them pleasure,67 forget they might outward misery, concentrate on salient negative events and ignore offsetting happier ones,68 and misgauge the ef-fect of physiological sensations like pain.69 Given this rich stew of re-search on people’s missteps in pre-dicting their tastes generally, we should expect misapprehensions about end-of-life preferences. Indeed, those preferences should be especially volatile, since people lack experience deciding to die.

Can People Articulate What They Want?

Suppose, arguendo, that patients regularly made sound choices about future treatments and write liv-ing wills. Can they articulate their choices accurately? This question is crucially unrealistic, of course, be-cause the assumption is false. People have trouble reaching well-considered decisions, and you cannot state clearly on paper what is muddled in your mind. And indeed people do, for in-stance, issue mutually inconsistent instructions in living wills.70

But assume this difficulty away and the problem of articulation per-sists. In one sense, the best way to di-vine patients’ preferences is to have them write their own living wills to give surrogates the patient’s gloriously unmediated voice. This is not a prac-tical policy. Too many people are functionally illiterate,71 and most of the literate cannot express themselves clearly in writing. It’s hard, even for the expert writer. Furthermore, most people know too little about their choices to cover all the relevant sub-jects. Hence living wills are generally forms that demand little writing. But the forms have failed. For example, “several studies suggest that even those patients who have completed AD forms . . . may not fully under stand the function of the form or its language.”72 Living wills routinely baffle patients with their “syntactic complexity, concept density, abstractness, organization, coherence, sequence of ideas, page format, length of line of print, length of paragraph, punctuation, illustrations, color, and reader in-terest.” Unfortunately, most ad-ance directive forms . . . often have neither a reasonable scope nor depth. They do not ask all the right questions and they do not ask those questions in a manner that elicits clear responses.73

Doctors and lawyers who believe their clients are all above average should ask them what their living will says. One of us (CES) has tried the experiment. The modal answer is, in its entirety: “It says I don’t want to be a vegetable.”

No doubt the forms could be im-proved, but not enough to matter. The world abounds in dreadfully drafted forms because writing com-plex instructions for the future is crushingly difficult. Statutes read horribly because their authors are struggling to (1) work out exactly what rule they want, (2) imagine all the circumstances in which it might apply, and (3) find language to speci-fy all those but only those circum-stances. Each task is ultimately im-possible, which is why statutes explicit-ly or implicitly confide their en-forcers with some discretion and why
courts must interpret—rewrite?—statutes. However, these skills and resources are not available to physicians or surrogates.

One might retort that property wills work and that living wills are not that far removed from property wills. But wills work as well as they do to distribute property because their scope is—compared to living wills—narrow and routinized. Most people have little property to distribute and few plausible heirs. As property accumulates and ambitions swell, problems proliferate. Many of them are resolvable because experts—lawyers—exclusively draft and interpret wills. Lawyers have been experimenting for centuries with testamentary language in a process which has produced standard formulas with predictable meanings and standard ways of distributing property into which testators are channeled. Finally, if testators didn’t say it clearly enough in the right words and following the right procedures, courts coolly ignore their wishes and substitute default rules.

The lamentable history of the living will demonstrates just how recalcitrant these problems are. There have been, essentially, three generations of living wills. At first, they stated fatuously general desires in absurdly general terms. As the vacuity of over-generality became clear, advocates of living wills did the obvious: Were living wills too general? Make them specific. Were they “one size fits all”? Make them elaborate questionnaires. Were they uncritically signed? “Require” probing discussions between doctor and patient. However, the demand for specificity forced patients to address more questions than they could comprehend. So, generalities were insufficiently specific and insufficiently considered. Specifics were insufficiently general and perhaps still insufficiently considered. What was a doctor—or lawyer—to do? Behold the “values history,” a disquisition on the patient’s supposed overarching beliefs from which to infer answers to specific questions. That patients can be induced to trek through these inextricable and imponderable documents is unproved and unlikely. That useful conclusions can be drawn from the platitudes they evoke is false. As Justice Holmes knew, “General propositions do not decide concrete cases.”

The lessons of this story are that drafting instructions is harder than proponents of living wills seem to believe and that when you move toward one blessing in structuring these documents, you walk away from another. The failure to devise workable forms is not a failure of effort or intelligence. It is a consequence of attempting the impossible.

Where Is the Living Will?
Suppose that, mirabile dictu, people executed living wills, knew what they will want, and could say it. That will not matter unless the living will reaches the people responsible for the incompetent patient. Often, it does not. This should be no surprise, for long can be the road from the draftee’s chair to the ICU bed.

First, the living will may be signed years before it is used, and its existence and location may vanish in the mists of time. Roughly half of all living wills are drawn up by lawyers and must somehow reach the hospital, and 62 percent of patients do not give their living will to their physician. On admission to the hospital, patients can be too assailed and anxious to recall and mention their advance directives. Admission clerks can be harried, neglectful, and loath to ask patients awkward questions.

Thus when a team of researchers reviewed the charts of 182 patients who had completed a living will before being hospitalized, they found that only 26 percent of the charts accurately recorded information about those directives, and only 16 percent of the charts contained the form.

Will Proxies Read It Accurately?
Suppose, per impossibile, that patients wrote living wills, correctly anticipated their preferences, articulated their desires lucidly, and conveyed their document to its interpreters. How acutely will the interpreters analyze their instructions? Living wills are not self-executing; some-
one must decide whether the patient is incompetent, whether a medical situation described in the living will has arisen, and what the living will then commands.

Usually, the patient's intimates will be central among a living will's inter-
preters. We might hope that intimates already know the patient's mind, so that only modest demands need be made on their interpreting skills. But many studies have asked such sur-
gates to predict what treatment the patient would choose.81 Across these
studies, approximately 70 percent of the predictions were correct—not in-
spiring success for life and death deci-
sions.

Do living wills help? We know of only one study that addresses that
question. In a randomized trial, re-
searchers asked elderly patients to
complete a disease- and treatment-
based or a value-based living will.82 A
control group of elderly patients com-
piled no living will. The surrogates
were generally spouses or children
who had known the patient for
decades. Surrogates who were not
able to consult their loved one's living
will predicted patients' preferences
about 70 percent of the time. Strik-
ingly, surrogates who consulted the
living will did no better than surro-
gates denied it. Nor were surrogates
more successful when they discussed
living wills with patients just before
their prediction.

What is more, a similar study
found that primary care physi-
cians' predictions were similarly unim-
proved by providing them with pa-
tients' advance directives.83 On the
other hand, emergency room doctors
(complete strangers) given a living
will more accurately predicted pa-
tients' preferences than ER doctors
without one.84

Do Living Wills Alter Patient
Care?

O ur survey of the mounting em-
pirical evidence shows that none of the five requisites to making living
wills successful social policy is met
now or is likely to be. The program
has failed, and indeed is impossible.

That impossibility is confirmed by
studies of how living wills are imple-
mented, which show that living wills
seem not to affect patients' treat-
ments. For instance, one study con-
cluded that living wills "do not infl-
ence the level of medical care overall.
This finding was manifested in the
quantitatively equal use of diagnostic
testing, operations, and invasive he-
modynamic monitoring among pa-
tients with and without advance di-
rectives. Hospital and ICU lengths of
stay, as well as health care costs, were
also similar for patients with and
without advance directive state-
ments."85 Another study found that
in thirty of thirty-nine cases in which a
patient was incompetent and the
living will was in the patient's medical
record, the surrogate decisionmaker
was not the person the patient had
appointed.86 In yet a third study, a
quarter of the patients received care
that was inconsistent with their living
will.87

But all this is normal. Harry Tru-
man rightly predicted that his succe-
sor would "sit here, and he'll say, 'Do
this! Do that!' And nothing will hap-
pen. Poor Ike—it won't be a bit like
the army. He'll find it very frustrat-
ing." (Of course, the army isn't like
the army. He'll find it very frustrat-
pen. Poor Ike—it won't be a bit like

Third, "family members or the
surrogate designated in a [durable
power of attorney] were not available,
were ineffectual, or were overwhelmed with their own concerns and did not effectively advocate for the patient.” Family members are crucial surrogates because they should be: patients commonly want them to be; they commonly want to be; they specially cherish the patient's interests. Doctors ordinarily assume families know the patient's situation and preferences and may not relish responsibility for life-and-death decisions, and doctors intent on avoiding litigation may realize that the only plausible plaintiffs are families. The family, however, may not direct attention to the advance directive and may not insist on its enforcement. In fact, surrogates may be guided by either their own treatment preferences or an urgent desire to keep their beloved alive.94

In sum, not only are we awash in evidence that the prerequisites for a successful living wills policy are unachievable, but there is direct evidence that living wills regularly fail to have their intended effect. That failure is confirmed by the numerous convincing explanations for it. And if living wills do not affect treatment, they do not work.

Do Living Wills Have Beneficial Side Effects?

Even if living wills do not effectively promote patients’ autonomy, they might have other benefits that justify their costs. There are three promising candidates.

First, living wills might stimulate conversation between doctor and patient about terminal treatment. However, at least one study finds little association between patients’ reports of executing an advance directive and their reports of such conversations.95 Nor do these conversations, when they occur, appear satisfactory.96 James Tulsky and colleagues asked experienced clinicians who had relationships with patients who were over sixty-five or seriously ill to “discuss advance directives in whatever way you think is appropriate” with them. Although the doctors knew they were being taped, the conversations were impressively short and one-sided: The median discussion “lasted 5.6 minutes (range, 0.9 to 15.0 minutes.) Physicians spoke for a median of 3.9 minutes (range, 0.6 to 10.9 minutes), and patients spoke for the remaining 1.7 minutes (range, 0.3 to 9.6 minutes). . . . Usually, the conversation ended without any specific follow-up plan.” The “(p)atients’ personal values, goals for care, and reasons for treatment preferences were discussed in 71% of cases and were explicitly elicited by 34% of physicians.” But doctors commonly “did not explore the reasons for patient’s preferences and merely determined whether they wanted specific interventions.”97

We should abjure programs intended to cajole everyone into signing living wills. We should repeal the PSDA, which was passed with arrant and arrogant indifference to its effectiveness and its costs and which today imposes accumulating paperwork and administrative expense for paltry rewards.

True, the patients all thought “their physicians did a good job talking about the issues,” but this only suggests that patients did not understand how little they were told.

The second candidate for beneficial side effect arises from evidence that living wills may comfort patients and surrogates. People with a living will apparently gain confidence that their surrogates will understand their preferences and will implement them comfortably, and the surrogates concur.98 Improved satisfaction with decisions was also a rare positive effect of the SUPPORT study (which devoted enormous resources to improving end of life decisions and care but made dismayingly little difference).99

In another study, living wills reduced the stress and unhappiness of family members who had recently with-
drawn life support from a relative. But even if living wills make patients and surrogates more confident and comfortable, those qualities are apparently unrelated to the accuracy of surrogates’ decisions. Thus we are left with the irony that one of the best arguments for a tool for enhancing people’s autonomy is that it deceives them into confidence.

Third, because living wills generally constrain treatment, they might reduce the onerous costs of terminal illness. Although several studies associated living wills with small decreases in those costs, several studies have reached the opposite conclusion. The old Scotch verdict, “not proven,” seems apt.

The Costs

There is no free living will, and the better (or at least more thorough assurance and when we are spending more of our gross domestic product on health care than comparable countries without buying commensurately better health. If programs to promote and provide living wills showed signs of achieving the goals cherished for them, we would have to decide whether their valuable but in calculable rewards exceeded their diffuse but daunting costs. However, since those programs have failed, their costs plainly outweigh their benefits.

What Is To Be Done?

Living wills attempt what undertakers like to call “pre-need planning,” and on inspection they are as otiose as the mortuary version. Critically, empiricists cannot show that advance directives affect care. This is damning, but were it our only evidence, perhaps we might not be weary in well doing; for in due season we might reap, if we faint not. However, our survey of the evidence suggests that living wills fail not for want of effort, or education, or intelligence, or good will, but because of stubborn traits of human psychology and persistent features of social organization.

Thus when we reviewed the five conditions for a successful program of living wills, we encountered evidence that not one condition has been achieved or, we think, can be. First, despite the millions of dollars lavished on propaganda, most people do not have living wills. And they often have considered and considerable reasons for their choice. Second, people who sign living wills have generally not thought through its instructions in a way we should want for life-and-death decisions. Nor can we expect people to make thoughtful and stable decisions about so complex a question so far in the future. Third, drafters of living wills have failed to offer people the means to articulate their preferences accurately. And the fault lies primarily not with the drafters; it lies with the inherent impossibility of living wills’ task. Fourth, living wills too often do not reach the people actually making decisions for incompetent patients. This is the most remediable of the five problems, but it is remediable only with unsustainable effort and unjustifiable expense. Fifth, living wills seem not to increase the accuracy with

Patients anxious to control future medical decisions should be told about durable powers of attorney, which have many advantages over living wills. As these things go, they are simple, direct, modest, straightforward, and thrifty.

and careful) the living will, the more it costs. Living wills consume patient’s time and energy. When doctors or lawyers help, costs soar. On a broader view, Jeremy Sugarman and colleagues estimated that the Patient Self-Determination Act imposed on all hospitals a start-up cost of $101,569,922 and imposed on one hospital (Johns Hopkins) initial costs of $114,528. These figures omit the expenses, paid even as we write and you read, of administering the program. And this money has bought only pro forma compliance.

These are real costs incurred when over 40 million people lack health insurance, perhaps we might not be weary in well doing; for in due season we might reap, if we faint not. However, our survey of the evidence suggests that living wills fail not for want of effort, or education, or intelligence, or good will, but because of stubborn traits of human psychology and persistent features of social organization.

Thus when we reviewed the five conditions for a successful program of living wills, we encountered evidence that not one condition has been achieved or, we think, can be. First, despite the millions of dollars lavished on propaganda, most people which surrogates identify patients’ preferences. And the reasons we surveyed when we explained why living wills do not affect patients’ care suggest that these problems are insurmountable.

The cost-benefit analysis here is simple: If living wills lack detectable benefits, they cannot justify any cost, much less the considerable costs they now exact. Any attempt to increase their incidence and their availability to surrogates must be expensive. And the evidence suggests that broader use of living wills can actually disserve rather than promote patients’ autonomy: If, as we have argued, patients
sign living wills without adequate reflection, lack necessary information, and have fluctuating preferences anyway, then living wills will not lead surrogates to make the choices patients would have wanted. Thus, as Pope suggests, the “PSDA, rather than promoting autonomy has ‘done a disservice to most real patients and their families and caregivers.’” It has promoted the execution of uninformed and under-informed advance directives, and has undermined, not protected, self-determination.”

If living wills have failed, we must say so. We must say so to patients. If we believe our declarations about truth-telling, we should frankly warn patients how faint is the chance that living wills can have their intended effect. More broadly, we should abjure programs intended to cajole everyone into signing living wills. We should also repeal the PSDA, which was passed with arrant and arrogant indifference to its effectiveness and its costs and which today imposes accumulating paperwork and administrative expense for paltry rewards.

Of course we recognize the problems presented by the decisions that must be made for incompetent patients, and our counsel is not wholly negative. Patients anxious to control future medical decisions should be told about durable powers of attorney. These surely do not guarantee patients that their wishes will blossoms into fact, but nothing does. What matters is that powers of attorney have advantages over living wills. First, the choices that powers of attorney demand of patients are relatively few, familiar, and simple. Second, a regime of powers of attorney requires little change from current practice, in which family members ordinarily act informally for incompetent patients. Third, powers of attorney probably improve decisions for patients, since surrogates know more at the time of the decision than patients can know in advance. Fourth, powers of attorney are cheap; they require only a little advice. Fifth, powers of attorney can be supplemented by legislation (already in force in some states) akin to statutes of intestacy. These statutes specify who is to act for incompetent patients who have not specified a surrogate. In short, durable powers of attorney are—as these things go—simple, direct, modest, straightforward, and thrifty.

In social policy as in medicine, plausible notions can turn out to be bad ideas. Bad ideas should be renounced. Bloodletting once seemed plausible, but when it demonstrably failed, the course of wisdom was to abandon it, not to insist on its virtues and to scrounge for alternative justifications for it. Living wills were praised and peddled before they were fully developed, much less studied. They have now failed repeated tests of practice. It is time to say, “enough.”

Disclaimer

This report and its conclusions are the opinions of the authors and do not necessarily represent those of the Department of Veterans Affairs.

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7. See Conservatorship of Wendland, where the California Supreme Court construed the state’s Health Care Decisions Law as “requiring clear and convincing evidence of a conscious conservatee’s wish to justify withholding life-sustaining treatment” but held that decision did not affect patients who had left “formal directions for health care.” 28 P3d 151; 2001.
11. A document that “[g]ives person responsible for making medical decisions greater information, specificity and insight about your specific health-care related decisions, wishes, and objectives” is “A MUST FOR NEARLY EVERYONE” (P. A. Meints, “A Trust and Estate Planning Questionnaire for Families with Minor Children,” The Practical Tax Lawyer 16, no. 1, 2001: 33). Providing living wills has also become a pro bono activity. “Wills on Wheels was established by a committee of paralegals and consulting attorneys determined to provide . . . low-income adults with simple wills and living wills” (J.M. Price, “pro Bono and Paralegals: Helping to Make a Difference” Colorado Lawyer (September 30, 2000), 55-56.
13. The form’s critical paragraph reads; “My desires concerning medical treatment are—.” Then it leaves fourteen bland lines the patient may fill in. Available at www.med.umich.edu/1libi/aha/umdgal04.htm.

18. For example, the form provided by a consortium of the American Bar Association, the American Medical Association, and the American Association of Retired Persons combines and expands the traditional Living Will and Health Care Power of Attorney into a single, comprehensive document (http://www.ama-assn.org/public/booklets/livewill.htm).


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34. High, "Why Are Elderly People Not Using Advance Directives?"

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78. R.S. Morrison et al., "The Inaccessibility of Advance Directives on Transfer
79. Ibid.
84. Ibid.
86. Morrison et al., “The Inaccessibility of Advance Directives.”
90. Teno et al., “Do Advance Directives Provide Instructions that Direct Care?”