

Living with Alzheimer's: A Fate Worse than Death?

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Date : December 14, 2016

Rebecca Dresser, *A Fate Worse than Death? How Biomarkers for Alzheimer's Disease Could Affect End-of-Life Choices*, 12 *Ind. Health L. Rev.* 651 (2015), available at [SSRN](#).

According to the Alzheimer's Association's [2016 Alzheimer's Disease Facts and Figures](#), one in nine persons in the U.S. over the age of 65 suffers from Alzheimer's disease, with the prevalence rising to one in three persons over the age of 85. With lengthening life spans and the Baby Boom generation's aging, the number of Americans with Alzheimer's is projected to increase dramatically in the coming decades, from 5.2 million in 2016 to somewhere between 13.8 and 16 million in 2050. The sheer enormity of this projected number sobers medical researchers and health policy makers, inspiring initiatives to develop preventive and curative therapies and humane and sustainable care financing and delivery models.

By contrast, just one case of Alzheimer's haunts most members of the public: the case they, or a loved one, might develop in the future. The title of [Rebecca Dresser's](#) article acknowledges this fear. In [A Fate Worse than Death? How Biomarkers for Alzheimer's Disease Could Affect End-of-Life Choices](#), Dresser considers how knowledge of an increased personal risk of developing Alzheimer's, gained from biomarker tests, might prompt persons to take steps aimed at avoiding a prolonged course of illness. Wishing to act before symptoms of the disease render them incapable of action, persons fearful of their relatively high risk of developing Alzheimer's might commit pre-emptive suicide. Less drastically, they might execute advance directives instructing that they should not receive life-saving medical care—or even food and water—once the Alzheimer's manifests and erases their competency. They might even seek to take advantage of laws in the handful of jurisdictions sanctioning physician-assisted death by executing an advance request for assisted death. For each of these potential responses, Dresser cogently and concisely considers the feasibility and legality of the particular strategy for avoiding “a fate worse than death.”

This analytical part of the article is useful and thought provoking, but what I really love about this short piece is Dresser's examination of policy responses to the increasing number of people who may be terrified by the results of their Alzheimer's biomarker tests. These responses include the obvious need for adequate disclosure protocols and counseling of persons considering the testing, but Dresser emphasizes the need to address people's fears head on by developing a deeper medical and public understanding of what it is actually like to live with Alzheimer's. According to Dresser, empirical evidence suggests that many Alzheimer's patients have a good quality of life, and that the effects of the disease may be more distressing for family members than for patients themselves. If indeed the fear associated with anticipating Alzheimer's is often worse than having the disease, people who receive positive biomarker results should know that before they make decisions to shorten or end their lives.

The other reason I appreciate Dresser's latest article so much, though, is that it reminded me of a longer article she wrote more than two decades ago. I first read *Missing Persons: Legal Perceptions of Incompetent Patients*, 46 *Rutgers L. Rev.* 609 (1994), years ago, and it made a strong impression on me. Reading *A Fate Worse than Death?* prompted me to go back to and reread *Missing Persons*. The earlier article explored how the autonomy model for end-of-life decision making fails, in many cases, to provide a reliable resolution of cases involving incompetent patients. It challenged the largely unquestioned primacy of autonomy as the North Star for deciding on treatments for incompetent patients, a challenge that I do not believe has been adequately answered in the past two decades.

In both articles, Dresser stresses the need to understand the lived experience of persons with dementia. Rather than assuming that their earlier, dread-inspired projections of their future wishes should control medical decisions, we

should ask how those persons might subjectively experience different treatment options available today. This approach accords with the disability community's insistence that decisions about people with disabilities be informed by their actual lived experience, instead of being infected with cultural biases against disability. Dresser does not insist that continued life will always be valuable for a person with severely compromised cognitive faculties, but she contends that the appropriate inquiry involves the subjective value of continued life to the person whose life is at issue. In short, *A Fate Worse than Death?* reminds readers that uninformed stereotypes are a dangerous basis on which to make life-shortening decisions.

Cite as: Mary Crossley, *Living with Alzheimer's: A Fate Worse than Death?*, JOTWELL (December 14, 2016) (reviewing Rebecca Dresser, *A Fate Worse than Death? How Biomarkers for Alzheimer's Disease Could Affect End-of-Life Choices*, 12 **Ind. Health L. Rev.** 651 (2015), available at SSRN), <http://health.jotwell.com/living-with-alzheimers-a-fate-worse-than-death/>.