

THE LEGACY OF CAREGIVING

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This narrative describes a social worker's caregiving and end-of-life experiences with her mother, who had Alzheimer's disease. The author explains how her personal caregiving experience changed her perception of the caregiver issues of her hospice clients and brought surprise at the distress and the joy of the journey. She describes her experience as a crucial developmental life phase and the legacy her mother left to her in the process.

Introduction to Caregiving

My education about end-of-life issues began the year my father existed in a persistent vegetative state after a stroke. Until his doctor suggested removing his feeding tube so he could die naturally, I was unaware this was an option, despite being a social worker for over ten years. Certain this would be our father's preference, our family made this difficult choice, and he died three weeks later. Not long after his death, my two sisters and I realized that our mother had Alzheimer's disease. Since both of her sisters had been diagnosed with Alzheimer's and my father's illness and death had been very stressful on her, we had considered this possibility. Years later, when the Alzheimer's had progressed to the point where my mother could no longer live alone, my husband and I relocated to move in with her. Over the next ten years, I cared for my mother in her own home, in an assisted-living facility, as a relief person when my sister became the primary caregiver, and finally when my mother was in a long-term care facility. Like other caregivers, my journey held experiences of despair, exhaustion, grief, guilt, and frustration. It also brought much tenderness, joy, humor, creativity, satisfaction, and love. It was a crucial developmental phase of my life that I would not trade for anything.

Preparation for Caregiving

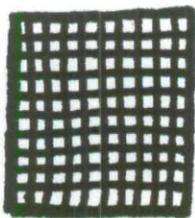
I was not prepared for the journey of caregiving. While working as a social worker in a family service agency for the first several years of my career, older adult clients comprised about 20% of my caseload. These

community-dwelling clients required case-management services for crisis situations. After that, in my private practice of many years, I did not have any clients who were older adults or had end-of-life issues. I recall little substantive course content in my social work education on older adult issues, except for one course in my doctoral program covering later life as a developmental stage. As a result, I had little experience or educational content in end-of-life issues. When my husband and I moved in with my mother, being appalled at the lack of information I had had to help my father at the end of his life, I decided to work at a hospice in the community. Hospice work gave me valuable knowledge and experience in end-of-life and caregiver issues, which helped a great deal in my own experience as a caregiver. Having this knowledge and having empathized with others in similar situations served as a bridge to my own experiences, which nevertheless were qualitatively different when they were happening to me instead of to a client. Many times along the caregiving journey, I recall thinking how differently I felt about an experience than I expected based on my professional work with caregivers. These differences included feeling more distressed and despairing, as well as more joyful and grateful than I anticipated.

The Acceptance Process

Several authors have described phases in the life of a caregiver (for a summary, see Jones, 2006), and I experienced many of these. One part of this journey that was more difficult

than I anticipated was accepting what was happening to my mother. It came in layers with several painful turning points. One of these was an event that marked a clear recognition that she indeed had the disease. We were at a restaurant ordering Mexican food, which, as an adult, my mother had loved, when she asked "Now what is a taco?" It was stunning, despite my intellectual knowledge of what was happening, to realize that her memory had disappeared to that degree. Another turning point came when I was helping my mother shop for clothes. In the dressing room, she tried on several outfits and chose one to buy. Then, when she put her own clothes back on, she looked in the mirror and said, "I like this outfit. Let's buy this." I had not yet learned how to handle these situations, and so reminded her that those were her clothes she wore to the store. She was horrified and tearfully asked me what was happening to her. It was so painful for both of us to stare the reality in the face. Each new step in the acceptance process brought feelings of grief. I knew about the anticipatory grief process (Meuser & Marwit, 2001) and had helped others through it. I had also felt impatience with those who seemed slow to accept their own or their loved one's condition, which professionals often label as denial. Experiencing the process personally gave me more compassion for the price of acceptance and more understanding of each person's unique path through that process.



Caregiving Challenges and Resources

The stresses of caregiving on the well-being of the caregiver are well-known (Sales, 2003). Unpleasant habits, memory problems, incessant talking, aggressive, agitated, or disruptive behaviors are described in the literature as being challenging for the caregiver (Gottlieb & Gignac, 1996). One of the

challenging aspects that became a reality for me was the 36-hour day experience (Mace & Rabins, 2006). Although I knew intellectually that caring for someone with Alzheimer's made the days seem interminably long, my own experience allowed me to fully grasp the intensity of the struggle and motivated me to find resources to break up these days. There were several sources of this type of stress. One was my mother's constant desire for some meaningful activity, combined with the extreme limitations in her ability to engage in activities. I tried a host of activities, with very limited success. When an activity proved to be too difficult, she became frustrated and said she was just no good anymore, at which point I felt I had failed. I found websites and books that had long lists of suggested activities for those with dementia. Folding towels became a favorite activity that she could do repeatedly throughout the day. Another aspect of the long days was the debacle that often resulted from leaving her alone in her room. These could be her disastrous attempts to clean up toileting accidents, putting lipstick on her eyebrows, hiding things in a different spot every day, changing her clothes several times a day, or washing her face with some mysterious substance that gave her a rash. I recall the relief when I discovered the Video Respite Series (Innovative Caregiving Resources). Developed by researchers at the University of Utah, the videos were designed to engage a person with dementia using just the right degree of stimulation. An actor engages the listener in thinking about a simple subject, inviting responses to questions, and singing along with a song on the topic. These kept my mother involved and happy for a full hour, interacting with the person on the video and singing along at the top of her lungs. The relief these videos provided was indescribable. I came to appreciate the desperate search for activities and respite from those long days, and how necessary respite is for survival as a caregiver.

Another source of stress was my mother's repeated incessant questions all day long. I was surprised by the limits of my patience. Despite knowledge that she was not able to remember, I still lost my patience and snapped

at her. She then felt horrible, and I felt like a monster. I could not understand why my knowledge did not translate into experience. I gradually learned to gauge my level of patience and find ways to avoid the snapping, such as diversion tactics or, as a last resort, disappearing into my room and closing the door. This did not always work, however, forcing me to face my own limitations. When the desire to be a good, loving caregiver clashed with the vision of me as causing my mother harm, it was agonizing.

If I was able to find humor in the situation or laugh at myself, I managed much better. This was easier when with a family member or friend. One example was a time my sister and I were taking my mother on a long plane trip to visit my other sister. I dreaded the incessant, repetitive questions asking where we were going, when we would get there, who was meeting us, and how long we were staying. So I came up with the idea of a little red notebook that had all the answers in it. I wrote in big letters on the outside, "Answer Book" and put it in her purse. I was so proud of this idea. According to plan, she began to ask the questions once we were on the plane, and I pulled out the book and explained it to her. She was delighted and thanked me and put it back in her purse. In a few minutes, however, she went rummaging in her purse for something and pulled out the red notebook, exclaiming angrily, "What's this? This isn't mine! Who put this in my purse?" I looked at my sister and we dissolved into laughter. In my well-laid plans, I had forgotten she could no longer learn new things. Since we were laughing, my mother laughed too and we threw away the red notebook. Humor saved us all that day.

Another situation when I lost patience was when my mother did not cooperate with my timetable, particularly when I was on a tight time schedule for an appointment or deadline. If she felt rushed, she balked. I learned to enter into a certain "zone" with her where there was no time. This turned out to be one of the rewards of caregiving, learning to be flexible and to live in the moment. Since the present moment was where she lived, I had to live in that time orientation in order to be fully present with her. An example of this occurred when

she chose to move from her home of many years to an assisted-living facility. In the process of packing, we found, in various locations throughout the house, "stashes" of things she had collected, such as plastic bags and safety pins of various sizes. My plan for getting her moved did not include her desire to sit for two hours and sort the safety pins by size. She remained insistent on this goal despite all attempts on my part to reason with or distract her. I recall the moment I simply gave in and sat with her to sort the safety pins. I realized as we were sorting the pins that this was a necessary part of the transition for her, and that my being with her in the moment was more important than my time schedule. I had to learn this again and again. Entering into the "no time zone" is a skill I still use to de-stress. I also learned to start early and arrange for things to be done ahead of time so she would not feel rushed. Although these skills helped a great deal, there were still occasions of strong frustration when I ended up being late to something important. My mother picked up on this and was angry with me or with herself. Later, as the disease progressed, she just knew something was wrong although she did not know what it was, so she would start apologizing repeatedly. These were dreadful times.

I came to appreciate the difficulties for caregivers who do not have the flexibility with work hours that I did or who had children to care for in addition to a parent. Painful lessons about my own limitations, combined with the limitations imposed by the disease, gave me more compassion for caregivers who are facing this experience. It also taught me to be open to the hidden lessons from caregiving that can turn into helpful life skills and part of the legacy left to us from our parents.

Sharing Caregiving with Siblings

In hospice social work, I worked with adult siblings on resolving caregiving conflicts, ranging from mild to severe, including will disputes ending up in court. So, I knew and had experience with the stress that caregiving puts on sibling relationships. In addition, the literature suggests that caring for parents can put a strain on sibling relationships (Connidis,

2007). My belief that the relationships among my sisters and me would weather these challenges well was confirmed in some ways and challenged in others. Bringing together our different perspectives included times of tension and conflict over finances and the best way to care for our mother. The conflicts required hard discussions with some resulting hard feelings. Although there was not permanent damage to our relationships, I saw how easily the challenges of caregiving could erode a family's equilibrium. Realizing some gaps in our abilities to handle conflict in a healthy way, we worked to find new ways to resolve differences with some success. Looking back, we would have benefited from professional help. Despite the struggles, we were available to each other in ways that were invaluable, providing support that only a sibling can. My sister who lived far away provided a valuable big picture perspective and was physically present at important transition times. My other sister and I were together in the everyday experiences, sharing the pain and the joy, offering suggestions, solace, and relief.

I have a new appreciation for the isolation and loneliness that must exist for only children who are faced with caregiving situations, as well as for the assistance siblings need to prevent and deal well with inevitable conflicts. Although underlying tension or deficits will appear in family relationships under the stress of caregiving, there is also an opportunity for siblings to move the family dynamic into a healthier realm, by replacing old patterns with new ones that allow for fuller adult relationships. I came to see how important it is for helping professionals to assess this aspect of the caregiving situation and to offer assistance to prevent, ameliorate, or enrich family relating. It is an opportunity that is another aspect of the legacy from our parents' final years of life.

Aging Parent as Teacher

A surprising experience was the way I came to value caring for my mother's personal hygiene needs. Although at times trying, I came to view this part of caregiving as a gift. Needing help to bathe, go to the bathroom, remove and insert dentures, and get dressed

brought up issues of dependency for my mother. We developed a ritual in which she would say, "I hate that you have to do this for me" or "What would I do without you?" to which I would respond, "Well, just think, Mom, if it weren't for you I wouldn't even be here." She would laugh and move out of her distress about being dependent for a few minutes, and then the ritual would begin again. I cherished these moments.

Conceptualizations of an adult child caring for a parent include role reversal, stress mediated by coping, and a developmental model (Sherrell & Newton, 1996; Sherrell, Buckwalter, & Morhardt, 2001). The idea of caring for a parent as a developmental undertaking fit my experience. In the process of the caretaking tasks being reversed, I found that my mother was still teaching me about aging and dependency. Because my maternal grandmother died suddenly with no preceding disability, my mother had not experienced caring for her own mother as she got older and declined. Genealogical research revealed a three-generational pattern of my foremothers who did not experience taking care of their mothers in their declining years. In addition, my mother, my sisters, and I did not experience caring for our grandmothers, who died before or shortly after we were born. We had not been a part of caregiving for aging mothers or grandmothers before the experience of taking care of our mother. Caregiving was, therefore, a gift to me of becoming a part of the reciprocal, intergenerational caregiving during a time in life when I am focused on generativity (Erikson, 1950; Peterson, 2002). I became aware, as I was intimately involved in my mother's bodily needs as she aged, that I was learning about my own aging in a way that could only occur through this experience. Perhaps, because I cared for my mother and found joy in it, I will be more comfortable in the part of the cycle when I need care. Perhaps I will not have the anxiety or distress about becoming dependent and needing care for my own bodily needs when I get to that point in life. I felt privileged to be inheriting from my mother this rich knowledge and experience from which I can draw in my own later life.

Rewards of Caregiving: Personality Changes

Before caring for my mother, the predominant theme in what I had learned or experienced about those with Alzheimer's disease was the decline in functioning, sometimes with a negative change in personality (Epple, 2002). There were a few exceptions. I had a friend whose parent's longstanding harshness changed to a sweet, loving attitude. In a favorite documentary about Alzheimer's, *Complaints of a Dutiful Daughter* (Hoffman, 1994), the mother forgot her learned prejudice against homosexuality and became very accepting of her daughter's lesbian relationship. Since then, there has been more of a focus in the literature on rewarding aspects of caregiving (Berg-Weger, Rubio, & Tebb, 2001; Kramer, 1997). My mother had always been a very loving, sweet, positive person with some deep fears leftover from childhood, and this did not change. However, she did change in some ways that were humorous and enjoyable.

As the disease progressed, my mother's properness in terms of how a lady should act and speak faded. My sisters and I would find ourselves slack jawed to hear profanity occasionally come out of our mother's mouth, as if she had said those things her whole life. This was a great source of humor for us. More importantly, as she became more childlike, it seemed that in many ways she became delightfully freer than she had been as an adult. I wondered if she was experiencing herself as she would have been without the prohibitions and hardships of her childhood with a harsh father and unhappy mother. She danced, sang, hugged, said exactly what she thought, and seemed much less afraid than the person I had experienced or how she described herself as a child.

Moments of Clarity

As she became increasingly lost in her dementia, I came to cherish the moments of clarity she experienced, which seemed like the clouds parting to allow the sun to shine through. One of the most prized examples of this was a time she wanted to talk about her own death and what would happen in the afterlife. I told

her that some people said that loved ones would come to meet her. When I asked who she would want to meet her, she was clear that she wanted her mother in that role. I then asked, "When it comes my time, will you meet me?" She very tenderly said that of course she would. We were both a bit tearful and I felt her very present with me as a mother to a daughter. Then she suddenly began to worry about how she would find people in heaven and asked if they had a directory of some kind. Although the moment had passed as she moved back into the concrete thinking of a child, I came to treasure moments such as these.

From these experiences, I have come to appreciate the significance of the rewards of caregiving. It is vital for professionals to develop the skills to recognize and carefully explore positive caregiving experiences, without minimizing the challenges. Discovering and mining the positive experiences not only can buffer against the stresses of caregiving, but can also help the caregiver find the legacy that lasts long after the caregiving ends.

Transition into Long-Term Care

Clearly the worst time as a caregiver for me was when we moved our mother into a long-term care facility. Again, I knew intellectually and from empathizing with clients that this was a very difficult transition (Aneshensel, Pearlin, Mullan, Zarit, & Whitlatch, 1995). But, I never knew how difficult until I experienced it. For two years prior to this, my mother lived with my sister and her husband. She had help from my sister and me, as well as from a paid caregiver a few hours a day. However, my sister developed serious health problems, in part from stress, common among caregivers (Vitaliano, Young & Zhang, 2004), and her doctor urged her to consider nursing-home placement. Without money for full-time caregivers, my new faculty position did not allow the time to have her live with me, and immigration kept her from living with my other sister in another country.

My middle sister and I shopped for a nursing home, a discouraging task, but we found one that seemed to be a good option. The first day Mother was there went smoothly, but she was not able to comprehend what was

happening. At bedtime, my sister and I left to allow the aides to put her to bed and then returned to say goodnight. She was tucked in bed and with wide, frightened eyes said, "Something's very wrong. You may never see me again." She clearly knew something was different but could not understand what it was, no matter how we explained it to her, and she was very frightened. After she fell asleep, my sister and I left. I cried all night, sobbed to my other sister on the phone, and called the night nurses to check on her. I felt like a murderer. I decided I would have to find a way for her to live with me. My middle sister was so upset she went back to the nursing home and stayed in Mother's room until the early hours of the morning. We returned to the nursing home the next day, prepared to pack her up to come live with me. We found our mother thoroughly enjoying herself with the other residents and, although she was very happy to see us, it was clear the trauma had been mostly ours. We decided to try this out for a while. She ended up responding well to the nursing home's excellent care. My sister visited daily, and we kept on top of her care.

I now have a much deeper grasp of the difficulty of this transition. I realize that some people endure additional stress because the nursing home changes management or ownership and the quality of care declines, one of the most helpless feelings a caregiver can have and warrants great attention. This has spurred my interest in housing alternatives for older adults, especially for when I reach that point in my life.

The Need for Advocacy

Still another experience that deepened my understanding of caregivers' issues was the need to advocate for my mother's wishes with physicians. When my mother began to have trouble swallowing, an outpatient swallow study was done. Because of religious beliefs, my mother had never been in a hospital aside from when she had her three children. When I arrived, she was in a hospital bed in the emergency room area with my sister. Despite having lost most of her language abilities by then, my mother said clearly "They're trying to make me into someone I'm not." I took this

as a clear directive that she did not want further procedures. She had completed her Advanced Directives and Durable Power of Attorney for Health Care earlier when she was fully competent. Therefore, when we were informed by the hospital physicians that a feeding tube procedure had been scheduled to remove an obstruction they found, we refused. They began to put pressure on us, at first mildly and then more forcefully. When we did not relent, they explored and found a mass they were able to remove. However, even when the follow-up study results indicated my mother could swallow well enough to return to the nursing home, the doctor insisted a feeding tube was necessary. He even used the well-known tactic of "you don't want to starve your mother to death do you?" Luckily, my hospice work had taught me about feeding tubes (Hoeffler, 2000), that they increase the likelihood of infection, that they do not prolong life, and that they can greatly reduce quality of life. In addition, once a feeding tube is put in, it can be challenging to get some doctors to remove it. We also knew our mother's wishes and had them in writing. Without adequate knowledge, the pressure tactics are hard to resist. Even with the knowledge, the doctor's authority and the way he presented the information was daunting. My first-hand experience fighting for my mother's rights strengthened my belief that it takes a strong support system and knowledge to advocate for clients' rights.

Transition to Hospice Care

The time came for my mother to be placed on hospice care. Soon, we were told that the hospice social worker wanted to meet with the family. I recall my next thought being that I did not need a hospice social worker because I was a hospice social worker. This thought surprised me since, in my 25 years of experience in the field, I sought professional help at times and strongly advised supervisees and students to do the same. I told myself that I was focused on my mother and wanted to spend all of my available time at her side, not with a social worker. When the social worker arrived, I was thinking we could get this over quickly, since I knew the things she would need

to know. My sisters and I walked into the meeting room, sat down, and after introductions, the social worker said to me, "How are you handling all this?" I surprised myself again by bursting into tears and talking quite a lot about how difficult this was. I also found it surprisingly helpful to listen to my sisters discuss their feelings about the situation. The hospice workers provided excellent care. It was so relieving, when I had a question about her condition or the comfort measures, to talk to the nurse and get the help I needed. My sisters and I were not alone in helping my mother die comfortably.

Helpers can sometimes deny our own needs for help. This experience gave me more understanding for hospice clients' family members who are reluctant to see the social worker. The relief I felt from hospice support also taught me a great deal about the value of that support to other hospice families.

Caregiver Grief

The night came when the end was imminent. My sisters and I took turns staying up to assure my mother was comfortable and to alert the others when the time had come. During my turn, I sat and spoke silently to my mother, at times stroking her hand or hair. When her breathing began to change, I knew the end was near and quickly woke my sisters. Shortly after that, my mother died peacefully with her daughters around her bed holding her hands and holding each other. We were simultaneously extremely sad and grateful for all she had given us and for the privilege of being with her through to the end.

The grief I felt after her death was intense and difficult, which I had expected. What surprised me, however, was the feeling that I had lost the ground on which I stood. I had not felt very dependent on my mother for as long as I can remember. Fairly early in childhood I viewed her as someone who often mustered up a great deal of strength, but who needed a lot of reassurance and help with many fears and insecurities. Certainly in adulthood I did not rely on her for advice or friendship, as I knew other women did with their mothers. In fact, I had experienced longing for that kind of mother-daughter relationship earlier in life,

grieved it, and moved on to have a very satisfying relationship with my mother which had deepened over the years. So, why, now in my 50s, would I feel so lost? The phrase that kept coming to me was that I had lost my "training wheels."

I have since learned first-hand about the developmental phase of losing one's parents and the growth that can result (Sherrell & Newton, 1996). I have learned that she was indeed my foundation and that, although I did not rely on her the way I perceived others relied on their mothers, I counted on her presence in a way I did not realize. I had never been in a world without my parents. As I told my mother in our ritual, I would not exist without her, physically or emotionally. My world is profoundly changed; yet the sense of being lost has gradually transformed into knowledge that the foundation she was for me is now part of who I am. It is not all that I need, because my mother was not perfect and had gaps in her life that impacted me. Yet, I draw upon the foundation, which has many surprisingly strong places and treasures buried within. This internalization could occur only after my mother's death and as I allow myself to experience her loss.

When I have taught the concept of object constancy, I have spoken about death as the ultimate test of the ability to hold on to all a person is to you without his or her physical presence (Mahler, Pine & Bergman, 1975). I have viewed this as the task of grief and worked with bereaved clients based on this concept. I now view the internalization of the loved one as more of a product of grief and a process that can occur only after the loved one dies. I have also learned that grief is always unfamiliar, no matter how many times you have empathized with others' grief or even how many times you have experienced it yourself. The relationship, circumstances, phase of life, and support available make each grief experience a new one for the bereaved, with new trials and new gifts. Although there are commonalities, I now see more variations than similarities and approach grieving persons with this openness.

The natural outgrowth of losing my parents is facing my own death, which has become

much more real now that there is no one in line ahead of me. I am experiencing some fears, some desires to assure I am focusing on the things in life that are most important to me, and the need to plan for when I will need assistance in my later years. Having experienced my mother's aging and death from such a close perspective has given me some rich resources with which to approach this phase of my own life.

The Legacy

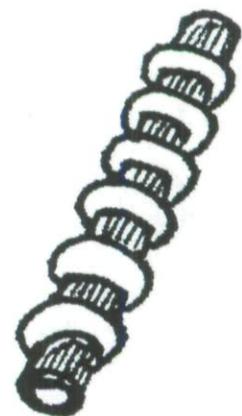
In consulting with hospice social workers, I find myself asking them to explore what the hospice client desires his or her legacy to be. Many times that exploration can focus the client's desires to leave something behind for his or her family members. I believe I ask this question more often because of the legacy I realize my mother left me throughout her life and through our experiences while I cared for her at the end of her life. The legacy includes increased knowledge and compassion for caregivers in many areas. It also includes the gifts of caregiving that I have received and can listen for in conversations with other caregivers. Perhaps having seen my mother's aging, dependent body while experiencing deep love for her, I will be able to fend off society's pervasive negative messages about aging bodies and dependence. Perhaps having experienced caregiving, my planning for my own older adulthood will provide me with caregivers, and I will be able to trust that I can be loveable while needing care. Perhaps even if my mind is clouded with Alzheimer's, the lessons I have learned will be imprinted on my being and come through my spirit, leaving a legacy of my own.

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