

LESSONS FROM MY FATHER: MY MOTHER'S END-OF-LIFE CAREGIVER

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In the following narrative, the author reflects on the end-of-life caregiving his father provided for his mother, who suffered from dementia. Throughout fourteen years of his father's patient and loving care for her as she slowly declined, the author learned important personal and professional lessons. He gained greater empathy and insight into the depth of his father's character, which influenced his professional perspective on end-of-life dementia caregiving. While grieving the gradual loss of one parent, he discovered a new interpretation of caregiving compassion from the other.

Introduction

My story of end-of-life caregiving is no different from many others, neither special nor unique. However, witnessing my father provide care for my mother through the end of her life prompted my interest in guest editing this special edition. What has stayed with me is how the experience changed me as a professional social worker. Just when I thought I was an expert in the provision of care, I found I knew very little.

In May 2002, my mother died from dementia-related complications. I wasn't her personal caregiver—that was my father's role. However, both he and my mother were in their later years, so to allow him the dignity of caring for his cognitively impaired wife, I was always working behind the scenes making complex preparations so her care and accommodations were seamless and carried off with a minimum of disruption to her, and to him. What I was doing wasn't a secret, and whether or not my father knew that I was paving the road ahead was generally irrelevant. Maybe he knew and never let on. Regardless, he made decisions regarding her care and I helped him to carry out those decisions. It gives me great peace to know that he is still fairly oblivious to all the complexities of the healthcare system. My job was to handle insurance problems and copayments, to answer repetitious requests for my mother's history and physical information, and to attend to countless other tedious problems associated with home care. All these were, and still are, generally unknown to him.

My caregiving experience is not one of hands-on care; it is about my support for my father who was the actual primary caregiver, so this narrative of end-of-life caregiving is refracted through him. The best way to describe my father is that he's a consistent man. His temperament is always composed and he can be frustratingly literal. He laughs, but never hysterically. He gets irritated, but never enraged. Hardly anything flusters or upsets him. He worked in a union labor job for nearly 40 years and rarely missed a day. He's just a regular, predictable, reliable, conventional, monotonous kind of guy. As a child I often longed for the stereotypical father throwing temper tantrums and asserting masculine authority around the house. Why couldn't he be like the other dads on TV? However, that was clearly not his way to be a father. As a child when I would run home with some problem or seeming crisis, he would always be the anchor keeping a healthy perspective. Sometimes I would be deliberately provocative just to elicit a response from him, to challenge his stability. He wasn't stoic for the sake of manliness or pride; he was just matter-of-fact about most situations he encountered in life, good or bad. He just accepts life on life's terms and deals with any situation accordingly.

My mother, on the other hand, was the diametric opposite. In her prime, she was always outgoing and gregarious and often, embarrassingly, the greatest show on earth. Yet, she was also very emotionally sensitive and could be mercurial in temperament. So I guess my mother and my father were a

matched set. I would often compare them to television's odd couples. If she was Gracie Allen, he was George Burns. If she was Lucy Ricardo, he was Fred Mertz. I could always count on my mother for the hysterics and drama which were far more interesting than dependability. Consistency was nice at times, but constant commotion got my adrenaline pumping. My father became like a shadow figure in my life, the family wage earner who drifted in and out of the house every day. I only came to appreciate his reliable and calm nature as I grew much older. After my mother became functionally impaired, and by watching his diligent care of her, day after day, year after year, I learned a lot about dignity and integrity.

My Father as Caregiver

The caregiving challenge for our family began in 1988 when my mother suffered a severe stroke. My sister lived out of town and was a long-distance caregiver. Consequently, I was the primary contact (and social worker) for my parents. My father showed the first signs of his consistently honorable character as my mother lay unconscious in a hospital bed when we were uncertain of her outcome. His attendance to her in the hospital was unwavering and, just as he was in his day-to-day life, he was compassionate and gentle with her. During that time, my sister and I were confused and grieving since her prognosis didn't seem hopeful. My father's consistency was both an anchor and a comfort. He once broke down in tears when discussing her condition at the hospital with me, and I realized that this was the first time I had ever seen him overcome by sadness. I wasn't quite sure how to handle his vulnerability. Since he was never one to be consoled, my comforting comments sounded shallow to me. I am still not aware of how he received them, but I was honored that he felt he could cry with me. Over time, my mother recovered from her stroke, but with many physical and mental limitations. One of her limitations was a very impaired memory. She had multi-infarct dementia, which is memory loss as a result of a stroke. Over the years she experienced many more silent strokes (or mini-strokes as we called them)

disrupting the blood flow and causing damaged brain tissue. As a result she had increasingly more dementia-like symptoms including confusion, short-term memory loss, wandering or getting lost in familiar places, loss of bladder control, and, most baffling to my father, laughing or crying inappropriately. He rarely spoke of her limitations and one day when I was asking him about her communication he said, "We don't talk as much as we used to because it is hard for her to have the answers. I think she realizes that she can't remember a lot of what she wants to say so putting sentences together is hard for her." This seemed so emblematic of his care for her. He wouldn't try to compel her to speak since he knew it would be difficult for her, yet it was the one aspect of their relationship that could have been reciprocal.

As a researcher on caregiving and end-of-life care, what I always found surprising was that my father never exhibited typical symptoms associated with caregiver stress or burden. I can't think of any significant primary (or secondary) stressors; he had a few informal supports through friends and family, but he never utilized any formal systems of support. He looked at me strangely when I suggested using outside resources from time to time to help him with the tasks of caregiving. His response was that he and my mother were "doing fine." When asked, his only complaint was that caring for her needs (ADLs and IADLs) "takes a lot of time out of my day." Sometimes he would say about the tasks, "It's difficult sometimes, but not too bad." He always denied offers of help and felt his caregiving was what he could handle and what he needed to do for her. A neighbor stopped by one day to visit while I was there and she was telling me how "wonderful" and "saintly" my father was for his dutiful attention my mother. She became tearful in describing how touching it was to see them go for walks in the morning and how gently he helps her into the car. During her brief visit, my father kept looking at me with the oddest expression, and when she left, he wondered what she was talking about. I tried to explain that what he does for mother is really extraordinary at a time when many people might hire help at home or place family members in nursing

homes when they need more care. He kept shaking his head, not understanding. To him, we were all speaking another language. I told him not to worry, "just keep doing what you're doing."

Caregiving Benefits

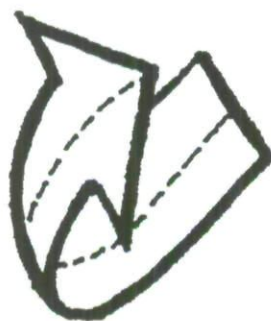
Although much of the research I have seen on caregivers of individuals with dementia has focused on negative outcomes from the caregiving experience, positive outcomes from the experience have also been documented (Kramer, 1997; Sanders, 2005; Tarlow et al., 2006). I had the opportunity to see my parents' relationship dramatically change context and form and even become deeper despite my mother's mental impairments. Lewis, Hepburn, Narayan, and Kirk (2005) have described spousal dementia caregiving in various ways, but I have felt my father best reflected what they have described as relational spousal caregiving. They describe this type of caregiving experience as a continuation of a spousal bond. These spouses integrated their role of caregiver with their relationship with their spouse. Consequently they describe caregiving not as a separate occupation, but as part of their overall life fabric. My father's acceptance of his and my mother's new roles was a reflection not only of his life as a caregiver, but of how he dealt with all changes in his life. He was never mourning or grieving over what was lost; he simply accepted what he had been given and had the existential understanding that his own life satisfaction is self-determined.

I suppose what gave him meaning in the caregiving was the satisfaction that he was helping my mother with those things she was not able to do for herself, and that was enough. That's just what married people do for each other. He did not fit typical mediating and moderating models of care; he just took each day as it came and did the best he could. In fact, over the years, he rarely asked for any rational explanation of her condition, the causes or the cure—instead he just persisted with his day-to-day attendant care of her.

As with many dementia patients, my mother continued to decline slowly for the next several years. It was often bittersweet to see

the two of them together. Each day my father would prepare my mother to meet the day. She would be up and dressed and smiling despite her lack of awareness of him, or me, or any of her surroundings. My father had the daily ritual of getting her breakfast ready, doing laundry, cleaning the house, doing dishes, going grocery shopping with her, taking her to doctors, bathing and grooming her, and then later putting her to bed and getting ready for the daily routine again tomorrow. Still, he never complained.

As part of my mother's therapy, the doctor recommended that she walk a little bit every day to stimulate her limbs. So each day, my father would help her put on her walking shoes and dress her for the day's weather, and they would head out on their daily walk around the block. To steady her, he would hold her hand, so they would walk down the block hand-in-hand like a young couple in love. Although my mother was virtually unaware, he would still point out houses and people on the block to her. These were his rituals every day and the challenges of caregiving never manifested in stress or grief or depression or resentment such as seen in much of the caregiving literature. In his own mysterious way, he found meaning in his caregiving role and I believe it deepened their relationship.



Facility Placement

After many years at home, my mother eventually needed more care than what my father could provide. It took some convincing, but he reluctantly agreed to look into facilities where she could receive adequate care. We agreed that a Board and Care facility would work best since she had more custodial needs

than he could provide, but she did not require continual nursing care. After visiting several facilities, he agreed on one that was nearby. With the small number of beds at the facility, we felt she would receive lots of attention from the workers and that pleased my dad. My sister and I wondered how he would adjust to having her placed at a facility when so much of his identity for so long was tied together with his caregiving. Could he adjust to a relatively independent life? How he adjusted was consistent with the rest of his life. Each day he went to the facility and went for a walk with her around the neighborhood. I would go with him at times and even after seeing it for many years I was still in awe of his devoted attention to her. He was never frustrated nor fatigued by her behaviors. Children would sometimes stop and stare at her as we were walking by, but my father never even acknowledged them. Somehow these kids never made it onto his radar and he was oblivious to their insensitive actions. He was attentive only to her and to me.

When my mother lost the ability to feed herself, my father would occasionally go over to help feed her lunch. Each spoonful he would carefully measure out and then give to her respectfully and calmly. They would occasionally make eye contact with each other and I felt my mother was aware of who was there helping her and maybe somehow she was communicating her love back to him in some psychic way unrecognizable to an outside observer.

His adaptation to independence was flawless. Since his daily routine had revolved around spousal caregiving for years, I worried that he would be at a loss to find a new role. However, in between visits to the facility to see my mother, he started new hobbies, socialized at a senior center, and developed a social network of other caregivers. It was seamless, but almost expected, in the way he adapted, given his personality. My sister and I are slow learners. Despite the fact that we were raised in a home with a resilient father, his ability to adapt to new circumstances still amazes us.

My Mother's Passing

After a year at the facility, my mother's health declined further and at one point she was rushed to the hospital. After a series of tests, the doctor had the inevitable conversation with our family that her health was declining fast and there was nothing more medically that could be done. Since she had been on artificial respiration and nutrition, the doctor recommended discontinuing those and assured her comfort care for her remaining few days. After a brief family meeting, we agreed. We waited and were at her bedside frequently over the next few days. One evening we took my father home to rest and during the time we were away, the hospital called to tell us that my mother had passed away. I had some remorse that we weren't there at the very end and asked my father how he felt about it. He said that he was fine with being at home when she passed. He was exceptionally quiet and only stated that he was grateful that she was at peace. He sat in his favorite chair and very quickly fell into a deep sleep. Fourteen years of caregiving took its toll and he was now able to finally relax as well.

The Memorial

Above all else, my mother valued education. Neither she nor my father attended college, so the higher education that my sister and I received was something both my parents always treasured. Many years before her stroke, I recall our family had a few light-hearted discussions about how we would like our body disposed of after we were gone. To offset the darkness of such morose talk, our conversations were usually peppered with lots of gallows humor about death and dying. None of it sacred, all of it hilarious—or at least it was to us. I recall that in a moment of candor my mother mentioned that she despised funerals and burials. She often said, "I want all my flowers while I can smell them!" Not only did she think funerals were a waste of money, but she felt it benefitted no one, not even the living. When we had attended funerals, I recall my mother muttering, "Just look at all this," gesturing around the cemetery. "All this money could have been spent on something worthwhile." Much later she had

heard of a program through a local university where people could donate their body to science for the education of medical students. She later learned that many current life-saving medical practices began with the use of human bodies which were donated through anatomical gift programs at medical schools throughout the country. If her organs and bones could benefit others in pursuit of knowledge about disease to give others the opportunity to live longer and healthier lives, then she wanted to have that as her legacy. And so it was to be. She and my father sent her completed documents to a local university medical school and it was set. No funerals, no flowers, no mortuary, no burial, no cremation, no tears at the gravesite. We were to honor her life through allowing others to learn from her.

After my mother passed away, what my father wanted for her was to have our small family together in the living room at home. We brought out some photo albums from too long ago and reminisced for hours about my mother, including our chaotic family vacations, Christmas morning gift openings, embarrassing Halloween costumes, dreadful teenage romances, unruly family pets, and fondly recalling our extended family long since passed on. It was a joyful day reflecting on the days when my mother was most vibrant. That was probably the best memorial she could have received. What gave my sister and me the greatest comfort was that it was exactly what my father wanted. We hardly spoke of the years of her impairment and her caregiving needs, but instead it was a loving tribute to her in her prime as well as to my father, the reliable head of our family.

For several years I thought that there might be pathology that I never felt intense sadness following her loss. More than once I felt that there must be a rational explanation for the absence of a typical grief response that I saw in many others when I was a hospice social worker. But there are many possible explanations as to why a person may not feel distress following an expected loss. There was an early adjustment preceding an expected loss, which is to say that my anticipatory grief was well processed. In essence, she died a psychological death long before her physical

death. An illness like my mother's that keeps changing in severity over time can continually reactivate the grieving process (Sanders & Corley, 2003). As a family caregiver along with my father, I repeatedly went through various stages of the loss including sadness, anger, depression, even despair. But more importantly, perhaps this long good-bye gave me time to grieve her loss, while simultaneously deeply appreciating the love, respect, and loyalty my father showed to my mother.

Lessons Learned

I think by watching my father lovingly care for my mother over the years has matured my attitude and respect as to what a loving relationship is supposed to be. I have a clearer understanding of how loving your spouse transcends anything including when she doesn't even recognize you. Even more, I have a deeper understanding of acceptance. My father *refused* to be troubled by her illness. He never denied her limitations or his own, he would never tolerate pity, and he never considered himself a martyr. His job was nothing more and nothing less than the daily courage of upholding his marital vows, doing what he believed any husband would do for his wife. Caring for his cognitively impaired wife was yet another condition that he accepted; he adapted to the changes just as he had done throughout his entire life. This is a remarkable feat given the vast amount of literature on caregiver stress and the consequences of caregiving burden. His tenacity and resilience is a testimony to the love between partners.

As I reflect on this experience, I can see how my emotional connections between my parents changed from my youth to my adulthood. As a child, I was drawn to my mother's personality simply because she was far more vivid and labile than my father. With only a two-dimensional perspective of my father's role in our family, I hardly knew of him or his character. As an adult, seeing my mother's condition decline over time and witnessing his gentle caregiving, I could feel a change also occurring in me. Through the years of her decline, I gradually grieved the loss of

my mother, yet I also gained a much deeper empathy for my father with his quiet courage of caring for my mother day after day, year after year. This empathy allowed me to renew my relationship with my father. He became not just my father but also my friend. My own catharsis occurred. It gave me the opportunity to reflect on my own relationships with those I love and the depth of commitment I could demonstrate if someone I loved were in a situation similar to my mother's. Do I have the same depth of character as my father? I would hope so.

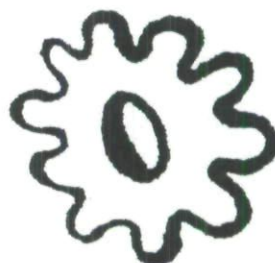
My father never overtly or verbally expressed love for my mother or, for that matter, any of us. However, he transmitted his love in a special code through his unshakable conviction to his wife and family. Though he never said it out loud, my sister, mother, and I never questioned his profound love for any of us. The consistency and discipline and gentleness and compassionate care he showed my mother for 14 years far exceeds any Hallmark card sentiment.

We often tell him how proud we are of his accomplishment of handling mother's care at home and in the facility, as well as of maintaining his own health. He still today minimizes his role. However, he taught us the dignity of showing compassion and respect for a terminally ill spouse. His gift is that he showed me what real love is at any stage of life.

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