

Responses and Dialogue

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A Hauntingly Familiar Scenario

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We welcome the comprehensive argument presented by Joseph DeMarco and Samuel LePuma in “Dementia, Advance Directives and Discontinuity of Personality.” With the increase in persons affected with dementia (PADs) in the United States projected to rise to approximately 14,000,000 by 2050, it is necessary that more attention be paid to writing advance directives (AD) and to how, if necessary, they should be applied.

The authors presented the hypothetical, but realistic, case of Mrs. R., who was first diagnosed with a dementia at age 85 and lived another 9 years. Over that period of time, she had significant changes in her disposition and knowledge, associated with anxiety and agitation. As per the narrative, Mrs. R was given antibiotics for pneumonia when she had reached a state of disease in which she no longer recognized her children, and was noncommunicative and confined to a wheelchair. After that episode, she lived another 3 years, requiring full attendant care. It is suggested in this example that Mrs. R. left her beloved family only a small portion of what they might have received if her life had not been so prolonged.

Having worked with patients such as Mrs. R. and their families for more than 30 years—as well as having lived through this in my own family—the scenario is

hauntingly familiar. There are several layers of loss that need to be considered: a shift from critical to experiential interests; the increased burden on, and grieving of, care partners; the loss of personal dignity for the patient; and the specter of potentially draining financial resources intended to support the well-being of patient and partner. Although the case of Mrs. R. involved depleting funds that she might have preferred be used for other purposes (e.g., her children), it is even more tragic when the financial support of a changed individual threatens the security of that person's partner. This person frequently does not feel able to withhold life-prolonging treatments without clearly written authorization. This is true even if in the PAD the patient had shared oral objections to living in a compromised state.

It is crucial to be aware of a slippery slope when raising the topic of limiting life, prolonging interventions, or even mentioning self-directed death. The complexities of these issues became front and center in the discussions surrounding the decision of Sandy Bem in 2014, an American psychologist and author who, upon learning she had Alzheimer's Disease, resolved to kill herself. Sandy feared becoming a person with no mind, memory, or sense of self. She was determined to end her life while she could still do so without assistance and when

the disease became too debilitating for what she deemed a meaningful quality of life. Her family and closest friends, although deeply saddened, accepted her plan, and the ceremony celebrating her life achievements that they held before she took the medication helped them make sense of their loss. For those witnessing the inevitable cognitive decline of a person they love with a dementia, it can be difficult to make sense of this

process. And as time drags on, the degree of harm tends to increase gradually and relentlessly.

Having clear discussions about what qualities of life are acceptable and *not* acceptable becomes more important as the increasing prevalence of dementia continues to outpace gains in research efforts to prevent or effectively treat a disease that alters the landscape of more than one person's life.