

case study

Shouldering the Burden of Care

TW, a fifty-two-year-old Ohio woman, cares daily for her elderly mother. Shortly after TW's father died, TW's mother became increasingly forgetful and easily flustered. After several medical consultations, doctors diagnosed Alzheimer's disease. Within a few years, TW's mother required constant supervision, so she came to live with TW and her family.

Since TW could not afford a home health aid during the day, she reduced her hours and now works part time. Keeping her job is a struggle, but TW finds solace in it. Being unable to focus on her career frustrates her. A similar conflict arises regarding her family. TW senses they would like more time with

her, just as she wants more time with them, but her current schedule does not allow it. TW strongly believes that she has a responsibility to care for her mother, but she finds little satisfaction in her caregiving role. She feels guilty about this.

In recent months, TW's mother has declined rapidly. She is more agitated and less aware of her surroundings. TW must take a more active role in helping her mother use the bathroom, bathe, and eat. As her mother's needs multiply, TW becomes more stressed and easily angered. She can't concentrate at work and has even less time and energy to give her husband and children. Her mother often does not recognize TW and cannot acknowledge or appreciate

the care she gives. TW misses conversing with her mother and feels depressed.

TW's mother told TW on many occasions that she never wanted to be placed in a nursing home, but TW is now considering it. She has one brother who lives in Texas. He also has a career and family. He calls often and visits sometimes, but finds it difficult to get away. He strongly opposes nursing home care. TW's husband also is reluctant to place his mother-in-law in a nursing home, but he is more aware of the toll that caring for her takes on his wife. TW is reviewing the application process for a Medicaid-sponsored bed in a nursing home.

TW faces a dilemma. She can place her mother in a nursing home to ease her own burdens, despite knowing her mother did not want to live in one. Alternatively, she can respect her mother's stated wishes by continuing to care for her at home, despite the unforeseen personal and financial difficulties the situation causes her and her family. What aspects of this case are most important to help TW reach an acceptable decision?

by Eva Feder Kittay

This dilemma has no really adequate solution, as either choice will be costly for TW. But that does not mean there is no solution at all. Resolving the problem requires a change in the way our society treats and rewards the work of caregiving. It must acknowledge its responsibility both to the caregiver and the one needing care.

Society does not see caregiving as work in its own right, but rather as a familial obligation, as a natural capacity of a woman, as a gift we give to those we love. However, caregiving is a *human* capacity, not a gendered one, and it can be a gift only when given ungrudgingly, generously, joyfully, and most of all *freely*—it cannot be coerced in the way TW's dilemma coerces her care. To give the kind of care that expresses love, we need to be able to maintain our own selves from which our gift can flow. TW cannot do this; no wonder she resents the burden to attend to her own beloved mother.

To solve this dilemma, TW must first realize that she is not an undutiful daughter. She must then imagine the conditions under which resolution is possible and attempt to approximate that ideal. Ultimately, a greater resolution to this kind of dilemma will be found in collective action to alter the so-

cial expectations and policies that lead to it.

Imagine a world where familial caregiving was remunerated through paid family leave policies and funds to provide care, so that families were not forced to assume additional financial hardships. Imagine further that home health care were adequately subsidized, required extensive training, and commanded a respect it currently lacks. In this scenario, TW could hire assistants to help her and be assured of high quality care. Help with her burdens would not relieve TW's heartache of missing her mother as she once knew her, but by approaching her tasks refreshed, she might be better equipped to appreciate the positive aspects of her mother's existence, as well as to deal with its difficulties. She could also maintain her employment, feel confident that good care would be provided in her absence, and form a relationship with her mother as she is now while keeping her in her familiar home environment.

Consider another possible alternative—a nursing home—and why TW's mother expressed a wish not to enter one. Nursing homes conjure up a depressing and joyless image: lots of discarded old folks receiving kindly but barely adequate care. But other models of good, caring residential facilities do exist. If nursing homes were personalized and varied places, with appealing activities for people with diminished capacities and the nursing expertise that impairments like Alzheimer's require,

then they would not be a dreaded specter hovering over old age. One's last days could be comfortable, interesting, inviting to family and friends, and especially well suited to one's specific ailments (including Alzheimer's).

Clearly these remedies involve substantial investment of public funds. Good care is costly. But who is to pay, and in what coin? In the case before us, TW pays—not only financially, but also with her health and emotional well-being. She may well develop serious medical problems, as do so many who care for elderly, disabled, or chronically ill family members, and then her health costs will redound back to the larger society. The cost of good care needs to be, and can be, more justly dispersed.

TW is trapped in a social situation where these answers are not forthcoming, yet the vision of them should guide her. First she and those around her should try to distribute the burden of caregiving more equitably. For example, if her brother cannot contribute time, he must assist in other ways, such as contributing funds for home assistance. Second, if her mother's hostility to a nursing home was based on the characteristic dismal image, she must look for a better facility, especially one that offers excellent care for Alzheimer's patients. To continue the current situation can only further embitter TW, alienating her from her mother and her family, and this fracturing of relations would be the most injurious of all outcomes.