

My Living Will

I, William Arthur Hensel, being of sound mind, desire that my life not be prolonged by extraordinary means if my condition is determined to be terminal and incurable. I am aware and understand that this writing authorizes a physician to withhold or discontinue extraordinary means.

My living will of ten years ago contained only these words. Since then, living wills have become less ambiguous, omitting such words as “extraordinary means” and substituting more specific terminology. However, my work with the dying has shown me that ambiguity persists despite these improvements. I continue to witness difficult deaths, countless variations on the same painful theme of patients, families, and physicians struggling to choose the best course of action when “best” eludes the grasp of definition. So, in an attempt to save myself and my family from this fate, I am compelled to write this addendum to my living will. Perhaps it will not be considered binding, but at least my family will know what I believe is “best” for me.

Let me begin with what I value—for it is upon my values that my wishes are based. I have spent many years working to build a better life for myself and my family. I have tried to be more of a giver than a taker, more a source of strength than a burden. I want to have enough money saved by my retirement to be self-sufficient, and so that I can leave my family a modest inheritance. But even more than money, I want to leave my children with memories of a father who gave them strength and a sense of security. I know that how I die is only the final paragraph of my legacy, but I also know how important that final paragraph can be. I take great comfort in knowing that my father’s death, though unexpected, was a fitting end to the story of his life. Like me, he was fiercely independent and, despite serious health problems, he was able to be self-sufficient to the end. If at all possible, I too want my death to be consistent with the life I have led.

I am in no hurry to die. I have been greatly blessed and would like to enjoy those blessings as long as I can. But I am also past the youthful denial of my own inevitable death. Part of the privilege of being a physician is the opportunity to bear witness to patients’ lives. Too many patients—good friends—have died while I was powerless to prevent their deaths. But I have learned from them: There is a time to fight death with every ounce of strength one has—and a time to let go.

So as I consider my own death, I have the poignant lessons learned from my patients to guide me. This gives me great confidence, for I know that as long as I have my mind, I will know how long to keep fighting. It is the loss of the mind such as would occur with dementia or severe head injury that I dread. For to be helpless, to not recognize my family, to lose wisdom would be the loss of all I value.

Such severe and permanent central nervous system damage would render me unable to write the final paragraph of my life. For example, I know that people with dementia can seem to hang on indefinitely, even when they are receiving only the most

basic of comfort and nutritional care. Even a detailed living will that includes the refusal of all active treatments such as cardiopulmonary resuscitation, antibiotics, artificial nutrition, and hydration may be inadequate in such a situation. I do not want to become a vacant-looking body, reflexively swallowing food and water placed in my mouth, my soul frozen inside while my life goes on and on without any apparent purpose or understanding.

There is also the cost. The financial cost of caring for patients in such a state is great, but I am more worried about the emotional cost. I know my family would struggle to care for me at home and would feel guilty if they had to put me in a nursing home. Then they would be driven by love and a sense of obligation to visit my body—perhaps for years. I have seen what this can do to loved ones, and I know I do not want to put my family through that ordeal.

So it is important that I make this clear: If I ever suffer irreversible central nervous system damage to the point that I do not recognize my family, I believe that it would be best for me to die. I want no active treatments that might prolong such an existence. Even more, if physician-assisted death is legal, that is what I choose. If not, do not place food or water in my mouth. Instead, place it on my bed table. If I feed myself, I live another day; if I do not, I will die and that is fine.

I know that such a request invites criticism, that some would call this suicide. To them I would answer that I don’t consider this suicide, for I believe that if I am markedly neurologically impaired I will have already ceased to exist. Others will also object on religious grounds, and say that God absolutely forbids this. To them, I would say that my understanding of God’s will is different from theirs, that faith is not fact. I would add that my final request is an act of faith, based on my belief that there is a better life beyond this one.

Finally, logic alone would prompt many to reject my plan on the grounds that it is impossible to know the state of being of a neurologically damaged patient who cannot communicate. I would concede the point that one cannot know; but precisely because neither I nor anyone else can know, personal assumptions and faith are all we have to guide our actions. Based on their values and beliefs, then, others will make different choices; but for myself, I stand firm: If I have severe, irreversible central nervous system damage, I wish to die.

I hope I have made my choice clear; but I realize this means my family and my physician may also face difficult choices. So I end this, my living will, with a plea: If the time ever comes that I would desire assisted death, I will be powerless to act on my choice. I will need the understanding, love, and support of others to die with dignity. May God grant these others the courage to carry out this, my final wish.

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We welcome contributions to A Piece of My Mind. Manuscripts should be sent to Roxanne K. Young, *The Journal of the American Medical Association*, 515 N State St, Chicago, IL 60610.