

Opinion: Can you trust doctors to honor your end-of-life wishes? Here's what to consider.

By Stanley A. Terman, Karl E. Steinberg
San Diego Union-Tribune June 2, 2021

Terman, Ph.D., M.D., is a psychiatrist and bioethicist. He lives in Sausalito. **Steinberg, M.D.**, is a hospice and palliative medicine specialist, bioethicist and nursing home and hospice medical director in Oceanside. The opinions expressed are those of the authors, not the organizations with which they are associated.

No one doubts the importance of completing living wills — especially for advanced dementia — a cruel disease that most people dread since it can cause prolonged dying with severe, irreversible suffering as it imposes huge burdens on loved ones. But by themselves, living wills will not be adequate if your future physician refuses to honor its requests. A recommended request is: “Cease putting food and fluid into my mouth if I reach a specific condition.” Honoring this request can prevent being forced to endure years of suffering since you will not need to wait to die from a heart attack, or untreated infection such as pneumonia. After you no longer can feed yourself, the only legal, peaceful and effective intervention may be to cease assisted feeding and hydrating by another’s hand. This challenging and controversial intervention raises questions for your physician, and for you.

Is your physician’s refusal to honor your wishes good or bad? “Good” means in your “best interest” such as preventing premature dying. “Bad” means forcing you to endure prolonged, and likely increased, suffering with little or no benefit.

Are physicians’ actions well-meaning or selfish? “Selfish” means refusal benefits your physician as it harms you. Physicians’ hubris leads to their desiring that their actions are viewed favorably — while you suffer longer, and more. Many physicians want to view themselves as heroes who sustained your life. But the ethical position of the American Medical Association is clear: “The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail.”

A comprehensive question for physicians to ask: Are their actions legal, ethical and respectful? You have a claim right to self-determination (what happens to

your body) and to avoid suffering. Claim rights impose a duty on others to act by honoring your rights, so ... physicians should attempt to reduce your suffering and physicians should not violate your bodily integrity. This includes assisted oral feeding and hydrating — if you previously refused it. In addition to being unethical, force feeding may be illegal since battery is a crime. Yet some physicians argue they must consider all available information, strive to do no harm and maximize what they feel is your benefit. Hence, your living will's future success depends on your resolving common conflicts during advance care planning.

Some questions for you: Do you prefer fast and easy living wills that ask you only to check a few boxes before signing? Do you consider your task complete once you clearly expressed your wishes? Is your living will specific enough to avoid conflict? Is it comprehensive so you don't suffer from omitted conditions? Does it strive to be "clear and convincing" — the highest evidence standard in civil law? Will you record a persuasive video on which you state what you want, and explain why?

Even the above amount of effort may not be successful. A large, influential physician organization, [The Society for Post-Acute and Long-Term Care Medicine](#), recommends not honoring requests to stop assisted feeding until you manifest behavior it interprets as either refusal or distress. Also, physicians and others can allege you changed your mind based on observing you open your mouth and swallow what others put in. But your apparently cooperative behavior may result from reflex or habit, after dementia has caused you to forget your critically important life values — to avoid suffering and imposing burdens on others.

Advance care planning must lay the groundwork to persuade future physicians to honor your end-of-life wishes. Living wills can include cogent arguments that cite clinical literature and case law to compel your physician to respond — especially if conflicts escalate to court. Among several recommended strategies, here are two.

Insist no one can claim you changed your mind to want spoon feeding — unless two experts qualified in the fields of dementia, capacity and assisted feeding so testify within a reasonable degree of medical certainty.

Store your printed forms and videos in an electronic registry so physicians and EMTs can expeditiously retrieve the current versions.

Admittedly, there is no proof (yet) that adding recommended strategies will increase your chance of success. (The reason: it will take years to gather enough data for those who completed advance care planning to eventually encounter conflicts.)

So can you trust doctors to honor your end-of-life wishes? Are you kidding? Current experience leads to this recommendation: Do not kid around. Put in the required time and effort to give yourself the best chance of experiencing a peaceful and timely dying.

Terman, Ph.D., M.D., is a psychiatrist and bioethicist. He lives in Sausalito. Steinberg, M.D., is a hospice and palliative medicine specialist, bioethicist and nursing home and hospice medical director in Oceanside. The opinions expressed are those of the authors, not the organizations with which they are associated.

Meeting the Challenges of Advance Care Planning for Advanced Dementia – A Social Justice Imperative.

Posted: 20 Mar 2020 05:36 AM PDT

By Dr. Stanley Terman

It is not easy to die of advanced dementia. Yet almost everyone has this goal: a dying that is private, peaceful, and timely.

Dementia patients cannot qualify for Medical Aid in Dying (Physician-Assisted Suicide). Usually, their only legal, peaceful option is to stop ingesting food and fluid. Yet some authorities strongly oppose this way of dying. Knowing that traditional advance directives are not effective, and learning that [authorities](#) may oppose newer “dementia-specific” directives/living wills, many patients harbor the “Dementia Fear.” They have reason to worry that others will force them to endure prolonged dying, possibly with increased suffering, perhaps for years.

Some patients strive to make their ultimate existential decision at “five minutes before midnight”—to live as long as possible. But they live with this source of daily anxiety, which decreases their ability to enjoy life: “If I wait too long, I will miss the opportunity to kill myself by losing my mental or physical

capacity.” Some commit preemptive suicide, an option that requires sacrificing up to years of good living that is not only sad but tragic. Premature dying would not be necessary if patients could trust others to honor their end-of-life wishes.

End of Life Choices of New York’s [directive](#) attempts to overcome opposition by offering an “aggressive” option that totally dismisses patients’ feeding behavior as criteria to stop assisted feeding. But their alternative—reaching [Stage 6](#) of any version of the Functional Assessment Staging Tool—brings up another problem: most physicians will continue assisted feeding even if patients manifest all the tool’s listed behaviors: patient needs help putting on clothes, bathing, and toileting; and has urinary and fecal incontinence.

Compassion & Choices’ Dementia Values and Priorities [Tool](#) lets planning principals choose one or two of 15 conditions as sufficient to be allowed to die naturally, and a separate list of 7 behaviors as sufficient to stop assisted feeding. Yet treating physicians and [their organizations](#) may insist patients’ best interest is to continue assisted feeding unless they manifest distress.

To overcome physician refusal, one could insist on the criterion, severe enough suffering. But clinicians recognize it is difficult to determine if non-verbal advanced dementia patients are experiencing severe suffering—especially with the certainty needed to allow patients to die.

[Strategic Advance Care Planning](#) could offer a possible solution: During advance care planning, planning principals judge each condition by responding to: “Would this condition cause severe enough suffering for you to want to die of your underlying disease?” To determine if it is time to stop assisted feeding, treating physicians then need only assess if their patients have contemporaneously reached at least one of these pre-judged clinical conditions.

The online [patient decision aid](#) informs planning principals what it is like to live with advanced dementia using 50 illustrated descriptions at a level of reading comprehension of grade 4, which many early stage dementia patients can understand. It achieves this by broadening the concept of suffering to comprehensively reflect what people dread most about prolonged dying in advanced dementia and other terminal illnesses. In addition to physical and emotional suffering, it considers existential suffering (loss of meaning in life

and the ability to relate to others); suffering due to disruption of life narrative; suffering the disease causes loved ones; and moderate suffering from several conditions that add up to severe.

Recording planning principals' semi-structured interviews on video can: memorialize their advance decisions; demonstrate if they possessed decision-making capacity; let them add personal details about their end-of-life wishes; and, most importantly, give them an opportunity to be convincing.

In cases of advanced dementia, clear, comprehensive, consistent, and convincing directives/living wills may not, by themselves, be effective. It is important that an advance directive include over a dozen strategies in order to compel physicians to honor, and to prevent third parties from sabotaging planning principals' end-of-life goal.

The post [Meeting the Challenges of Advance Care Planning for Advanced Dementia – A Social Justice Imperative](#) appeared first on [Bill of Health](#). *Bill of Health* was launched in September 2012 by the [Petrie-Flom Center](#) at [Harvard Law School](#) to provide a one-stop shop for readers interested in news, commentary, and scholarship in the fields of health law policy, biotechnology, and bioethics.