



CAREGIVER'S PERSPECTIVE

By Julie Masters, PhD

The Grace and Dignity of Caregiving

To be a caregiver is more than being in place to take a call, hold a hand, or jot down the recommendations of a health care professional. It is about being fully present to someone whose life is changing in a way neither of you could have anticipated.

Both Dr. Arthur Kleinman in “Caregiving as a Moral Experience” (*Lancet* 2012;380:1550–1551) and Fr. Henri J.M. Nouwen in *A Spirituality of Caregiving* (Nashville: Upper Room, 2011) have referred to caregiving as a process of becoming fully human. Caring for another person has great value in helping us become the person we are meant to be in life. The challenges, the setbacks, and the moments of grace shape and mold us in meaningful ways. And it takes courage and grace to take this first step and allow oneself to be transformed by the experience.

Gerontologists whose scholarly focus is on the experience of aging are well aware of the research that has taken place over the last several decades on what it means to be a caregiver. Whether in lectures, community presentations, or service learning activities, the reality of caregiving is a necessary part of the conversation. People in the midst of the experience can relate to this — for others, the discussion may only serve as a glimpse into the future.

When those who find themselves knocking at the door of a role as a caregiver pick up an article or pamphlet, inevitably the words *burden*, *stress*, or *strain* will surface. Research dating back to the 1980s has highlighted the burdens and stresses of caregiving, which has led other researchers to take a similar approach to explaining this aspect of the aging experience. Only in the past decade or so have researchers identified the *positive* aspects of caregiving, which emphasize its strengths and benefits. Growth in areas such as competency, role satisfaction, well-being, and fulfillment highlight what can be gained as a caregiver. This is the story not always told.

For me, as a gerontologist, caregiving was a space occupied by others. It was something to respect and honor, but it existed at a distance. In the fall of 2008, the experience of caregiving became more real for me. My dad, a 59-year veteran of the real estate business, had sold homes and land with an undying commitment to giving it his all — but then his cognitive health became more than just a passing concern.

Despite knowing the insidious nature of cognitive impairment and acknowledging the difficulty in completing complex tasks, I was shocked to see my

dad discard credit card statements, utility bills, and other vital pieces of mail shortly after opening the envelopes. This out-of-character behavior — along with his being persuaded by TV programs to buy copious amounts of fruit juices to cure his rheumatoid arthritis — was enough to trigger my call to a geriatrician friend.



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My friend agreed to meet with him. And my friend was the one who broke the news of my dad's diagnosis and future. I often think of how hard this must be for my friend and his staff — to provide the news that changes the course of life for so many others.

It was curious that someone who had a knack for quickly calculating a potential mortgage payment on the fly, whose social skills were off the charts, could not muster the ability to beat the clock test. For me, being present during the test and knowing of its purpose in the diagnosis of probable Alzheimer's disease was important and sobering for many reasons: it signaled the start of a new chapter for my dad.

How he went about his life would change, as would the lives of his children. This was not an experience we had sought, but it revealed who and what we could become as people — one of many grace moments of our new roles in life.

Caregiving, like jury duty, is a journey that affords an opportunity to meet people you would never have met otherwise. From the postal worker selling Alzheimer's postage stamps to the cable television clerk who made the shut-off possible when the service seemed destined to continue for eternity, people were there to help to us. How many of

these same people had experienced their own journey with Alzheimer's disease? Did it allow them to put things into perspective?

Nancy Cobb, in her book *In Lieu of Flowers: A Conversation for the Living* (New York: Pantheon, 2000), writes of the value of giving yourself permission to talk about your experiences as a way

our journey. He let us know we were not in this alone, especially when we had to make the decision about signing the do-not-resuscitate order after dad's final hospitalization. Putting him through another hospitalization or move was not fair to him or his well-being. He had shared with a cousin that he was ready to go, which was an important discovery for us as we planned for the end. As my dad readied for his last days, so did we, although the thought of letting him go was not easy.

I was not aware enough at the onset to recognize how rewarding the caregiving experience could be. My knowledge of the subject was limited to the stress and burden of it all, along with a misguided perception of who fit the profile of the typical caregiver. Without question, there were challenges and setbacks that pushed us in ways we had not thought possible. But isn't this true of life in general?

Caregiving, I discovered, was so much more. The positive aspects of caregiving sustained and carried us through to the end. The experience also influenced how I now look at caregiving in general. My brother demonstrated the value of family in providing support, thereby proving how the frequently cited profile of the typical caregiver is limited. Men are involved as well — we are all in this together.

I am grateful for the gift of having lived the life of a caregiver, of being able to ensure dad had dignity throughout his remaining days. Our time with him and with all the others who came into our lives proved to be a great source of instruction and compassion. Without question, grace has been and continues to be a source of strength.

In her book, Ms. Cobb has offered a powerful thought, which adds to the depth and grace of our caregiving role: “In a way, your mother was your first love affair. You knew her heartbeat, her voice, her moods, her emotions ... her eyes were the first you saw coming into this world, just as yours will be the last she sees going out of it. You are giving birth to her and to yourself as you grow to the next stage of your life.”

to encourage others to talk about theirs. Surprisingly, others will share their story, giving you the support and courage to continue in your own efforts to make life as a good as possible while maintaining the dignity of the person you love. It is also about knowing you are not alone.

It has been ten years since our dad died on Father's Day. My brother was at his side, another grace moment. From New Year's Eve 2008 through June 21, 2009, our dad was hospitalized six times and moved five times. Each move was based on a level of care or was prompted by a payer source. We quickly learned that a move to a new place was not based on caregiver convenience — it was about moving *now*, regardless of other obligations.

In hindsight, my brother and I became skilled at moving him with minimal disruption to his life. So much so that we were prepared to hire ourselves out for the witness protection program, as any memory of his presence was wiped clean! There were other amusing moments along the journey — such as his comment about possession being 9/10ths of the law while wearing someone else's shirt to dinner — and tender moments as well.

The support of my dad's parish priest, Fr. Shane, was grace-filled throughout

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