

# An Open Letter to Norman Cantor Regarding Dementia and Physician- Assisted Suicide

by DANIEL P. SULMASY

Dear Norm,

Thank you for sharing such a personal and heartfelt essay.<sup>1</sup> I have been asked by the editors to comment. Reading it inspires me to do so in a similarly heartfelt way. Although I don't know you well, I thought I'd write to you as if you were my patient. You are not my patient, so pardon me if this seems presumptuous.

You and I have been fellow travelers on the road to improve care at the end of life for a long time—you for a longer time than I.<sup>2</sup> I deeply admire and appreciate all your effort, your keen intellect, your careful legal scholarship, and your passion. I also appreciate your honesty—manifest especially in this latest essay. Unlike many who share your views, you're not afraid to call things as they are—using words like “suicide” and frankly describing committing suicide by means of measures like carbon monoxide poisoning or voluntarily stopping eating and drinking. You then argue that suicide is justified in the circumstances you describe rather than falling back on euphemisms that obscure the ethical issues.

I share your sense that Alzheimer disease is a terrible scourge. I've seen much of this disease over a lifetime of practice, and I deeply understand its ravages and the debility and suffering it causes. All the progress medicine has made in curing other illnesses has resulted in more people living long enough to develop dementia. If I were a physician-scientist, it's the disease for which I would most like to do the research that would lead to a cure.

But what you propose is not a good solution for the problems that Alzheimer disease poses for patients, families, and society. It will ultimately do far more harm than good. Please let me try to explain.

*We should not ratify your desire to kill yourself.* Most of your essay concerns finding legal justifications for various methods of ending your life should you become afflicted by Alzheimer disease. Rather than discuss your legal reasoning, I want to address this issue of “self-deliverance” (your preferred term for suicide under these circumstances)<sup>3</sup> head on.

I know how you feel. Many of us have been there, witnessing someone who was once a professor lying in bed, staring vacantly, no longer able to converse, no longer in

control of bowel and bladder function. Reasonable people are bound to think, “I never want to end up this way. I'll kill myself first.”

But we should not endorse letting you, or anyone else, act on such inclinations. We should never ratify the idea that the world is better off without you even if you come to believe it. We should mourn your loss, not precipitate it. The reason we shouldn't endorse your killing yourself is the same reason you gave in your essay about why we should not let you soil yourself—out of respect for your basic human dignity. You are valuable not only for your intellect but as a fellow human being. Should you develop a dementing illness, we should keep you warm, comfortable, and clean, treat your pain, and care for you.

You may counter by asserting that if you develop deep dementia, we will then, in a sense, already have lost you. Yet you know that's not really true. The most profound pathos we feel in seeing someone we love develop dementia comes from knowing the person who suffers from that awful disease. It will be you, or Aunt Molly, or Cousin George who is now demented, not really “someone else” and certainly not nobody. Everybody is a somebody—even a demented person. Martin Luther King had to forcefully remind us that this is what respecting dignity really means—recognizing that everybody is a somebody.<sup>4</sup>

You say you don't want to be a burden on others. I understand that sentiment, but we should not construct a society in which that feeling is endorsed by those who would be charged with caring for you. Even common courtesy suggests that when someone says, “I wouldn't want to be a burden,” the proper response is, “Not at all.” It is not respectful of human dignity to endorse anyone's belief that their illness makes them too much of a burden on the rest of us.

Anyone who sees someone with Alzheimer disease feels bad for that person. Yet your view of what it is like to be a person with Alzheimer disease is not necessarily the view of a person with the disease; that person may not know what has been lost and may even be content. Your fear is based on how you now believe you will appear to others. As a fellow human being, but especially as a physician, I have moral obligations that are less dependent on an abstraction like your precedent autonomy than on treating the actual patient before me. To sedate you rather than feed you if you say you are hungry because the person before me is not the “real” patient seems cruel, based

---

Daniel P. Sulmasy, “An Open Letter to Norman Cantor Regarding Dementia and Physician-Assisted Suicide,” *Hastings Center Report* 48, no. 4 (2018): 28-29. DOI: 10.1002/hast.868

on allegiance to a cold ideology. Ethics is best when it is a response to reality rather than to abstractions.<sup>5</sup>

*We should not ask doctors to help you to do so.* None of this is to say that we must do everything conceivable to prolong your life. We both agree that you can forgo life-sustaining treatments that you (or those who represent you) deem to be more burdensome than beneficial. Urinary tract infections need not be treated, if that accords with your wishes. When the end approaches, pneumonia can become the old person's friend. And we have good evidence that when patients with Alzheimer disease become bedbound and unable to swallow in a coordinated way, feeding tubes do not even prolong their lives.<sup>6</sup>

Moreover, we can do more now than in the whole history of humankind to treat your symptoms. Alzheimer disease is typically not painful, but associated conditions may be painful, and pain and other symptoms ought to be treated vigorously. Clinicians and society have obligations to work to improve palliative care and hospice for the demented among us, and to do more to help caregivers. These are the pressing issues to which we should be devoting our attention. Assisted suicide is both a distraction and a seductively inexpensive alternative to this kind of hard work.

You might disagree, but clinicians, the law, and the person on the street all recognize that there is a difference between forgoing life-sustaining treatments and killing a patient (or assisting a patient in killing himself or herself).<sup>7</sup> When I, as a physician, discontinue ventilator support because the patient has determined that it has become more burdensome than beneficial, I am acknowledging the limits of medicine. That is a good thing. When I act with the intention of making someone dead, or help someone to make herself dead, because I cannot otherwise cure or relieve the suffering that she has deemed unacceptable, then I have, in effect, refused to accept the limits of medicine. Medicine becomes the ultimate solution to the problem of human suffering. That is a terrible power—a power so great that it cannot help but be corrupting. It is a power no doctor should want and no wise society should grant to its healers.

Behind the closed door of the examination room, even powerful and independent persons like you become vulnerable. This is the nature of illness. Countertransference is a powerful force in the patient-physician relationship. As a physician, I know that it can make *my* feelings of helplessness in the face of incurable disease seem like *your* independent judgment; your choice to ask me to help you end your life can be an acquiescence to my judgment that your life is not worth living or is too much of a burden on others.<sup>8</sup> We need a firm boundary. The understanding that this option is off the table helps to establish the conditions of trust that make the healing relationship possible for you and for all patients.

*We should not give this the force of law.* Autonomy is a thin reed upon which to rest the massive weight of

legalized medical killing. Even if your decision is genuinely substantially autonomous, free from any coercive, manipulative, or misinformed influences, you really need to think about the impact that legal sanction of the practices you describe will have on others. Once we let you make a first-person determination that your life is not worth living, then it is really not that big a step to permit third-person determinations that the lives of others are not worth living. After all, it was not fanatics but a respectable psychiatrist and a law professor who introduced the phrase "*lebensunwerten Lebens*" ("life unworthy of being lived") in 1922.<sup>9</sup> They first argued that "mercy killing" was justified for terminally ill persons who autonomously decided that their lives were no longer worth living, and then they extended this logic to allow others to decide this for the mentally incapacitated.

This is why people living with disabilities are so fearful of legalized assisted suicide and other forms of medically assisted killing. It is not so much that they anticipate being lined up in wheelchairs and forcibly injected (at least not in the near term). It is the assault to their dignity that comes with social sanction of the idea that lives characterized by incontinence, cognitive incapacity, and dependence on others are unworthy of life and so can be ended by direct killing. Norm, if we sanction your starving yourself to death so that you don't suffer Alzheimer disease, then we throw a question smack in the face of countless disabled persons everywhere: why are *you* still burdening yourself (and us) with your life, which is similarly unworthy of life?

Moreover, suicide is not a purely self-regarding act. We know that publicity about assisted suicide for the terminally ill can lead to copycat suicides among the mentally ill.<sup>10</sup> And there is emerging evidence that overall suicide rates increase in places where physician-assisted suicide is legalized for the terminally ill.<sup>11</sup>

Above all, your essay illustrates the disingenuousness of arguments that legalized physician-assisted suicide (PAS) is the end goal of proponents. As you well note, under current laws, patients with Alzheimer disease who want to end their lives directly face a catch-22. When someone with Alzheimer disease is still competent, it is too early in the course of the disease to qualify for PAS since the condition is not yet terminal. Yet if one waits until one is terminal, then because of the depth of the dementia, one would be disqualified by lack of decisional capacity. The whole point of your essay is to find legal ways out of that catch-22. Yet the terrain is, as you freely admit, murky. If I stop hand feeding you and sedate you, at your advance request, is that really a refusal of life-sustaining treatment? Is it assisted suicide? Or is it euthanasia? All this points out is that there will be pressure to permit third parties to make substituted judgments, interpret advance directives, and provide euthanasia for those unable to participate in assisted suicide due to dementia. This is not a psychological slippery slope; it is just logic. If the terminally ill with

capacity can access PAS, then it just seems like discrimination to prevent those who lack capacity from equal access to death. Voluntary assisted suicide laws will beget nonvoluntary euthanasia.<sup>12</sup> Legislation to move in this direction is already brewing.<sup>13</sup>

We agree, Norm, that Alzheimer disease is bad. It's really bad. But the ramifications of your proposed solution are wide. And the compassionate care we are capable of providing for you, if we are wise and respectful, is probably better than you think. So, before you sign your advance directive, let's talk it over. What we really need is your intellect and energy focused on the struggle to improve care at the end of life—providing better access to hospice and palliative care, better education about forgoing life-sustaining treatments, better financial and social support for the frail elderly and their caregivers.

Please give me a call. When your time comes, we can promise to care for you without forcing you to linger. But we never want to endorse the idea that the world would be a better place without you.

With admiration and gratitude,  
Your colleague,  
Dan

1. N. O. Cantor, "On Avoiding Deep Dementia," *Hastings Center Report* 48, no. 4 (2018): 15-24.

2. Norman Cantor has been working on issues related to care at the end of life since the 1970s and was involved as a legal advisor to the family in the landmark Karen Ann Quinlan case. See, for example, N. L. Cantor, "A Patient's Decision to Decline Lifesaving Medical Treatment: Bodily Integrity versus the Preservation of Life," *Rutgers Law Review* 26, no. 2 (1973): 228-64.

3. Cantor, "On Avoiding Deep Dementia," 16.

4. G. Baker-Fletcher, *Somebodiness: Martin Luther King, Jr. and the Theory of Dignity* (Minneapolis, MN: Fortress Press, 1993).

5. See I. Murdoch, *Metaphysics as a Guide to Morals* (New York: Penguin, 1993).

6. D. P. Sulmasy, "Ethical Issues in Medically Assisted Nutrition and Hydration at the End of Life: Separating the Wheat from the Chaff," in *The Oxford Handbook of Ethics at the End of Life* ed. R. M. Arnold and S. Youngner (New York: Oxford University Press, 2016), 126-53.

7. D. P. Sulmasy, "Killing and Allowing to Die: Another Look," *Journal of Law, Medicine & Ethics* 26 (1998): 55-64; *Washington v. Glucksberg*, 117 S.Ct. 2258 (1997); *Vacco v. Quill*, 117 S.Ct. 2293 (1997); *Morris v Brandenburg*, Supreme Court of New Mexico No. S-1-SC-35478; 2016-NMSC-027; 356 P.3d 836 (2016).

8. S. H. Miles, "Physician-Assisted Suicide and the Profession's Gyrocompass," *Hastings Center Report* 25, no. 3 (1995): 17-19; F. T. Varghese and B. Kelly, "Countertransference and Assisted Suicide," *Issues in Law and Medicine* 16, no. 3 (2001): 235-58.

9. K. Binding and A. Hoche, *Die Freigabe der Vernichtung lebensunwerten Lebens: ihr Maß und ihre Form* (Leipzig, Germany: Felix Meiner Verlag, 1920; 2nd ed., 1922), available in English translation as: K. Binding and A. Hoche, "Permitting the Destruction of Unworthy Life: Its Extent and Form," *Issues in Law and Medicine* 8, no. 2 (1992): 231-65.

10. P. M. Marzuk et al., "Increase in Suicide by Asphyxiation in New York City after the Publication of Final Exit," *New England Journal of Medicine* 329 (1993): 1508-10; P. M. Marzuk, K. Tardiff, and A. C. Leon, "Increase in Fatal Suicidal Poisonings and Suffocations in the Year Final Exit Was Published: A National Study," *American Journal of Psychiatry* 151 (1994): 1813-14.

11. T. A. Boer, "Does Euthanasia Have a Dampening Effect on Suicide Rates? Recent Experiences from the Netherlands," *Journal of Ethics in Mental Health* 9, special theme issue II (2017): <https://www.jemh.ca/issues/v9/theme2.html>; D. A. Jones and D. Paton, "How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide?," *Southern Medical Journal* 108 (2015): 599-604.

12. D. A. Jones, "Is There a Logical Slippery Slope from Voluntary to Nonvoluntary Euthanasia?," *Kennedy Institute of Ethics Journal* 21 (2011): 379-404; N. Gorsuch, *The Future of Euthanasia and Assisted Suicide* (Princeton, NJ: Princeton University Press, 2006): 93-101; J. Keown, *Euthanasia, Ethics, and Public Policy* (Cambridge: Cambridge University Press, 2002): 70-80.

13. J. Richer, "Quebec Opens Door to Expanding End-of-Life Law to Alzheimer's Disease," *Montreal Gazette*, February 23, 2017; Oregon Senate Bill 893, 2017; M. Harbarger "Legislator's Promise to a Dying Friend," *Oregonian*, April 30, 2015.