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ane, an 88-year-old resident living independently with her husband, John, was brought to the emergency department delirious after an episode of unresponsiveness. She had had a dual-function implantable cardioverter-defibrillator (ICD) and pacemaker implanted several years ago. Although the ICD had discharged properly on two occasions in the past 6 months, interrogation of the device in the emergency department revealed that this time she experienced a 4-minute episode of ventricular fibrillation with several shocks failing to convert her rhythm before the last shock reestablished a paced rhythm.

During Jane’s delirium, her only child Julie handled her health care decisions. After a week in the hospital Jane’s mental status returned to baseline. It was determined that the malfunctioning device could be corrected with the addition of a new lead, a relatively simple procedure. Because of a minor infection, the procedure had to be delayed, so she was discharged to the skilled nursing facility wearing an external defibrillator vest.

On her admission to the SNF, Jane expressed interest in proceeding with revision of the device. However, 4 days later she expressed ambivalence, questioning the purpose of seeking to extend her life. When asked why she was reluctant, she said, “I don’t want to be a burden. I don’t want to be a burden to my husband.”

Before this episode, Jane had been fully independent, and her recovery of function after this episode was complete. She was not depressed. John was healthy, and their relationship was good. Her primary care physician discussed with her the alternative to repairing the device, but no decision was made. Four days later the physician returned, expecting to have an advance care planning discussion and further explore what Jane meant by “being a burden.” However, Jane said she was feeling better after talking through her options, and she was ready to undergo the procedure. She expressed appreciation for the talk they’d had 4 days before. Three days later the device was revised, and Jane returned home.

The Concept of Burden

What may have been behind Jane’s fear of “being a burden”? Was it a barrier to her consent? A study by Eileen Cahill, BA, and colleagues of the University of Pennsylvania found that 23 out of 50 (46%) older adults interviewed about their family’s involvement in their care mentioned the concept of burden (J Fam Nurs 2009;15:295–317). Those who were concerned about being a burden focused on three themes: 1) not wanting to interfere with their children’s busy family routine, 2) guilt over loss of function causing the need for caregiver help, and 3) concern that the family caregivers were overly concerned about their functional status. The first two themes were more prevalent among older adults with low levels of function; the third theme came from those with higher levels of function. Of note, the white respondents were proportionally more likely to refer to the concept of burden than the black respondents.

Beyond the fear of becoming a burden to their immediate family, older adults also may experience this concern within the context of the larger society. In a review of the literature on the psychology of feeling like a burden, Lucy Corvin, PsyD, and D. Brown of the University of Surrey in the United Kingdom reported that the Western ideal of autonomy creates a sense of burden and shame when one’s body is sick or dying (Soc Psychol Rev 2012;14:28–41). Chronic conditions may lead to a feeling of worthlessness. Independence is seen as a virtue, and dependence as a burden. Some researchers see interdependence rather than independence as characteristic of the human condition, and if embraced may lessen a person’s sense of being a burden.

Research suggests that Jane, like many older adults, feared the loss of independent function and the disruption to her social network that might result. Even though serious complications from the procedure were unlikely, the fear of subsequent becoming a burden was for several days very real — and perhaps unnecessarily coercive — barrier to her consent.

Is Caring a Burden?

In 2009 and 2011 surveys, 43.5 million Americans (18.9%) cared for someone 50 or older. Among these family caregivers, 66% were women. The average age of caregivers was 61, and they provided care for an average of 4.6 years. Spouses accounted for 20% of all caregivers, and they provided one-third of all assistance. Nearly 75% of all caregivers lived within 20 minutes of the need for care recipient. The average age of the care recipients was close to 80; nearly 70% were women, and 40% of them lived alone. Fifty-eight percent of family caregivers assisted in at least one activity of daily living: 43% assisted in transfers, 32% in dressing, and 25% in bathing, showering, or toiletting. Objectively, the enormous burden of care for older adults borne by family members is a nationwide phenomenon.

Yet in an online survey at Debate.org, 61% of respondents said the elderly are not a burden on society. Ms. Cahill and coauthors in the University of Pennsylvania study discussed the reasons why some may not consider older adults to be a burden, including repaying the debt of being raised as a child, fulfilling a family commitment to mutual concern, and providing an example to one’s children.

What Does Society Say?

In 1984, Colorado Governor Richard Lamm compared older adults who die without artificially extending their life to “leaves falling off a tree and forming humus for the other plants to grow up” (The New York Times, Mar. 29, 1984). Terminally ill older adults, he said, have a “duty to die and get out of the way.” In 2013, Mr. Lamm updated his message for a new generation with the trendy title “Society’s Un sustainable Burden” (Denver Post, Sept. 13, 2013). He wrote, “In a world of limited resources, we have a larger duty to a 10-year-old than to a 90-year-old … I am a fan and a friend of Dan Callahan, a medical ethicist who believes that beyond age 85 we should not make available expensive, high-technology medicine. At age 85, Callahan suggests we have had our ‘fair innings’ [Norm Daniels’s term] and that money would be better spent on the health needs of younger Americans who have not had their fair innings.”

Mr. Lamm is not the only public voice challenging the value of living into later years. Ezekiel J. Emanuel, MD, PhD, proclaimed his hope to die at age 75 (The Atlantic, Oct. 2014; https://goo.gl/YVk4N1R). While he stopped short of advocating for age-based rationing of care, he justified his personal preference for his own mortality by describing those “living too long” as “eefable, ineffectual, even pathetic.” He challenged the ideal of longevity by asking “whether our consumption is worth our contribution.” Such ruminations clearly communicate a devaluing of older adults.

Finally, it is worth noting that of Oregons who requested assisted suicide (aid in dying) in 2016, 48.9% cited being a burden on family, friends, or caregiver as a reason for their request; only 35.3% cited inadequate pain control as a factor (Oregon Public Health Division, Oregon Death with Dignity Act: Data Summary 2016 [Salem: Oregon Health Authority, Feb. 10, 2017; https://goo.gl/1AhKUJ]). As the focus in health care policy shifts more and more toward “value” and cost containment, the consistent message reveals a utilitarian bias against the care of older adults. If their health care is labeled an “unsustainable burden” and their future is considered “ineffec tual, even pathetic,” it is inevitable that at least some of these older adults will internalize that message and increasingly accept its coercive influence on their personal health care choices.

How Should We Respond?

We must acknowledge that to be human is to be a burden at times, as any age. What other species takes the better part of two decades to launch into quasi-independence? Yet loving parents joyfully bear the burdens of childbirth and child care. Even in our mature, “independent” stage we may experience difficulties, emotional stress, and uncertainty — and do we not sometimes seek others with whom to share these burdens?

The health care of all individuals at all ages carries a burden. As a third-year medical student, I was asked to insert an intravenous catheter into a 4-year-old girl with leukemia who had lost all her hair. I wept as she looked at me with sad eyes, and I thought of my little brother who had died of that same disease 8 years earlier. I knew I didn’t emotionally have what it would take to inflict pain on a helpless child so that she might be healed. Yet thankfully there are those who know just how to bear the burdens of caring for children with aplomb and excellence, and likewise with those who care for older adults.

If being a burden is an essential part of being human, then an ethical, existential, and fully human response to reality is to be a burden-bearer for others in need. We who are called to care for older adults must be willing to bear their burdens when it is in our power to do so. In his essay “Forgoing Treatment,” ethicist John Kilner, MDiv, PhD, noted the defining characteristics of older adults as weakness and wisdom (Dignity and Dying, Grand Rapids, MI: Paternoster Press; 1996:69–83). These attributes call us to respond to them with protection and respect.

In Jane’s case, I am glad I did not accept her initial refusal of the proposed procedure too readily. I am thankful that all it took to help her get past “being a burden” was a listening ear and a little time. And I am humbled and motivated by the love expressed by a nursing assistant for her own mother, whose care is not too heavy a burden to bear.