MY mother died September 26, 2007, two months shy of her 89th birthday, of Alzheimer’s disease. In the years since the excruciating trajectory of her death I have grappled with the crippling sense of guilt, helplessness, and sadness that I felt as a physician-daughter when my mother slipped ever deeper into the gauzy unreality that was the twilight of her life. As a physician, I was not adept at accommodating the notion that I could not control the course of Mom’s devastating illness, having been partial to such concepts as fix, cure, and conquer. I had not yet come to understand on a profound level that ensuring a good death is just as much a part of being a physician as improving or prolonging life. As a daughter, I could not bear to realize that my beautiful mother was not immortal after all. Moreover, it has always vexed me that far more than discussions about political or religious beliefs or money, dying remains a taboo topic in our otherwise relentlessly confessional age. We need to expose death, and the process of dying, to the disinfectant of sunlight. If we stop avoiding the topic, perhaps we can file down death’s claws and defang it.

Regardless of the nature of a person’s terminal illness, major problems and crises are common when caring for an elderly, frail parent. Moreover, I would argue that independent of the particulars of class and money, the elderly are an especially vulnerable demographic. They are diminished by circumstances, no matter how simple or cosseted their surroundings, that leave them ripe for their being infantilized and at the mercy of others. Surely, we are obliged to honor the integrity of the person they once were, before time and illness rendered them helpless, even if they are seemingly unaware of what’s going on around them. I am hounded by things I wish I had done differently—been more frequent and upbeat in my visits and been more explicit about my gratitude for all the special times we shared—but I take comfort in the fact that I tried never to treat my mother as less than the intelligent, gentle, beautiful, caring person that she was before dementia reduced her to a hollow shell. While I am not impervious to regret about things left unsaid, my burden is mitigated by warm memories of the occasions when we seemingly followed the “right” path. My older brother, Don, and I
decided that love, respectful laughter, and sometimes painful honesty would be the tools with which we faced the challenges of the “long goodbye.” We wanted to be the emotional scaffolding with which Mom could maintain her dignity.

Examples abound of aged individuals who remained engaged and creative during the final chapter of their lives. Titian and Monet were painting in their 80s, Picasso and Chagall even into their 90s. George Bernard Shaw produced his last play at 93 yr, and Grandma Moses her last painting at 101 yr. If only Mom could have been among the fortunate!

Clearly, age-related changes in human cognitive function differ in detail and extent from individual to individual. Nonetheless, Alzheimer’s disease is a major part of the bad news about our new, longer life spans. At age 65, fewer than 5% of people show signs of the disease, but after age 85, as many as 40% to 50% suffer its effects. Today, there are more than 5 million individuals diagnosed with Alzheimer’s disease in the United States. The depredation associated with this neurodegenerative disease is multifaceted, affecting not only the afflicted, but their families and our entire society. As tens of millions of us baby boomers enter our later years, we almost obsessively monitor not just our parents, but siblings, friends, and ourselves for what we fear could be the beginning of a slide into oblivion. Moreover, on an economic level, we must acknowledge that—absent an effective intervention—caring for Alzheimer’s patients could bankrupt Medicare and Medicaid.

My mother was not a statistic. A mother is a treasured friend who knows your past, believes in your future, and loves you just as you are. Our beloved mother, Marion, was all of that and so much more. Mom had at her core an unrelenting commitment to her family. She would do anything for Dad, for Don, or for me. Unfailingly generous, she believed more in love than in discipline, often to the dismay of our more authoritarian father. She was the understanding tabula rasa on which we inscribed our obsessions of the moment, and her gentle smile salved many of our childhood wounds. Mom was a realist who thought and spoke with impar
tiality, neither sanctifying nor demonizing people or ideas. Her supply of love seemed inexhaustible, like the light of a candle that can spread its flame to many other candles and yet not lose any of its own glow and warmth. Parents are the matches that light the candles of our childhood dreams. Mom and Dad’s dedication to advancing their children’s education expanded our horizons, enriched our lives, and forever touched our hearts.

My brother and I shall retain an image of Mom in good health, gracefully wearing the crenellations of age, before Alzheimer’s disease grappled her to the ground. She was an avid reader but by age 84 or 85, she put aside her beloved books and increasingly had
difficulty remembering words, recent conversations, and faces. At age 87, six months after my father died, Mom remembered little about him other than the fact that “he was a doctor.” I had been warned that the worst day of my life would be the day Mom failed to recognize me. Such was not the case, however, and it may be because she recognized me until about 2 months before she died. The worst day was when I realized she had no memory of her husband of 60 yr. Penultimately, Mom slipped into the remote past and — quietly, peacefully—let go of the future. Finally, she became unable to eat or swallow.

My mother’s decline is characteristic of the progression of Alzheimer’s disease. It first destroys neurons in the hippocampus, where memories are formed and stored. Then, the disease attacks the cerebral cortex and language skills and reasoning ability fade. Finally, so much of the brain atrophies that victims become unresponsive and helpless. The only saving grace about the disease is that, in its last stages, victims are oblivious to their plight.

It is a painful and daunting responsibility to be in charge of the last fragment of a life, to do right by it. Mom spent her final months at a nursing facility run by the Sisters of Notre Dame, who showered tender care on Mom, Don, and me. We all learned to live in the moment and to find joy in the simple pleasures life has to offer. Every glimmer of recognition became a precious gift. Don and I had frequently anguished about the apparent loss of dignity that can accompany Alzheimer’s disease, but we came to understand that we die with dignity when we are surrounded by love.

Mom was blessed with the gift of time, allowing her to touch countless lives. Whenever I reflect on her vital and durable presence in our lives, I recall the wisdom of St. Francis of Assisi who reminded us that when we leave this earth, we can take with us nothing that we have received—only what we have given. And Mom gave a full heart, enriched by service, sacrifice, courage, and—above all—love.