

Suggestions, Not Demands

Rethinking Living Wills



one's life—the guiding and terrifying image, the stuff of countless TV shows, being hooked to machines in ICU for weeks, dying a slow, painful and expensive death.

However, studies show that living wills have little impact on the medical treatment one actually gets at the end of life. Doctors,

perhaps recalling the medical school wisdom, “Only the living can sue,” usually do what families want: If they insist on aggressive treatment, the patient gets it, despite what the patient's living will might provide.

Is this a problem?

I don't think so. Living wills are too casual, too vague and too speculative to be taken too seriously. Many are of the “Check the Appropriate Box” variety and, in confusing legalese, tend to boil down to two choices:

- “No, I don't want to be hooked up to a lot of machines,” or
- “Yes, keep me alive as long as possible.”

Boxes are checked in crowded hospital waiting rooms, when you have more pressing matters, or in a lawyer's office, as part

Living wills promise a marvelous thing: the ability to decide now what kinds of medical treatment we will receive during our last illness. Although one can insist that everything be done to prolong life, generally they are used to curtail treatment, prohibiting such things as heroic treatment and feeding tubes that would otherwise extend

of your estate plan. With the meter running, there is no time to dally with stupid questions like, “Box 3(a) talks about ‘a permanent vegetative state,’ and just what is that, anyway?”

Matters of life and death should not turn on such casualness. But let's say you brooded over the matter and, with appropriate angst, finally checked “No heroics.” When the time comes, if

your family and physicians decide that heroics would be best, what then?

The root problem, the unsolvable problem, is that living wills are written long before they come into play: We are asked to decide *now* what we want *then*, and we don't have much of a clue. The stuff of a Greek tragedy.

Putting aside the inherent problem of changes between now and then, such as advances in medical treatment and pain control, if you found yourself dying and *you were able to communicate*, would you automatically reject (or automatically insist upon) all heroic medical interventions? Of course not. You would talk it over—with your family, with your religious advisers and with your doctors. You would consider a host of factors. Are you 43, 73 or 93? How certain the doctors and how great the pain? How costly the stay, and can your family afford it? How sharp your mind? Have you said your goodbyes? And, finally, of course, who's left?

We misjudge the future. When I was a teen, I firmly believed that sitting in an office all day, writing stuff, would be a fate worse than death. I no longer firmly believe this.

When we are healthy and visualize our older selves lying in a hospital bed, we think, "I would rather be dead" and check the "No machines" box. Nancy Mairs is paralyzed from the waist down and has lost total control of one arm, partial control of the other. She cannot feed or clothe herself. A fate worse than death? In *Waist-High in the World*, she writes, "There are readers who need, for a tangle of reasons, to be told that a life commonly held to be insufferable can be full and funny. I am living that life. I can tell them."

On the other hand, when we are green and golden, singing in our chains like the sea, we might check, with great bravado, the "Rage, rage against the dying of the light" box. But, when the time comes, will we still be pissed?

When he was a young man, the 16th-century French essayist Michel de Montaigne was thrown from his horse, sustaining serious injuries. He was a bloody mess:

It seemed to me that my life was hanging only by the tip of my lips. I closed my eyes in order, it seemed to me, to help push it out. I took pleasure in growing languid and letting myself go. I was not only free from distress but felt that sweet feeling of sliding into sleep. I believe that is how people feel whom we see in the agony of death. We pity them without cause, thinking that they are troubled by grievous pains or have their souls full of distressing thoughts.

None of this means you shouldn't have a living will. However, consider one less dogmatic, less demanding, less legalistic. Consider something more folksy, a letter sharing your thoughts. You also can address things that might skew the decisions away from your best interest: family guilt and physicians' fear of legal liability. Here's one possibility:

A Letter to My Family, My Friends and My Health Care Providers Concerning End-of-Life Matters

This letter addresses medical issues that may arise near the end of my life. I request that those involved in making decisions for me at that time do so only after careful consideration of what I say here. As no one can predict specific circumstances, I do not wish to bind those decisions in any way but to request that they be made in light of my preferences, in light of my best interests, and in light of the best interests of my family.

It is my hope that those involved, after carefully listening to each other, would come to agreement as to the best course of action. If division persists, I hereby appoint _____ as the final arbiter and as my health care power of attorney. If _____ cannot serve, then I appoint _____.

I fully appreciate that your decisions may hasten my death. No one should feel guilty in making such decisions or feel that the only way to show love for me is to prolong my life as long as possible. The opposite may be true.

Pain. Health care providers may fail to administer adequate pain medication in fear that it might addict or kill. My request is that I receive medication adequate to relieve my pain even if that runs the risk of creating addiction or hastening my death. I further request that none of my family or friends institute any action against any of my health care providers premised on the notion that I received too much pain medication and, furthermore, that they resist any governmental action against my health care providers, whether by prosecuting or licensing agencies, premised on that notion.

End-of-Life Medical Treatment. I do not want my life extended by medical interventions if my prognosis is grim in terms of my ultimate recovery and the quality of life. I realize that some health care providers, fearful of malpractice claims, may pursue aggressive treatment even if that is unwarranted. I request that none of my family institute any malpractice action premised on the notion that the treatment I received was not aggressive enough.

As a general matter, I disfavor cardiopulmonary resuscitation in any form and artificially administered food and fluids. I expressly authorize my family to reject, on my behalf, any form of resuscitation and to decline or later remove any forms of artificial administration of food or fluid. I want my family to know that death due to lack of hydration is not a horrible way to die; in fact it is rather peaceful and painless.

Furthermore, I would prefer not to be taken to the hospital.



Death. I would much prefer to die at home or in a hospice. I do not want to die alone or among strangers. I do not want to die in an intensive care unit or in a nursing home. If I am in intensive care for more than one week, then I strongly suspect that my life is being artificially extended.

I consent to organ donations and to an autopsy realizing that much can be learned from it to understand the cause of my death and to help others. Though I want to help my fellow humans, I am somewhat leery of experimental treatments and research studies.

Finally, as to burial, I prefer cremation and an Irish Wake.

I intend that this letter, which I shall sign before witnesses, shall be as legally binding and as enforceable as my Living Will and Appointment of Health Care Agent as is provided in any state in which I reside at the time that this letter would be effective. Furthermore, I intend that my wishes be binding on my estate.

Signed:

Dated:

Witnessed by:

We, the author's family members, have read and discussed this letter with the author. We understand it and agree to follow it.

Signed:

I am not proposing that you copy this out. Instead, tailor it to your own preferences, "Sitting Shiva" rather than "Irish Wake." Write your own. This will take more time than checking boxes, but you owe yourself an hour of serious thought.

When you're done, go over it with your family. As you have given it serious consideration, it should go better than, "Permanent vegetative state? I don't want to be hooked up to a lot of machines!" "Me neither; what's on Channel 4?" As Death is a reluctant topic, remember that malt does more than Milton can to justify God's way to Man.

Note that I have family members sign off on my letter. This is not required and, indeed, is rather novel. However, it is a wonderful idea.

Everyone agrees that it is essential for you to discuss your specific wishes with your family and your health care surrogate; this advice probably doesn't even make it to the "To Do" list. My approach requires this discussion. And it is simply easier to start it with "I need you to do something for me" rather than "Do you have 30 minutes for a dismal discussion about my death?"

Second, having family members agree to follow your wishes is an important prophylactic. As you want to convince health care workers that they will not face litigation if they give too much pain medication or too few medical interventions, the agreement of your family to follow your instructions will help.


Would such an agreement be an absolute bar to litigation? Perhaps, or perhaps not. This would turn on a complex assessment of contract law, tort law and health care law. Down the road courts may have to grapple with the issue. For now, realizing that drafting can take us only so far, let's trust our relatives and do what we can.

Some will object that my letter doesn't save loved ones "the anguish of making the tough call," the decision to let me die. I believe this sentiment does not go to the appropriateness of their decision—surely my family will have much better information concerning my situation *then* than I do *now*. But we do wish to save our families the guilt than comes with responsibility: "Maybe we pulled the plug too soon." I think my letter, by describing my fears and wishes, goes a long way to direct and support their decision.

Anguish and guilt cannot be avoided no matter what we do. A living will, which dogmatically asserts "No heroics," *might* be better in this regard. Of course, nothing is perfect. In all but the most extreme cases, there will be room to argue, and hence room to regret. "Yes, Dad wanted to die under those circumstances, but a good daughter would have challenged the doctors more—maybe they were wrong."

Leaving the tough decision to my family seems right, not only empirically (they will probably have to decide anyway), but philosophically. We are not islands, not in our lives and not in our deaths. Our families are fundamentally part of all of it, and they should play their proper role.

But the real value of the letter is *now*, not *then*; the real value is the simple message "I love you, I trust you, and it's time to spend a few minutes talking about my final illness and how it's really nothing to dread."

Tell your family this *now*. As to *then*, as to the tough choice, it probably won't ever come up; you'll probably be run over by a bus. 

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