

## OPEN PEER COMMENTARY

# Response to Stanley Terman: Too little, too late

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A recent study quantified what a lot of us already know: Alzheimer's disease (AD) has surpassed cancer as the disease Americans fear most.<sup>1</sup> The reason is obvious: Whereas cancer brings fear of pain, death, and financial stress, one is cognitively competent and has at least some control over what happens. With dementia, however, one faces a foggy future in which one must rely on others to carry out one's wishes.

There are a number of ongoing projects that seek to address this disheartening situation, most relying on some form of advance directive that focuses on the possibility of dementia.<sup>2</sup> Stanley Terman has been an indefatigable warrior in this regard, promulgating various strategies to make it less likely that a demented person will have a long and lingering death that is against their wishes.<sup>3</sup>

In this paper,<sup>4</sup> Terman comes up with a nuanced, dementia-focused understanding of "unbearable suffering" that he hopes will allow persons with AD, by virtue of the directives they wrote while competent, to refuse hand feeding, or "assisted feeding," as they near the end of their lives. Unfortunately, I do not believe that his strategy is effective or useful.

There has currently been a great deal of interest in voluntary stopping of eating and drinking (VSED) as an end-of-life strategy. Focusing on food and nutrition as a strategy to block the prolongation of the final stage of dying makes a lot of sense. In the United States, states that allow for medical assistance in dying (MAiD, aka physician-assisted suicide) require that the person be competent and within 6 months of their death, obviously of no use to someone facing dementia. If they are demented they are not competent, and if they are competent they are unlikely to be within 6 months of their death. Euthanasia, that is, giving someone a fatal drug, is not legal anywhere in this country. A person may, via their advance directive, refuse medical treatment in the face of, for example, cardiac arrest or pneumonia, but not everyone with dementia is fortunate enough to have such a medical condition. In many cases, the physical body keeps chugging on while the mind

continues to fail, and there is nothing for a proxy to refuse. Therefore, refusing food and water is the one remaining legal way to hasten one's death.<sup>5</sup> Tube feeding is generally accepted as a medical intervention that can be refused, whereas hand feeding, sometimes called "artful feeding" or "assisted feeding," seems more like basic human care, and thus has become a new frontier in end-of-life considerations. By tying his thesis to VSED and assisted feeding, Terman dooms his strategy to irrelevance.

As Paul Menzel and others have admitted,<sup>6</sup> and as Terman tacitly acknowledges in this paper, VSED is mostly applicable to people in the last stage of dementia. Yes, there is the occasional fortunate person who, facing a diagnosis of AD, has the determination, fortitude, and support system to end their life through VSED, but that is unusual. For most people, VSED is only realistic when they lose interest in food and are unable to feed themselves, thus the emphasis on refusing hand feeding. But people who need assisted feeding are usually in what the National Institute on Aging calls the "later stages,"<sup>7</sup> that is, the stages most people would never want to reach in the first place.

When we consider why people fear AD, we see why this approach is largely irrelevant. Over and over again, when people talk about their horror of AD, they express some version of the following:

1. Loss of self, of their identity as a parent, grandparent, spouse, skilled person, hobbyist, and so forth.
2. Loss of dignity, autonomy, independence. This can range from concerns over incontinence to giving up the car keys to being unable to live on their own. People are also concerned about how they are remembered. Norman Cantor described having severe dementia as "a stain on my memory."<sup>8</sup> Ronald Dworkin writes that people have an interest in how their final chapter influences the arc of their lives, as the final chapter of a book influences the narrative arc of the story.<sup>9</sup>

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3. Loss of resources. Not only do people fear that years of needing residential care will drive them to poverty, they also resent that money set aside for other uses, such as grandchildren's education or charitable giving, will be squandered on keeping them alive in a state they don't want.
4. Burdening others. More than eleven million Americans provide unpaid care for people with AD or other dementias. In 2022, caregivers of people with dementia provided an estimated 18 billion hours of unpaid assistance, a contribution worth \$339.5 billion.<sup>10</sup> The majority of those caregivers are women, and it is not uncommon for them to suffer fractured marriages and stymied careers due to the burdens of caregiving; this leads to greater likelihood of poverty for them later in life.<sup>11</sup>

The typical course of dementia after first diagnosis is 8 to 12 years of life, although some people can live 20 years or more. It is obvious that, if we look at the categories of concern described above, all of them come to pass long before the person reaches the stage at which hand feeding is necessary. Incontinence, for example, is commonly experienced in the middle stage. Inability to drive safely or to balance a checkbook—clear markers of independent adulthood—are often gone in the earliest stages.

Most Americans grasp this quite well. I have given many talks on this topic over the last decade, and I always begin by asking people to do a thought experiment with me. I tell them about three people, and ask them to tell me which of these three they would most want their lives to be like, should they be diagnosed with dementia. All three of the people I describe receive diagnoses of early stage AD at the age of 85. Alice dies of a heart attack shortly afterward, while still in the earliest stage, and living independently. Bob lives until 90, while living in a memory care facility. Charlie lives until 95, when he is largely incommunicative and in a wheelchair, unable to feed himself. I always emphasize that all three of these people are not in discernible physical or emotional pain; I describe them as enjoying food, smiling at caregivers, jiggling along with familiar music. Without exception, the overwhelming majority of the audience would want to be like Alice, and none would want to be like Charlie. As Terman quotes Menzel in this paper, it's not the misery, it's the "withering." And yet it is only Charlie who would benefit from Terman's strategy.

In other words, by the time someone is in need of assisted feeding, all their interests have long been defeated, and all their fears have long come to pass. VSED just isn't relevant to what concerns people most.

We see this in Terman's Table 1, in Boxes 3, 4, and 5. In "Existential suffering," he describes people who can no longer "recall their life goals or values." In "Disruption of life narrative," he talks about not "leaving their survivors tarnished, negative, embarrassing memories." In "Loved ones' suffering" he describes caregivers' feelings of exhaustion, financial pressures, helplessness, and so on. But as Terman surely knows, all these elements manifest themselves long before the person is likely to lose interest in food and need assisted feeding. For many currently competent people, fecal incontinence—the need to use diapers and to have them changed by others—is an important dividing line.

Yet this line is usually crossed years before the person needs assisted feeding.<sup>12</sup>

I applaud Terman for his careful and compelling analysis of the true meaning of suffering for people with dementia. But his analysis also points to the reality that these elements of suffering—for themselves and their loved ones—manifest long before feeding problems begin. To attempt to avoid the suffering associated with dementia, we need to look for interventions at a much earlier stage. In the Netherlands and Belgium, for example, people who are diagnosed with an early stage of AD can request and receive euthanasia, before they become incompetent.

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## CONFLICT OF INTEREST STATEMENT

The author declares no conflicts of interest. Author disclosures are available in the [supporting information](#).

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